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Bunbury support group hosting fundraiser to raise awareness about neuroendocrine cancer



Ezra Kaye | Bunbury Herald
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Ezra Kaye



Carl Jones, Christine Jones, Margaret Powell, Noel Powell, Dianne Ede and Ellen Davie. Credit: Ezra Kaye

A support group in Bunbury hopes to raise awareness about neuroendocrine cancer – an increasingly common disease in Australia widely unknown by the public and by medical professionals.

The South West Neuroendocrine Support Group hosts meetings on the first Tuesday of every second month at Cancer Council WA's Dot's Place in Bunbury to connect people with the disease.

NETS are tumours which usually develop in the pancreas, lungs, abdomen, reproductive organs and bowel within neuroendocrine cells which are responsible for producing the hormones that regulate many of our bodily functions.

Previously considered to be rare, NETS is now Australia's seventh most commonly diagnosed cancer, with more than 5755 Australian's diagnosed annually.

Christine Jones, who is a member of the support group, is participating in Neuroendocrine Cancer Australia's March4NETS fundraiser, by walking 3km to 4km every day this month to raise awareness and improve the lives of NET patients around the country.

Ms Jones – who is a registered nurse – was diagnosed in 2021 after five years of health problems.

After undergoing operations, including open heart surgery, she has made a significant recovery.



📷 Margaret Powell, Christine Jones and Cancer Council WA South West regional education officer Julie Rose. Credit: Ezra Kaye

“Unfortunately, I’m still a stage four cancer patient, so it’s incurable and I’ll just have to juggle my health for the rest of my life,” Ms Jones

“I’m doing this interview because I’d like to raise awareness of neuroendocrine tumours.

“I’m a registered nurse and I’ve worked in the health system my entire life, and I had never heard of neuroendocrine tumours until I was diagnosed with it.”

Ms Jones said it was “incredibly frustrating” it took so long to be diagnosed.

“I said to one doctor ‘I don’t understand how there could be not much wrong with me, because I am in so much pain’.

“He said ‘I’m sure it feels like that to you’ – so basically, it was dismissed.”

The support group’s facilitator Margaret Powell had a similar experience after it took eight years before she was eventually told she had multiple tumours throughout her mesenteric, liver, bowel, ovary, lung and nodes.

“It was almost a relief to know why I was experiencing the symptoms I had been having for years,” Mrs Powell said.

“I just hope eventually the community gets to know the symptoms, because at the end of the day, we are responsible for our own health and if we’re worried about something we should get it checked out.

NETS have a variety of symptoms which can be similar to other conditions such as irritable bowel syndrome, Crohn’s disease, peptic ulcer disease, other stomach and digestive disorders, asthma and facial flushing similar to that associated with menopause.

Mrs Powell encouraged those in the South West with NETS to join their support group.

“It’s given me a positive purpose, so it’s something I can do and it’s given me a lot of pleasure seeing how supported other people are,” she said.

“Sometimes support groups can be a bit sad, but generally we feel that they’re very positive – you meet people like yourself and you don’t feel so distant and alone.”

Donations for March4NETS can be made on the Neuroendocrine Australia website and for details about the South West support group, people can call 0427 426 025.