

LIVING WITH NEUROENDOCRINE CANCER: ONLINE PATIENT EDUCATION PROGRAM

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OBJECTIVES

INTRODUCTION

In 2022 NeuroEndocrine Cancer Australia (NECA) collaborated with Cancer Council Victoria to create and launch, Living with Neuroendocrine Cancer (NETs) an online patient education program for people with neuroendocrine cancer and those that support them. To our knowledge this is the first program of its kind in Australia designed specifically for neuroendocrine cancer.

NEUROENDOCRINE CANCER

Neuroendocrine cancer is uncommon, and so too are resources about the disease.

Neuroendocrine cancers can occur in many anatomical locations with common primary sites from the gastrointestinal tract, lungs and pancreas, to many other anatomical locations. Neuroendocrine cancer can be indolent or aggressive, functioning or non functioning, with subsequent hormonal syndromes only adding to the complexity of the disease.

24000 people in Australia are living with neuroendocrine cancer More than 5400 people are diagnosed annually. People often wait for over 5 years for a correct diagnosis once diagnosed people seek information from multiple sources. this online program has the capacity to assist those who are seeking further understanding of neuroendocrine cancer.

- Establishing an online program to deliver of resources directly to patients from every state and territory in Australia.
- Enhance knowledge about neuroendocrine cancer and its treatment options, and demystify medical information and terminology allowing participants a greater understanding of neuroendocrine cancer.
- Promote practical strategies, such as how to explain ambiguous symptoms to health care practitioners and management of ongoing disease symptoms, which has potential to enhance communication with health care practitioners and achieve more effective symptom management.
- Empowering people who are living with NETS with knowledge and building confidence and capacity to navigate and self advocate when engaging with the health care system.
- Create an interactive space where participants can meet other people with neuroendocrine cancer, share their stories and experiences and/or listen to others share their stories an experiences.

OUTCOMES

To date four Living with NETS Programs (2 pilot programs and 2 additional programs) have been attended by a total of 57 people. Feedback from participants was sought via survey following completion of each program.

COMBINED SURVEY RESULTS FROM OCTOBER 2022 AND MARCH 2023 PROGRAMS
RANKING OF SESSIONS BASED ON PARTICIPANT FEEDBACK

SESSION	RANKED BY PARTICIPANTS
Carcinoid syndrome, carcinoid crisis carcinoid heart disease	Extremely valuable 86%
Hearing the stories of others Living with NETS	Extremely valuable 60%
Fatigue management and NETS	Extremely valuable 57%
NETS and NETS treatment	Extremely valuable 44%
Navigating the health care system tips and resources	Extremely valuable 43%
Exercise and NETS	Extremely valuable 43%
Diet Nutrition and NETS	Extremely valuable 29%
Wellness	Extremely valuable 29%

CREATING THE PROGRAM

- Four two-hour sessions over four weeks.
- Sessions via zoom
- Facilitated by experienced cancer nurses with specialist training in neuroendocrine cancer
- Co-facilitated by trained volunteers who also have a diagnosis of neuroendocrine cancer
- Confidential safe space for questions and sharing personal experiences about Living with NETS
- Guest presenters including a dietician, exercise physiologist and occupational therapist
- The program aims to be interactive with presenters welcoming questions and conversation throughout presentations

Topics included:

- What are neuroendocrine cancers
- Treatments for neuroendocrine cancer
- Navigating the health care system
- Carcinoid Syndrome, Carcinoid Crisis and Carcinoid Heart Disease
- Nutrition for people with neuroendocrine cancer
- Exercise & Physical activity
- Management of Fatigue
- Finances, work and other concerns
- Wellbeing and self care
- Resources, networks and support available

CONCLUSION

The Living with NETS online education program aims to build knowledge and understanding of neuroendocrine cancer, it's symptoms and treatment options through accessible evidence based information. As an uncommon cancer, it is essential people with neuroendocrine cancer are supported to develop skills and confidence in self advocacy when navigating the health care system. The program is a valuable addition to the existing resources available for people with neuroendocrine cancer

NECA are motivated to create and continue the Living with NETS online education program is driven by a clear intention... to ensure the resource offering available for neuroendocrine cancer is on parity to the resources available for more common cancers.

NECA acknowledge the collaboration of

