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Kiwi women fighting for early ovarian cancer diagnosis and access to drugs

Joanne Carroll • 05:00, Feb 28 2019



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Sue Duncan, 56, a midwife who lives in Cambridge, was diagnosed with ovarian cancer in January 2017. She was given cancer drug Avastin, which is not publicly funded but was covered by her health insurance.

It took seven months of repeatedly going to her GP with bowel issues, bloating and pain before Lois Walton was diagnosed with stage 3c ovarian cancer.

She was finally diagnosed with ovarian cancer in December 2015.

"For seven months I was sent home with constipation medication. Then it only took one hour, following an ultrasound, and CT scan to find out I had stage 3c ovarian cancer, with a poor prognosis for long-term survival," she said.

A woman in New Zealand is diagnosed every 48 hours with ovarian cancer and is twice as likely to die than if they were diagnosed with breast cancer. They have to fight for access or fundraise thousands of dollars to get drugs that are not Government-funded which can prolong their life and increase their quality of life.

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Walton does not blame her Greymouth GP, who she says has been fantastic since diagnosis, but she says late diagnosis of ovarian cancer is all too common in New Zealand and is a result of a systemic failure among the medical profession and government departments.

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"Late diagnosis of this cancer in New Zealand is just another typical example of the lack of knowledge in the medical profession, not listening to their patients and early follow-up on testing when the symptoms occur," she said.

"Far too many women, many of them young, have died as a result of a late diagnosis. The medical profession, for far too long, have used the excuse it is hard to diagnose."

It can be hard to diagnose because the symptoms, especially the early ones, can be vague and mistaken for common complaints like irritable bowel syndrome. They may include abdominal bloating or swelling; pain in the abdomen, back or pelvis; change in bowel function, urinary frequency or urgency, eating less and feeling fuller, indigestion, unintentional weight loss, painful intercourse, fatigue and abnormal vaginal bleeding.

Walton believes there needs to be a national standard put in place, which means a patient who presents repeatedly with these symptoms is sent for early testing.

"It is becoming a national disgrace and a blight on the medical profession, who just send their patients away with medication for constipation, month after month.

"We all feel let down and ignored by government and health authorities, simply because it doesn't have the same exposure as breast cancer. They need to sit up and listen," she said.

Now 71, Walton has undergone four rounds of chemotherapy and is in palliative care.

Walton's friend and former work colleague Judith Day, 65, was diagnosed with stage 4 ovarian cancer almost 10 years ago. She was told she would only have five weeks to live if she did not begin treatment immediately.

"I thought because I'd been having regular smear tests I was fine. I didn't know smears don't pick up ovarian cancer. I had had a bowel prolapse so I put the symptoms down to that or menopause and kept putting off getting checked and was diagnosed far too late," she said.

"I have periods of good health and I try to keep fit and travel and enjoy my life but the cancer will never go away. I'm lucky I've responded well to treatment."

Day has undergone four rounds of chemotherapy and was given a trial of PARP inhibitor Lynparza but could not tolerate it. Lynparza is not funded in New Zealand and would have cost \$12,000 a month.

"It made me so sick that I had no quality of life, but it could help others and they should be given the chance to try it without worrying about the cost. People are so sick with this, they shouldn't have to be dealing with trying to get access to drugs that could extend their life," she said.



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Melanie Schonewille, from Whangarei, is fundraising for cancer drug Avastin, which she believes will prolong her life.

Melanie Schonewille, a travel agent in Whangarei, was diagnosed with stage 4 low grade ovarian cancer at 45 years old.

She first presented with symptoms three years before her diagnosis. Her doctor put her symptoms down to a previous fibroid and did no further investigation.

A scan she paid for herself showed a tumour measuring 14cm by 20 cm. She then had to wait four months to get an appointment with the hospital and another month for surgery. She wants to have cancer drug Avastin, which she believes will buy her more time and improve her quality of life. But it could cost up to \$50,000. Her friends have set up a [givealittle page](#) and are doing raffles and fundraising events.

Avastin is a tumour-starving therapy. Unlike chemotherapy, which attacks the cancer cells, the purpose of Avastin is to block the blood supply that feeds the tumour, which can stop it growing. Some women are lucky enough to have it covered by their health insurance.



JOANNE CARROLL/STUFF

Greymouth women Judith Day and Lois Walton are calling for more awareness about ovarian cancer.

Sue Duncan is 56, a midwife who lives in Cambridge. She was diagnosed with ovarian cancer in January 2017.

She was given Carboplatin and Paclitaxel, which are publicly funded, and Avastin, which is not.

Duncan was fortunate to have both health and income protection insurance. Insurance covered the whole cost – \$3900 each time, once every three weeks for nine months. She is now in remission.

For some, the cost of drugs is out of reach.

Karan Mortensen-Smith of Thames was diagnosed with stage 4 ovarian cancer in 2015.

Each time she goes to her regular oncology appointments she is told she could benefit from PARP inhibitors but they are not funded in New Zealand.

"It's \$9000 a month. I haven't done anything because we can't afford it. I'd have to take it every month for the rest of my life," she said.

"A friend offered to do fundraising but it's an ongoing cost every month. It's too much money to raise."

The last doctor she saw told her a couple of his patients were getting the medication from India for about half the price in New Zealand, but that price would still be too high for her.

She has been told the cancer will return in two or three years and she is determined to make the most of life while she can.

Rachel Brown co-founded [Ovarian Cancer Awareness NZ](#) and runs the organisation's support group to help women like her mother, who died of ovarian cancer in 2006. She wants the Government to ensure women are educated at smear time about all five types of gynaecological cancer and their symptoms. She wants more funding for cancer drugs and ultrasounds.

"Of the 120-plus women in our support group, about 95 per cent had experienced unnecessary delays to diagnosis and extreme distress and anger because of that, as well as potentially shortened life expectancy," she said.

It took most of the women about 12 months to receive a diagnosis from first experiencing their ovarian cancer symptoms. Kiwi women's five-year survival rate is almost 5 per cent worse than that of Australian sufferers.

"GPs are under funding restrictions and don't want to send all women with these symptoms for a blood test and an ultrasound because they don't want to put pressure on the system but if women are concerned they can

"We need GPs to change their mindset. Women in NZ are doubly short-changed. We get a late diagnosis due to failings of our medical practitioners and lack of access to the right diagnostic tools, and then, when trying to extend our lives as long as possible, we can't get access to the medicines we need. People affected by ovarian cancer are failed and forgotten by an unnecessarily fatalistic attitude," she said.

Pharmac director of operations Lisa Williams said it had received funding applications for Lynparza and Avastin.

The funding for Avastin has been recommended for decline by the Pharmacology and Therapeutics Advisory Committee.

In November 2018, the committee recommended that Lynparza be funded with a medium priority for the treatment of BRCA-mutated platinum-sensitive relapsed ovarian, fallopian tube cancer.

Williams said Pharmac needed to be absolutely sure the medicines delivered the benefits companies claim they do, and that public money was spent wisely. "The flipside is considering funding a treatment with high uncertainty about its results, with the reality that it would take away funding from other more proven treatments."

Ministry of Health cancer services manager Dawn Wilson said the ministry had planned a Cancer Action Plan which was expected to look at improvements in cancer care and compare the quality of care and outcomes for people with cancer in different DHBs and other countries.

"There has been a lot of research to develop a screening test for ovarian cancer, but unfortunately there hasn't been much success so far," she said.

"Unfortunately ovarian cancer is very difficult to detect and because it is often diagnosed at a later stage it is also difficult to treat to achieve good results. The ministry has considerable sympathy for anyone affected by ovarian cancer."

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