

After losing my sister and mother

I WANTED TO HELP OTHER WOMEN

When ovarian cancer killed both her mother and sister within weeks of each other, Joanna Barker, 53, decided to set up Target Ovarian Cancer, a charity dedicated to raising awareness and finding a cure for the disease

My sister, Sarah, and my mother died within six weeks of each other in the summer of 2005. My mother was 74, and diagnosed five years before, after she had some bleeding. She was whipped into hospital, a doctor picked it up and she was treated very quickly with surgery and chemotherapy, which was successful. Then she had a recurrence, which was treated, but without success.

But despite my mother's experience, we didn't recognise what was wrong with my sister, who was only 40 when she died. She had slightly different symptoms but what shocked us was that Sarah

didn't guess, her family didn't guess and her GP didn't guess what was wrong with her. So she went six months without being diagnosed. Sadly, I've since discovered that for almost a third of women with ovarian cancer, it takes six months or more to be diagnosed, because women themselves don't know much about the disease and GPs find it difficult to diagnose.

I was very close to my sister. Being the two girls in a family of boys, we had shared a room for 16 years. She worked in the National Health Service at Stoke Mandeville Hospital, and I'm glad that the

one thing I never had to regret was that we didn't spend enough time together. I'm very pleased that we did.

My mother was extraordinary. At one point she had six children under the age of eight. What I learned from her is that, however hard things are, you just get up in the morning and carry on; there's no point moaning about how difficult your life is. We were all incredibly fond of her.

When they lose somebody they love to cancer, a lot of people want to do something. Some want to set up a memorial trust, others want to raise money for the local hospital. These are extremely valuable and important things, but I wanted to do something that would have a more permanent impact.

I've spent 30 years working in business and finance. I'm a managing partner for Advent International, a global private equity firm that works closely with the companies that we invest in, so I have had a lot of experience of what good management teams can do. People with the right energy, skill and determination can change the world. I'm used to dealing with quite big things – and numbers with lots of zeros after them. I'm used to the idea that if you know what to do or who to talk to, you can do something quite big.

My original aim was to do something about the extremely low awareness of ovarian cancer, and therefore late detection. And also the fact that England has the worst survival rates in Europe – probably due to late detection. But also, many women with ovarian cancer say that they feel completely isolated and unsupported. And then we discovered there have been no new treatments for 20 years. So I wanted to address that too.

We outlined three areas of ambition for the next ten years: survival rates in Britain should be at least as good as the rest of Europe; women should no longer feel friendless and unsupported; and there should be at least two treatments in phase-three trials (meaning the most advanced stage of a clinical trial).

We hired an independent firm to do a public-awareness survey. It found that only four per cent of women could identify a single symptom of ovarian cancer and that the majority of GPs didn't know that the Department of Health had issued guidelines on diagnosing it. The problem is that ovarian cancer is not easy to diagnose because the symptoms are the kinds of things that all of us have at some time or another. But the guidance is that if you have a combination of one or more of them, persistently and regularly, then you should see your doctor.

My sister and mother tested positive for a particular genetic abnormality, which can make ovarian cancer more likely. Not everyone with this gene gets ovarian cancer, and not everyone with ovarian cancer has this gene, but if you have it in your family, you need to be aware of it. I am very fortunate because I don't have

it, but the gene can be passed down through men too, and two of my brothers tested positive.

It used to be believed that by the time you have symptoms of ovarian cancer it was already too late and that there were no early-stage symptoms. That's not true. It has been demonstrated that people who have symptoms can find their cancer is still eminently treatable. Women need to be persistent.

As the eldest of six children I was brought up not only with a sense of responsibility, but a sense of possibility. My father, who was a neurologist, taught

Women who are told that they have symptoms of ovarian cancer can find that it is still eminently treatable

us that if you work hard enough and apply yourself to something, you can succeed. He had very high expectations, which meant he was not an easy man to live with, but he was very inspiring and probably my greatest influence.

I was in the fortunate position of being able to find the start-up capital for Target Ovarian Cancer, but my financial involvement will reduce over time. The money comes first – and very importantly – from our volunteer supporters, the women with ovarian cancer and their families and friends who raise money, and that's a very important contribution. We also have support from some trusts and foundations, plus some major donors.

My job now consists of a lot of travel to eastern Europe. I work very long hours but the deal I have with my husband is that we know where each other is from Friday night to Sunday night. He's a human resources director by profession but he left corporate life a few years ago to dedicate himself to not-for-profit activities. He is enormously supportive

and I'm extremely fortunate – not many men would've put up with the kind of lifestyle I've had for the last few years. But I think he'd prefer to have a happy wife.

We're both extremely interested in music of all sorts, ranging from opera to musicals. I do yoga every Saturday and I swim every Sunday. And a few years ago I took up painting, not having painted since I was nine, but I find it extremely therapeutic. I painted a picture of a Caribbean sunset and gave it to my sister. She had it by her bed for the last six weeks of her life. It wasn't one of my best, but she liked looking at it.

Target Ovarian Cancer has short-term as well as long-term aims. Getting together with other women with ovarian cancer makes women feel less isolated, so we've started running courses around the country; general wellbeing days, but also training for women who want to become advocates and ambassadors, speaking out and giving interviews to raise awareness. It's their opportunity to try to turn this dreadful experience into something positive.

What's amazing is that the general atmosphere at these meetings is so positive, determined, and upbeat. These women are putting huge energy into making a difference. I cannot make a difference on my own, but by creating that spark and helping support it, I can enable all these other extraordinary people to come together and achieve something. I'm very proud of my charity for making that happen.

Turn the page to find out more about symptoms and how you can help Target Ovarian Cancer make a difference. >>



Target Ovarian Cancer is working to improve early diagnosis and save lives, find new treatments and support women so they can lead their lives to the full. For more, see targetovariancancer.org.uk