

“I’LL GIVE UP MY OVARIES TO SAVE MY LIFE”

As March is Ovarian Cancer awareness month, Nicki Whitaker, 31, shares her story of loss and sacrifice at the hands of the disease



AFTER A DOUBLE MASTECTOMY NICKI NOW FACES SURGERY TO HAVE HER OVARIES REMOVED

“ I don't make a habit of looking at my naked body in the mirror – but when I do, I see scars. I have two large ones, salmon pink in colour, that run underneath each breast, and a large raised white slash, across the width of my back. Two centimetre-long nicks sit on each hip, and a further two lines flank my belly button. There are seven scars in total. Sometimes it feels like I have been hacked to pieces and sewn back together like a rag doll. But that's OK; these scars could end up saving my life.

Between 2010 and 2013 I had five operations on my breasts and torso. First, a double mastectomy followed by immediate reconstructive surgery on my breasts, and then, after experiencing complications – including an infection that left a gaping hole in my breast – a further four invasive reconstructive operations over the next three years. This is because, four years ago, at the age of 26, I was diagnosed with the BRCA2 gene mutation. Doctors sat me down and gently told me that I had a 45% risk of developing breast cancer and

a 17% chance of ovarian cancer, but I wasn't remotely surprised to be given the diagnosis. I simply said to the consultant, “I knew that. Now what?”

It was my older sister Stephanie who had first suggested I get tested, back in 2007. She was well acquainted with the BRCA2 gene at that point. It all began with her going back and forth with GPs who told her that her bloated stomach and difficulty going to the toilet were a result of an umbilical hernia. She was rushed to hospital and underwent tests that would establish that actually she was

experiencing the symptoms of stage two ovarian cancer. She had her blood drawn and studied by geneticists who told her that her cancer was likely a result of a genetic mutation that could have been passed down for generations through either maternal or paternal lines.

At first, I put off having the same test. At that time, Stephanie was going through gruelling rounds of chemotherapy and suffering a lot from the side effects – I remember a nurse being called out to our house in the middle of the night to administer an injection to

stop her vomiting so much. I wasn't ready to face anything else; all my strength was channelled into worrying about Stephanie – finding out if I was carrying the gene wasn't a priority for me. Looking back, I can see this was just a way of putting off bad news. I knew the test would be positive. I was just shifting back the moment when I would have to make some very big decisions.

As well as the chemotherapy, Stephanie had her ovaries and fallopian tubes removed. But eventually, after a short period in remission, in 2008 the cancer returned and doctors told us it was terminal. Stephanie, then 28, spent her last two months in St Leonard's Hospice in York. It might sound odd, but it was a really lovely time. A hospice is designed to make people comfortable and it was a wonderfully calm environment. I would go and sit with her with my mum, dad and stepdad or we'd make ourselves a meal in the kitchen attached to her room. I remember lying in her bed with her and watching the *Sex And The City* film. She was desperate to see it but hadn't been well enough to get out to the cinema, so my father-in-law bought her a copy to watch.

We had a long time to prepare for the fact that Stephanie was going to pass away, and the last time I saw her, I just knew in my bones that I was never going to see her again. I told my mum and stepdad on the way home that I wasn't going to go back to the hospice; she died later that night. I was brought up as a Christian so when she did pass away, my overwhelming feeling was that it was all over and she was at peace. It was actually very comforting.

GETTING TESTED

After Stephanie died, it took a year for me to make the appointment with the geneticist. I kept putting it off – I hadn't felt ready to know – but I eventually made it to the clinic, and wasn't at all shocked to get the news that I carried the BRCA2 gene, too. My dad had lost his mum to breast cancer so the signs were there [BRCA1 and BRCA2 gene mutations are relatively rare but each child



NICKI (RIGHT) WITH HER OLDER SISTER STEPHANIE



NICKI WITH HER HUSBAND STUART

has a 50% chance of inheriting a parent's mutation]. I'm also a pessimist; I just assumed the tests would be positive.

I wasn't upset by the diagnosis at first. In fact, I didn't really feel anything at all. In my previous appointment with the consultant, we'd discussed what my options would be if I did carry the gene. We'd already established that I would immediately have a double mastectomy and then undergo surgery to remove my ovaries further down the line. I knew it was what I wanted. This was my chance to be in control of what happened in my life. The previous couple of years had been painfully out of my hands; I was still grieving for Stephanie

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and I would do anything I could to prevent my family having to go through that again. So I just thought, 'Let's get this ball rolling.' But a couple of days afterwards, when I walked into the restaurant where I work as a waitress, my boss asked how I was and I began to cry. Saying the words aloud hammered it home.

Once my surgery timetable was in place, emotion got left behind. When I met with the surgeon who was going to carry out my mastectomy he said, 'When you get breast cancer,' not *if*, and that's when it became something that just had to be done, and I went into full survival

mode. Seeing Stephanie ravaged by cancer spurred me on, too. What she endured was so much worse than anything

I would have to face; I don't think I'd cope with cancer in the stoic and dignified way she did. This was what I had to do to make sure I didn't have to put that theory to the test.

UNDER THE KNIFE

My husband Stuart was fully supportive of my decision to have my breasts removed, and before it happened I didn't give a second thought to aesthetics. In a way, I wish I'd thought about it more; that I'd stopped to understand that my body might look different, that I might feel less feminine and life might be slightly different after all this surgery.

In the weeks following the mastectomy – an operation during which surgeons removed my breast tissue and replaced it with artificial implants – I had a lot of complications. My body reacted badly to the silicone and I had multiple infections resulting in a hole forming in one of my breasts. I was in and out of hospital and there was talk of having to replace one of my implants completely. That was the only time I really paid attention to the physical effect this was having on me. I thought, 'I'm going to have to walk around with one boob and I'm going to look ridiculous.' In fact, I ended up having a further four reconstructive operations over the next three years to replace the tissue using fat and muscle from my back, hips and stomach – evening out my breasts and making them look 'normal' again. I've had dark moments and wallowing periods of 'why me?' But thankfully, they've been short-lived. I learnt early on that there's no point in feeling bitter or resentful; that won't change anything.

Now I've recovered, I'm faced with an oophorectomy [surgery to remove the ovaries], and I'm utterly terrified. Having your reproductive organs removed has a knock-on effect – it kickstarts early menopause and can cause health issues such as brittle bone disease. And the idea of the surgeons operating so deep inside me scares me too – with my breasts it felt like everything was on the surface. But it will be a huge relief when it's over. Because cancer in your ovaries is so difficult to detect, I have to stop myself obsessing over the fact that tumours could be spreading inside my body right now and I probably wouldn't know.

Stuart and I are actively trying to conceive. We've agreed that we'll just have the one baby – we both have the same image in our head of a happy three-person family. I'm giving myself four years, then when I'm 35 I'll have the surgery. Having the BRCA2 gene has put a timeline on our future with children but it's OK. This is not the end of the world. We have been posed a problem and this is how we're solving it. I'm lucky I will still have a family after all this. My sister never had that chance." 

For more information visit ovarian.org.uk

HOW TO SPOT OVARIAN CANCER

The symptoms of ovarian cancer are often hard to spot and can be confused for other illnesses such as IBS and polycystic ovary syndrome. If you experience any of the below on most days it's important to talk to your GP as soon as possible.

- ◆ Persistent stomach pain
- ◆ Persistent bloating
- ◆ Difficulty eating or feeling full quickly
- ◆ Needing to urinate more often
- ◆ Fatigue
- ◆ Back pain