

'Robbed of years': The cancer you need to know about

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NEUROENDOCRINE cancer patient Rob Hammond lives off a chemo needle every 28 days. The legacy he wants to leave is a dedicated neuroendocrine nurse in Tasmania.

Philippa Morgan's mother Julene was diagnosed with stage four neuroendocrine cancer (NETs) in 2016, but she had never heard of it before despite a long career in healthcare.

Mr Hammond, Ms Morgan, and other advocates are calling on the state and federal governments to provide funding for specialised NET nurses in Tasmania, something that is currently lacking despite recommendations from a parliamentary inquiry.

"Her treatment would have absolutely been better if she had been diagnosed earlier and not misdiagnosed," Ms Morgan said.

"Although she did better than some people, she was robbed of years."

Despite being Australia's 7th most diagnosed cancer, many medical professionals still don't recognise NETs symptoms which leads to many patients being misdiagnosed or diagnosed too late.

Neuroendocrine Cancer Australia chief executive officer Meredith Cummins said about 60 per cent of NETs patients across the country are at stage four.

"My biggest frustration is we're still not getting federal or state backing, and we need a NETs nurse here," Mr Hammond said.

"My time's up fighting with politicians because I'm not getting anywhere, so I just hope someone is going to really listen this time."

Mr Hammond has advocated for more awareness and funding for NETs patients in Tasmania. His annual fundraiser, Racing for a Cure, was held on Friday, October 25.

PATIENTS FACE PHYSICAL AND MENTAL ISOLATION

Despite more than 700 Tasmanians living with NETs, many patients are unaware that there are others in their communities going through the same thing - a specialised nurse would help bridge the divide and isolation.

In a state such as Tasmania, access to consistent and adequate healthcare is already at a slight disadvantage, and that's without being diagnosed with a rare form of cancer.

"There's a real feeling of isolation for the NET patients," Ms Cummins said.

"Last year ... we did a patient forum at Launceston, and we had quite a few patients who were in the room, and they were living close to each other, but never knew that each of them had NETs."

Ms Morgan said while her mum was lucky to have strong family support, many patients can't say the same.

"If you can imagine a man in his 50s living at Zeehan trying to cope with this, [or] a young person in St Helens trying to cope with this, they have no one to talk to who understands their symptoms, can provide support, who can answer questions for them," she said.

"There are people who are suffering, and such a small investment could change so many lives. Public awareness and a NET nurse in Tasmania - it's not a huge ask."



Tasmanian NET consumer advisory group representative Philippa Morgan, NETs patient and advocate Rob Hammond with NeuroEndocrine Cancer Australia marketing and partnerships manager Adie Williams. Picture by Paul Scambler

'CANCER IS CANCER'

Ms Morgan became her mother's carer during the years before Julene's death in March 2023, and said having a specialised Tasmanian NETs nurse would have provided much-needed support.

"Especially around her end of life care, it would have been really nice to have someone to talk to about symptoms and processes, and some of the really deeply personal stuff that you have to go through," Ms Morgan said.

"For us, it would have been good to have someone there who could tell us information rather than us googling it. Cancer is cancer - it's a massive diagnosis for anyone."

A few weeks before her mother died, Ms Morgan said an emergency doctor in Hobart had to ask her what one of Julene's medications was and what it did.

"There's so little known about it in the community and even in the medical world," Ms

Morgan said.

"Just because you can't pronounce it and you don't understand it and it's not that marketable, doesn't mean that it's not deserving of exactly the same amount of funding and support for its patients than every other cancer"

A rare and commonly misdiagnosed cancer, NETs symptoms are often mistaken for more common conditions. In many cases it's diagnosed too late to be curable.

Ms Cummins has worked in oncology with NETs patients for nearly 30 years and has called for more awareness and resources dedicated to the cancer.

"There needs to be a lot of education for doctors, for the general community so that they can actually get diagnoses earlier and not be as far progressed when they are diagnosed," she said.

"It really needs to be acknowledged, and it needs to have equitable funding and resources, as all other cancers do."