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m+ EXCLUSIVE My tiredness and IBS were signs of a devastating disease that is often found way too late. Don't make my mistake and brush it off as the menopause

By BEK DAY

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Jo O'Halloran was in her early fifties when the symptoms she and her friends had heard so much about started to appear.

'I was always tired,' she tells me.

'I was working a fairly busy job and caring for my ageing mother, so you expect to be tired, but this was quite severe. I also had nausea, brain fog, constipation, cramping in my stomach and things like that.'

When Jo spoke to girlfriends around the same age, they were quick to reassure her: it's **menopause**.

'Part of me thought, "Oh, well, I suppose I just need to get on with it", but the fatigue began to be really quite extreme,' Jo **recalls**.

She saw her GP and explained her symptoms. He ordered a blood test, which came back within the normal ranges, which left Jo thinking perhaps she'd been overstating her symptoms.

'I went away going, "Okay, am I making this up? Am I really this tired?"' Jo says.

'So I decided perhaps I needed to improve my lifestyle. I bought a treadmill, started getting fitter, eating better, all those types of things, but the exhaustion was just constant.'



Jo O'Halloran was tired all the time and suffering with nausea, brain fog, constipation and cramping in her stomach

It was then that Jo switched GPs, and saw someone specialising in women's health and menopause. With Jo's combination of symptoms, her new GP also suspected it was menopause-related, and started her on hormone replacement therapy (HRT).

'After that, I felt like, "Okay, I'm handling it. I'm looking after my menopause,"' says Jo.

'I was still so, so tired, still having hot flushes that weren't going away, but I was taking the tablets and just trying to get on with life, to be honest.'

It wasn't until a quiet Monday about two years later that Jo would discover there was something else very wrong.

'I had a niggling pain in my side that was getting worse,' she recounts.

'So I called my doctor to make an appointment. Because I had a fever, and they were following Covid protocols, they advised me to go straight to the emergency room.

'When I got there, they ordered scans and told me it was likely diverticulitis. A few hours later, I was waiting to be transferred to the ward when the doctor came in and told me they'd discovered a large mass on my pancreas that had already metastasised to my liver.'

Over the course of the following week, Jo was diagnosed with a cancer she'd never even heard of: neuroendocrine cancer.

Neuroendocrine cancers, also known as neuroendocrine tumors (NETs), are a group of uncommon cancers that originate in neuroendocrine cells, which are found throughout the body and produce hormones.



Doctors and friends told her the symptoms were likely caused by menopause



By the time Jo was diagnosed with neuroendocrine cancer, it was already stage 4 and inoperable. She describes it as a 'very lonely, surreal experience'

These tumors can be slow-growing or more aggressive, and can occur in various locations, including the digestive tract, lungs and pancreas.

'It's like everything you thought you knew about your life suddenly comes crumbling down,' Jo explains.

'To go from thinking everything was normal and fine, to being told that you have stage-four inoperable cancer, it's just a very lonely, surreal experience.'

According to the latest stats from the Australian Institute of Health and Welfare, there were just under 6,000 new diagnoses of neuroendocrine cancers last year. According to Meredith Cummins, CEO of Neuroendocrine

Cancer Australia (NECA), there are about 30,000 Aussies currently living with neuroendocrine cancer.

'Unfortunately, because many of the symptoms of these kinds of cancers can mimic symptoms of other, less-serious conditions, many of these patients have been misdiagnosed for an average of five to seven years,' she explains.

'For that reason, about 60 per cent are at stage four by the time they're diagnosed.'

This was also the case for Pat Meehan, whose diagnosis in 2014 came 12 years after she first started experiencing symptoms.



Pat was suffering with symptoms for 12 years before she got a diagnosis of neuroendocrine tumours

'At first, my iron stores just kept on dropping, and I was having a lot of gastrointestinal upset, so doctors kept sending me for endoscopies and gastroscopies,' Pat says.

'I'd go on iron pills for a while, my levels would come back up, and then they'd drop again. I also experienced flushing, as well as pain in my stomach.'

Pat was on holiday in Queensland when she recognised the now-familiar symptoms of very low iron.

'I was feeling awful, so I went to the doctor and this absolutely lovely doctor who did some blood tests and said, "Yes, your iron is very low, and if you were my mother, I wouldn't let you drive back to Albury until you had an iron infusion."

'So I ended up having to stay overnight in the Toowoomba hospital and have an infusion. By the time I got back home to NSW, I told my GP to send me to a new specialist, because I needed to get to the bottom of it.'

Pat's new specialist sent her for a new exploratory procedure, a capsule gastroscopy, where she swallowed a small camera to more thoroughly check what was going on.

'Within three weeks I'd been diagnosed with NETs (neuroendocrine tumours), and it was an absolute shock to find out it was inoperable and incurable.'

While both Pat and Jo are currently receiving targeted therapy to help manage their NETs, the women believe that if their cancer had been caught earlier, there would have been more treatment options, and it might even have been curable.

'When caught early, NETs are often able to be operated on and removed before they metastasise,' explains Meredith Cummins.

'But the problem is there is so little awareness about this type of cancer, even among the medical community. I've had GPs that say to me, "I've never seen a neuroendocrine cancer patient in my life." And I say: "well, you probably have, but you didn't diagnose them and they got frustrated and went to somebody else."

NECA continues to campaign for greater education surrounding the disease - now the seventh most commonly diagnosed cancer in the country - among both medical professionals and the general public.

'It's just a sneaky cancer,' says Cummins.

'Patients know something is wrong, with many of them going to their GP over and over with the same symptoms. It can really make it so frustrating for the patient.

'Some of them I know have actually been referred to psychiatric assessment, but it's not in their heads. They know they've got something wrong with them - it's just not been diagnosed.'

Because neuroendocrine cancers can develop in several different parts of the body, the symptoms can be hard to pin down, but include:

- Fatigue and loss of appetite
- Abdominal pain and bloating
- Unexplained weight loss
- Nausea or vomiting
- Changes in bowel habits
- Flushing of the face
- Wheezing or difficulty breathing
- Heart palpitations or rapid heartbeat

Jo, who is currently undergoing Peptide receptor radionuclide therapy (PRRT) to treat her cancer, says her biggest takeaway has been that if something doesn't feel right, don't stop trying to seek answers.

'Women know our bodies,' she says.

'We know when something isn't right. If you're having symptoms that don't resolve, keep pushing.'

'If they'd found my cancer earlier, there would have been so many more options.'

'Trust your instincts and advocate for more tests. Ask for a scan. Ask them to do more tests. You're allowed to keep pushing for answers.'