

Real Life Health – A Fatal Inheritance

By Vicky Honour & Sian Lewis - Women's Own Magazine 2003

When Jo Faulkner was told she would develop bowel cancer, she had her bowel removed - as did her son and daughter. Now her 13-year-old granddaughter faces the same fate....

It was the moment Jo Faulkner had always dreaded. 'I'm going to have my bowel removed just like you,' said her son, Kelcey. Shakily, he reached out to put his hand on his sister Lyndy's arm - 'And so is she.'

For 34 years, Jo, 55, had fought the cancer that had ravaged her body. She thought she had faced life's hardest test - and won. But now a simple test had turned her life upside down, proving that Jo's two children and even her 13-year-old granddaughter, Leanne, carry the same cancer gene that she does - one that will kill them unless each of them has their bowel removed.

'It broke my heart to think that my kids were going to have to go through serious surgery at such a young age,' says Jo. 'I never thought I would reach the age I have because of cancer, but the idea that my children and grandchild would also suffer was almost too much to bear. 'But we are a strong family and we will get through this.'

Jo, a mobile hairdresser from Leicester, first found a lump in her stomach when she was just 21. It was 1968 and life was good. She and husband Pete, now 58, had a healthy two-year-old daughter, Lyndy, now 37, and their son, Kelcey, now 35, had just been born.

She was washing up when she felt a lump in her stomach as she brushed past the kitchen counter. I went to the doctor the next day and was told it was a tumour the size of a golf ball and that it had to be removed immediately,' says Jo.

'It was only after I'd had the operation that I was told the lump had been cancerous. Hearing that word was as if a death knell had been sounded for me. 'I was faced with the prospect that I might not live to see my children grow up. It was early December, and I thought this could be my last Christmas.' Luckily, the operation was a success, but only two years later, another tumour appeared.

Over the next 15 years, Jo was operated on in Leicester City General Hospital every two years, having a total of seven tumours removed. Then, at the age of 37, it seemed that Jo was finally cancer free. There were no more tumours, and it looked as if the cancer had retreated.

But just three years later, Jo found yet another lump - this time in her breast. 'It was so unfair,' she says. 'To have gone through so much pain just to have the cancer appear somewhere else. I felt I might never be free of it.' However, after an operation to remove two lumps - which turned out not to be cancerous - Jo felt healthier than ever, and for the next five years she was tumour free.

Unfortunately, though, it wasn't to be the end of her association with cancer. Jo's cousin Ruth, who had also been fighting cancer for years, had a genetic test, which showed she had a gene called familial adenomatous polyposis (FAP) - a rare condition where carriers are 100 per cent guaranteed to get bowel cancer. 'Suddenly we had an explanation why my family were so susceptible to bowel cancer,' says Jo.

'I went for a gene test myself, and it came back positive. So my doctor told me I would need a colonoscopy - where surgeons would look at my bowel through tiny cameras.' Jo was told there was a five-year waiting list for the operation, but she was reassured that she was in no immediate danger.

During that time her thoughts turned to her children, Lyndy and Kelcey. There was a 50/50 chance they would have the gene - but Jo prayed that life wouldn't be so cruel. Sadly, it was. 'When both their test results came back positive, my guilt was overwhelming,' says Jo, her voice cracking as she speaks. 'I had passed on this killer gene to my children without realising it.' Lyndy and Kelcey were equally distraught. 'It was like a time bomb inside my body,' says Kelcey. 'I know Mum feels responsible, but it's not her fault.'

Lyndy and Kelcey started to discuss having their bowels removed - but their decision wasn't finalized until their mum went into hospital colonoscopy. Doctors found over 200 polyps or small growths, in her bowel, and because she carried the FAP gene it meant there was a 100 per cent chance that at least one of them would turn cancerous. Not only that, but the doctors warned that in a couple of years they would be having the same conversation with Jo's children.

The only chance of avoiding cancer was to remove her bowel before the cancer could develop. 'I fell apart after hearing that,' says Jo. 'All the fight was knocked from me.' However, she knew what had to be done. And in November 2001, Jo had her large colon, rectum and womb removed. When she came round from the anaesthetic, she saw her ileostomy bag - to collect her waste for the first time.

'The next few weeks were the hardest of my life,' Jo explains. Pete was a star though. He visited me every day, and he and the children even tried to make a joke of my bag by calling it Gizmo!

Yet all the time, Lyndy and Kelcey were facing their own private hell. 'The choice was easy for me,' says Lyndy. 'I had seen what Mum had been through over the years, and I just wanted to get my operation over and done with as soon as possible.'

In fact Lyndy was in The Leicester Royal Infirmary for her operation in January 2002, just three weeks after her mother had had hers, when Jo was rushed back in with postoperative complications.

Then, in April 2002, Kelcey had his bowel removed. Afterwards, doctors made a chilling discovery - without surgery he would have developed bowel cancer within a year. Any doubts the family had were erased by this shattering news.

So when Lyndy's 13-year-old daughter, Leanne, started to suffer bowel problems and was sent for a genetic test, the result sent further shock waves through the family. 'I can't describe how I felt when I was told that Leanne faced the same surgery at such a young age,' says Jo, shuddering at the memory. 'I felt so powerless against this tiny something inside of me that was moving through the generations of the family I love so much.'

Leanne's brother, 14-year-old Lewis, has tested negative for the gene. 'And we're here for Leanne. We'll conquer this together - as a family.'

To prove that life goes on, Jo has just completed a 300-mile walk with Pete to raise money for Macmillan Cancer Research. The walk, which ended in June this year, has so far raised more than £4,000.

'It was tough, but as I get older, I feel stronger and stronger,' says Jo, whose ileostomy bag has now been replaced by an internal pouch that collects her waste.

'When I was younger, I could never imagine how I was going to cope every time I got cancer again.'

'But now, after everything I've been through, I feel I can cope with absolutely anything. This fatal legacy tried its best to get rid of us, but we have beaten it.'