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28th ANNUAL CONGRESS • 17-19 JUNE 2026
Perth Convention and Exhibition Centre

Flip the Script

When the Person with Cancer is Educating
Health Care Professionals

We Have Much to Learn

Kahlia Wolsley

Project Officer & Nurse Educator (RN, CDE)
NeuroEndocrine Cancer Australia



**NeuroEndocrine
Cancer Australia**

Champions for early diagnosis and a cure

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- Project Officer / Nurse Educator



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- Specialist NET Nurse

Meredith Cummins
CEO -



Disclosures

No conflicts of interest to declare

NeuroEndocrine Cancer Australia (NECA)



Support



Education



Research



Awareness



Advocacy

Vision is to be the champions of earlier diagnosis and a cure for neuroendocrine cancer.

Mission:

- Assist patients and carers
- Lobby for new treatments and investigations
- Raise awareness among the medical community and public
- Support Australian research in neuroendocrine cancers.



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Neuroendocrine Cancer (NETs)



7th most diagnosed cancer

Neuroendocrine Cancer is Australia's 7th most commonly diagnosed cancer



31,380

Australians living with Neuroendocrine Cancer



5,719

Australians are diagnosed annually



The average Australian waits over 5 years for a correct diagnosis

1 in 2

Patients report being originally diagnosed with something else

60%

Of patients are at stage 4 by the time of diagnosis



NET Patient

*"it is **up to us as patients** to get GPs to learn about NETs"*

NET Patient

*"I am used to educating my physicians but it's a challenge for a lot of rural people and there are **people going undiagnosed or left too long because the GPs don't know out here.**"*

NET Nurse

*"Patient from NorthWest Tasmania shared that she must **regularly remind her GP to arrange** her husband's CGA blood tests and to recognise the **distinction between pancreatic cancer and pancreatic neuroendocrine cancer.**"*

NET Nurse

*"A patient who receives his Lanreotide injections through his GP clinic, reports that he must **repeatedly educate nursing staff** on how to administer the injection correctly. He also finds himself **explaining to locum GPs**, who frequently rotate through the practice, **what neuroendocrine cancer is** and how often his treatment is required."*

GP Survey in 2019

72% of GPs reported that patients had consulted them prior to a NET diagnosis, with **only 5% of them suspecting a NET.**



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Patient Experiences

-  Symptoms
-  Delayed correct diagnosis
-  Treatment
-  Psychosocial impact

HCP Knowledge Gap

-  Pathophysiology / epidemiology
-  Hormonal Syndrome
-  Path tests - CgA
-  Imaging - CT, MRI etc.
-  Classification, grading / staging
-  Medical management
-  Symptom control
-  Living with NETs

Opportunities

-  Value of patient stories
-  Patient empowerment
-  Development of resources
-  HCP education and support

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KAREN

- Finding the **key people**
- NETs is **now more accessible than it was 5 minutes** before starting out on this quest.
- Recognising that **patients bring expertise too**. They live with NETs every day.
- Experiences can provide **valuable insights** that help healthcare professionals better understand **what matters most** to the people they care for.

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KAREN

- Educating HCP despite adversity
- The **right information**, shared at the **right time**, can make a difference.
- Patients often **know more about this**, and healthcare professionals need to **listen**.

arterial
education

How to identify a
**NEUROENDOCRINE
CANCER**
when it's not part of the typical line-up



Join our patients in this interactive, case based, on-line activity where diagnosis and management of neuroendocrine tumours are addressed.

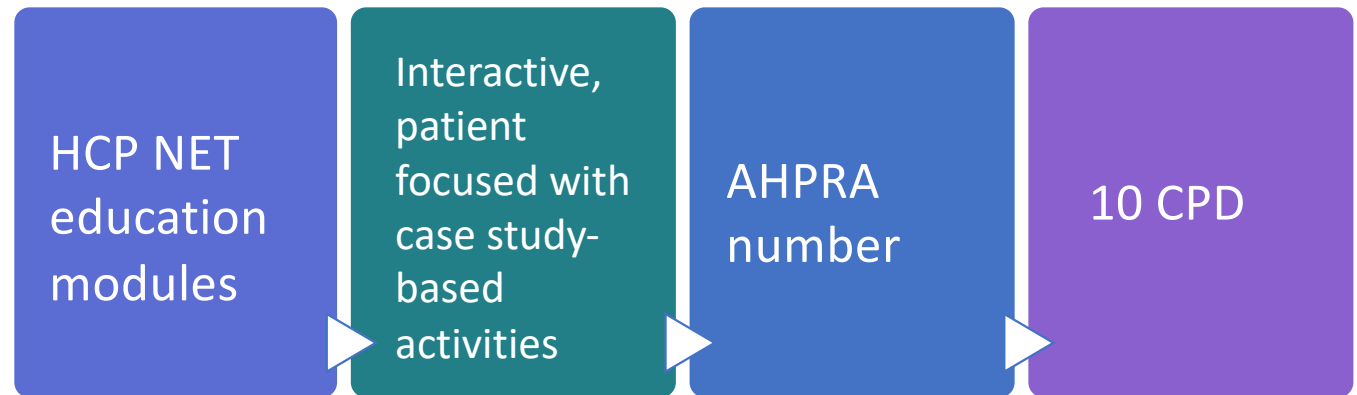
By the end of this course, participants will be able to:

- Discuss the pathophysiology and epidemiology of neuroendocrine tumours (NETs)
- Outline the symptoms of NETs
- Describe appropriate investigations and diagnostic pathways for patients with suspected NETs
- Outline pharmacological and non-pharmacological treatment options for NETs and their appropriate clinical application
- Using a multidisciplinary team, formulate a whole-person approach to the management of patients with NETs

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Champions for early diagnosis and a cure

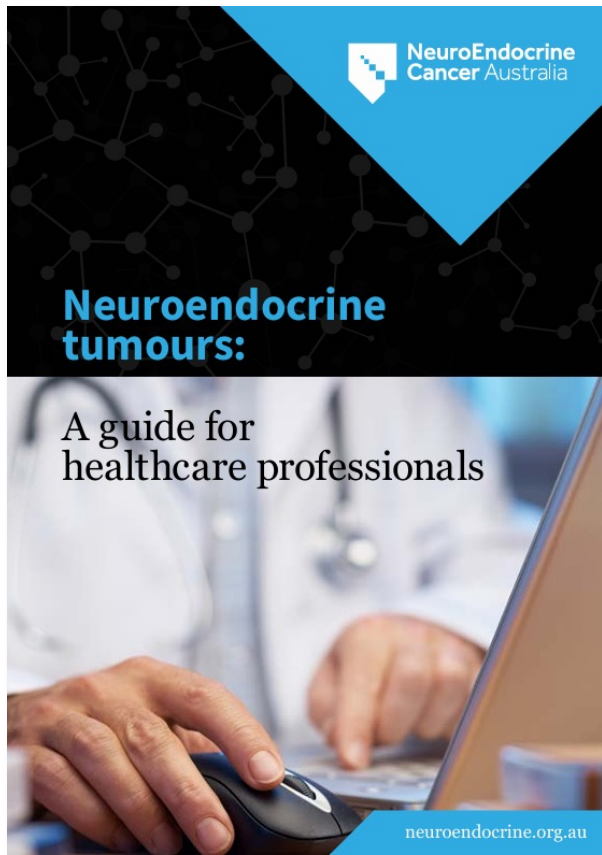
Supported by
An unrestricted educational grant from IPSEN Australia
Partnership project funding from Novartis Australia

HCP NET Education Modules

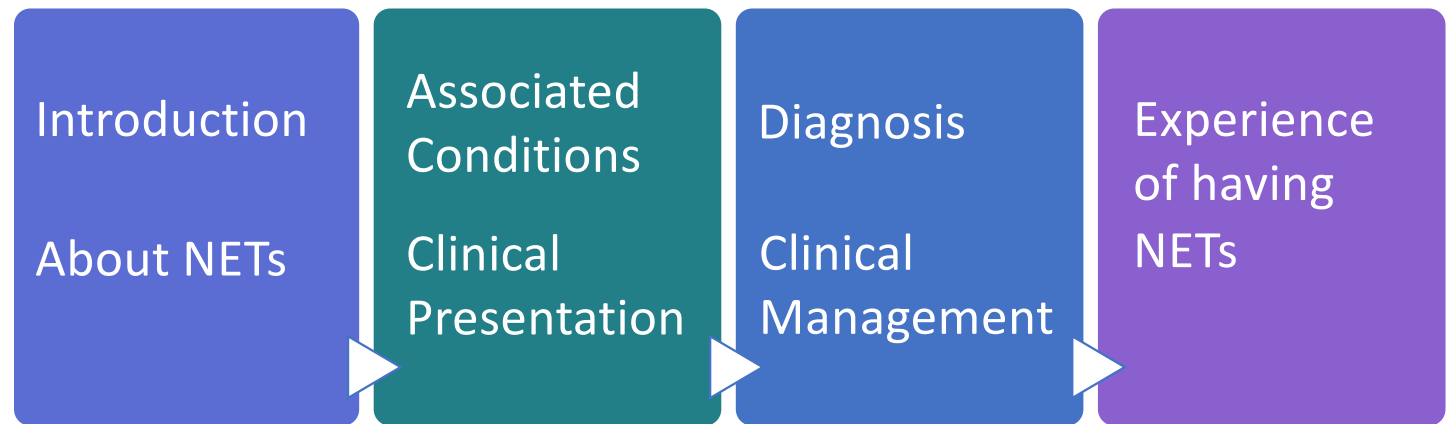


➤ Patient Stories

➤ Case Studies



NET Booklet: A guide for HCPs



- Revised by the NECA Consumer Advisory Group
- View on NECA website, PDF or FREE hard copy



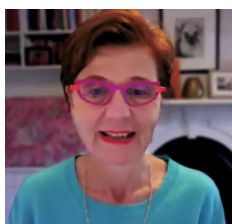
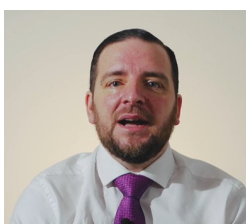
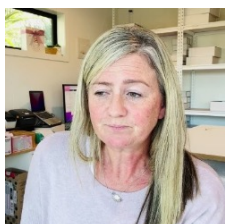
Optimal Care Pathway for people with NETs

Optimal
Care
Pathway

Quick
Reference
Guide

A guide to
best cancer
care

➤ Advocacy and Education Tool



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- NETs
- Risk Factors
- Symptoms
- Diagnosis
- Grading
- Staging

 **LIVE**

24



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- Treatments
- Carcinoid Syndrome
- Carcinoid Crisis
- Carcinoid Heart Disease
- Nursing approaches



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Feedback

60% of feedback from the **Will Norman Nurse Webinar** surveys indicated that **patient stories** and **lived experiences** were the **most valuable topic**.

"Great to hear from patients."

"Nice to appreciate the patient perspective especially from outside the UK."

"Learning about the different grading and staging. The patient stories to diagnosis".

"Patient experience regarding treatment"

Patients' perspective how **Optimal Care Pathway** has been useful for them.

HCPs should have it available, and that lack of knowledge in HCPs leads to less trust in them.

Indicated that they will take the OCP to their HCPs

Useful to give to their GP after diagnosis.

HCP Evaluation on **NET Modules**

"All the information I might ever want to know about NET is included here. I did like the video content and enjoyed much of the patient video content "

"good mix of medical focus, patient perspective and case study"



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Take home message



People living with cancer need to be recognised as experts through experience



HCPs gain unique perspectives that complement traditional clinical training



Improving awareness and empathy



Improved patient outcomes and more effective care for individuals with NETs



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