Changing the odds

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Changing the *odds*

Today, just one in two women diagnosed with ovarian cancer will be alive in five years. Yet advances in research are bringing new hope for one of the deadliest cancers affecting Australian women.

WORDS BY MELODY TEH

At 21, Emily Jol's life was busy and full. She was studying law at university, working a couple of jobs and living with her best friend in Sydney.

"Life was normal," she tells *The Weekly*. "And then I started to get these really strange heavy periods."

Emily told herself it was probably nothing. But soon she was bleeding through her jeans and changing tampons within minutes. Worried, her best friend booked a GP appointment and drove her there. "Periods suck," Emily remembers being told. "You're a woman. You're going to have to get used to it."

But over the following months, Emily's symptoms worsened. Her hair was falling out. She was vomiting and constantly needing to pee. The pain became so severe she couldn't sit through her classes or sleep at night. Every week or two, she went back to the doctor, trying to explain that something was seriously wrong.

"I really started to question my own reality," she recalls. "It was weird to have everybody tell me that there was nothing wrong with me while I felt trapped in a body that I could feel was deteriorating."

Then everything changed in a matter of days. A scan on Thursday. Emergency surgery by Monday.

Only after the tumour was removed did Emily learn what it was: Stage 1A ovarian cancer. She was 22.

Surgery was enough because the cancer was contained to one ovary. Her doctor told her it had been a "close call".

Today, Emily is 28 and in remission. She knows how lucky she is. "It's a happy ending," she reflects. "And not many people get that with ovarian cancer."

Ovarian cancer is one of the deadliest cancers affecting Australian women. Around 1900 Australians are diagnosed with ovarian cancer each year, and more than 1000 will lose their lives from it. Just 49 per cent of those diagnosed survive at least five years, compared with 92 per cent for breast cancer and 74 per cent for cervical cancer. The survival rate has remained stubbornly below 50 per cent for decades.

Playing catch-up

For Robin Penty, CEO of the Ovarian Cancer Research Foundation, ovarian cancer has been left behind for too long. "This is a disease where we're still playing catch-up."

There are many reasons. Symptoms are vague and easily mistaken for

other conditions – bloating, nausea, exhaustion, changes in bleeding or needing to urinate more often. Because ovarian cancer is more common after 50, those changes are sometimes put down to menopause. There is still no early detection test – and a pap smear does not detect ovarian cancer. Too often, by the time women are diagnosed, the disease has already advanced.

The problem is also one of long-standing neglect. Robin points out that less than one per cent of medical research funding in Australia has gone towards gynaecological cancers over the past 20 years, leaving ovarian cancer "overlooked, underfunded, and as a result, just under-researched."

That has consequences. "Only one in two women diagnosed today will be alive in five years' time," she says. "Treatments are poor and lagging behind many other cancer types."

Despite the scale of the challenge, Robin sees reason for hope. Breast cancer has shown that awareness, funding and research can shift survival rates. Ovarian cancer now needs the same sustained focus – and the same urgency.

Not one disease

Early detection remains one of the most pressing goals in ovarian cancer. But University of Sydney Professor Anna DeFazio, Head of Gynaecological Oncology Research at the Westmead Institute for Medical Research, cautions that it is not the whole answer. "The idea that, if we just pick it up early and everything will be fine, is too simplistic."

Ovarian cancer can be "intrinsically aggressive", Anna explains, and can spread outside the ovaries or fallopian tubes before a woman experiences any warning signs.

Even when ovarian cancer is found, there is another layer of complexity: it is not one disease. "There are many different types, and they're quite different from each other," Anna explains.

Ovarian cancer has more than 30 subtypes, meaning the cancer affecting one woman may not behave, respond to treatment or recur in the same way as another.

Treatment is commonly surgery plus chemotherapy. Yet DNA sequencing and molecular profiling are showing why subtypes matter – and why different approaches are needed. "By understanding more about the genes that drive the cancer in each woman," Anna says, "we can start to tell what treatments might work best."

The hope is that ovarian cancer treatment will become more personalised. "The key is to find what the molecular changes are and match therapies to those changes," she says.

Below left: Emily Jol was diagnosed with ovarian cancer at the age of 22. Right: Professor Anna DeFazio is hopeful more research will lead to better treatment options.

New ways forward

For some women, more targeted treatment is already changing care. PARP inhibitors are a class of targeted drugs used for some ovarian cancers with BRCA1, BRCA2 or similar DNA-repair changes. Anna describes them as "game changing".

Garvan Institute Lab Head and UNSW Associate Professor Liz Caldon has seen how PARP inhibitors have changed what treatment can look like. "It's a tablet," Liz explains. "People have great quality of life with this class of drug. They can take it home. They can travel and work more easily."

The challenge now is to keep them working for longer. Over time, some ovarian cancers find a way around PARP inhibitors. Liz's research is trying to understand what changes inside those cancer cells when the drugs stop working, so treatment can be adjusted sooner.

That search for more targeted answers is also at the heart of Anna's research into low-grade serous ovarian cancer – a rare subtype, and the one Emily was diagnosed with. It accounts for only about five per cent of ovarian cancers, making research and clinical trials harder. It tends to affect younger women and does not usually respond well to standard treatment.

As Robin puts it, ovarian cancer research is "a marathon, not a sprint". These are not discoveries that move from the lab to a patient's bedside overnight, but the work being done now is what researchers hope will change what is possible in the years ahead.

These days, Emily has built a life she loves. She still lives with her best friend in Sydney and works in policy and law reform.

But remission does not mean ovarian cancer simply disappears. For years after surgery, Emily had regular scans and blood tests every few months. Those appointments are now less frequent, but she knows she will always have to pay attention to her body.

Talking to other women affected by ovarian cancer has made Emily even more aware of how close her own story came to being different.

"It really drives home how fortunate I was. Not a day goes past where I don't think about that."

The hope is that more women get the same chance. **AWW**

For information and support, visit ovariancancer.net.au or call 1300 660 334.