



Running on ENDO

Often misdiagnosed, or not diagnosed at all, endometriosis is difficult to treat but it needn't mean an end to your running

Words: Laura Briggs

Philadelphia Holmes has raced in ultramarathons across the world, but the pain of endurance running pales into insignificance compared to the pain she has suffered with endometriosis.

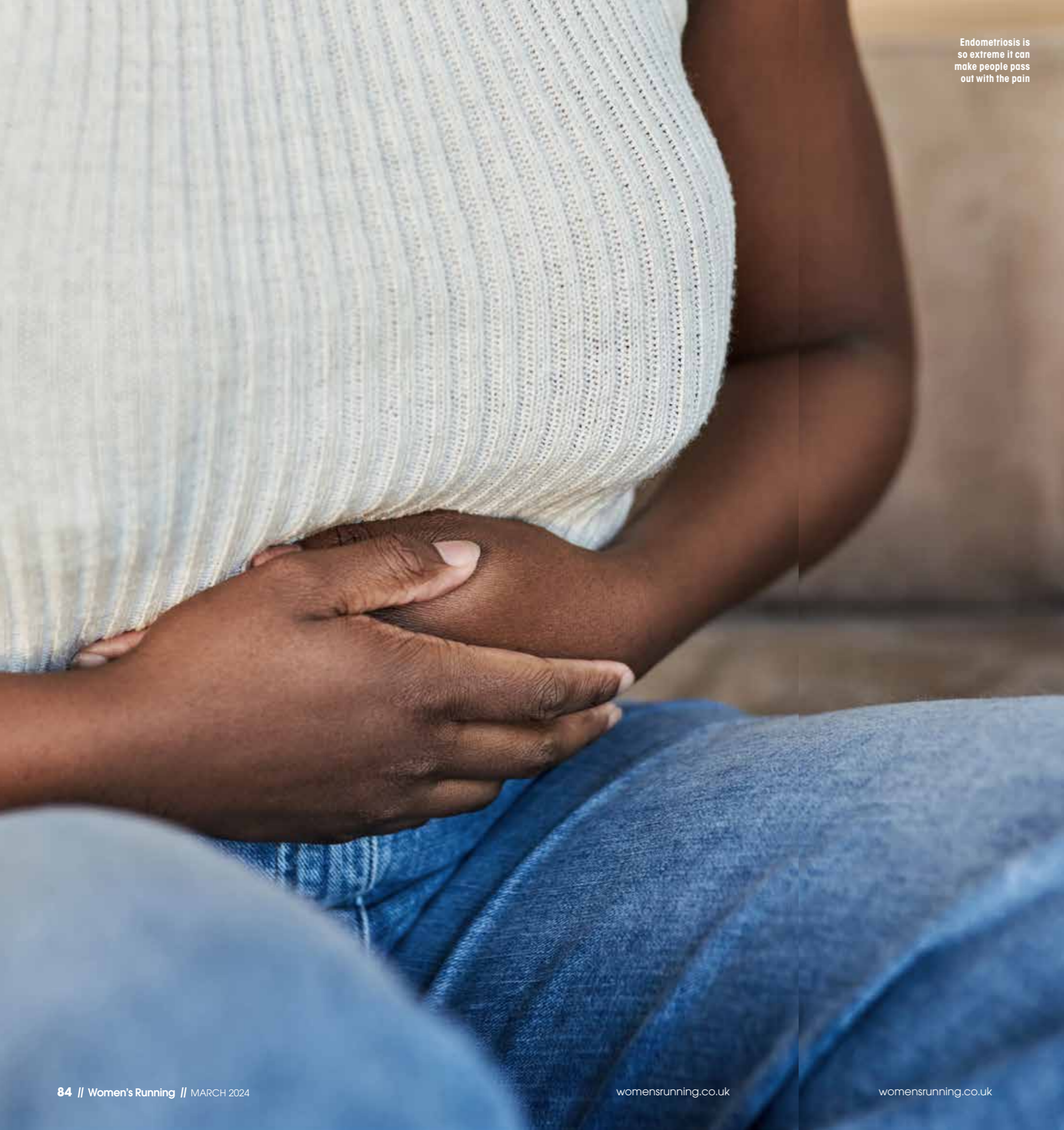
Undergoing a laparoscopy at the age of 36 in order to manage her endometriosis was the right decision for Philadelphia. When she woke up after the surgery, which removed lesions and scarring caused by the debilitating condition, she was in less pain than she'd been in for the previous 22 years of her life. But the fact that she got to that age before she was treated shows how little is known about the condition.

Philadelphia says: "After the op, my insides were raw from having extra tissue and adhesions removed – my organs and ligaments had been released from a lifetime of being glued to each other and moved to where they should have been. In short, the least amount of pain I've been in during my adult life was when my insides were raw, when I was fresh from surgery and when the drugs had stopped working. Is that not messed up?"

What is endometriosis?

Endometriosis is a condition that can affect anyone from the start of menstruation through to menopause. Triggered by the hormone oestrogen, it's where tissue





Endometriosis is so extreme it can make people pass out with the pain

» similar to that of the uterus lining grows in places like the ovaries, fallopian tubes, and much deeper into the pelvic cavity, in some cases spreading into the bowel and bladder. It can inflame the lining of the womb, and cause adhesions that trigger extreme pain and leave scar tissue.

During a woman's period, the symptoms worsen, and can cause chronic fatigue, nausea, sickness, diarrhoea and debilitating pain.

Just living day-to-day life with the condition is challenging enough, but to continue running while suffering from it involves careful planning and pain management.

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prevalence of endometriosis is the same as diabetes, it shows we need to do much more to raise awareness about this condition, which sadly is still thought of as a taboo women's issue."

Jo, like most health professionals, recommends keeping active where possible. Exercise is so important and although women may have to find 'workarounds' during certain times of their cycle, they can still run with endometriosis. Jo says: "For many women, running is an escape and, as a clinician, I would encourage people to do as much as they feel they can, but also to keep a symptoms diary so they can plan their

On the run

Philadelphia says it's a case of seeing how she feels each day of the week, and listening to what her body is telling her as to how far and how fast she runs. While it may sound unbelievable that she can run long distances with endometriosis, she says that running ultramarathons seems easy in comparison to the pain of disease. She says: "I don't think I have to train harder because of my condition; I just have to understand what's 'okay' pain and what's 'not okay' pain.

"Sometimes when I run, the endometriosis will get better at the start. But different muscles will protect the area that's damaged – so then that becomes more problematic."

According to Jo Hanley, endometriosis nurse and specialist advisor at Endometriosis UK, around one in 10 women suffers from the condition, with a diagnosis taking an average of up to eight years to establish. The disease and its symptoms are hugely individualised and the experience is different for all women.

Jo says: "Many women are misdiagnosed with bladder or bowel issues, and when you think that the

activity levels around certain days of the month."

Lack of resource

According to Philadelphia and many clinicians, there is a serious lack of resources documenting endometriosis, and particularly information about running with the condition.

Philadelphia explains: "There are literally zero resources for running ultras with endometriosis, in fact there's no literature on endometriosis for active people whatsoever. It's very hard to be well informed."

It was only a chance conversation Philadelphia had with a group of women in her trail running club that made her want to start finding answers.

"The frank conversation we had in a group of 13 revealed that two of us had very different experiences to the others. There was no way we could contemplate racing if we had our periods. Both of us finally went on to get diagnosis and surgery and better management to help change things."

Surgery is often the very last resort for sufferers of endometriosis, and according to one expert, if it gets to that point, it's been left undiagnosed »

Awareness

ENDOMETRIOSIS ACTION MONTH

As with many women's health issues, raising awareness about it can help many sufferers get the help and support they need

This March, Endometriosis UK has launched Endometriosis Action Month with the theme 'Could it be endometriosis?' The focus is to raise awareness of the most common symptoms of the disease.

The average time to get a diagnosis of endometriosis in the UK is now eight years and nine months, a rise of nine months since the last survey in 2020.

According to the charity, the most common symptoms include:

- Painful periods
- Pain during or after sex
- Infertility
- Painful bowel movements
- Fatigue

Periods should not be painful, despite what many women have been led to believe and if you find you're always having to take pain relief during your cycle then it could be that you have endometriosis.

Women with endometriosis are often misdiagnosed with bowel and bladder issues, whereas in actual fact, these



are problems that come alongside the condition.

Although there's no cure for endometriosis, there are various treatments that can be prescribed, depending on the severity of symptoms.

What to do if you suspect you or someone you know has endometriosis

- Speak out – talking about it helps to break the taboo

around women's health and wellbeing issues.

- See your GP – explain that you think you might be suffering from endometriosis and list your symptoms.
- Don't be afraid of getting a second opinion. If, after a first appointment, you feel you still don't have answers, don't be scared to try again with a different healthcare professional.

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too long. Jan Toledano of the London Hormone Clinic is on a mission to stop women being brushed off by their GP and facing decades living life in agony.

Early diagnosis

Jan believes that early diagnosis is crucial. "Endo can be diagnosed when someone is still very young – say 14 or 15. During teenage years endometriosis is still microscopic and often successfully treated. If it's diagnosed later, women can get to the stage where they need keyhole surgery to remove it, only for it to grow again. The only further option at that stage is

a hysterectomy and we need to stop it getting to this point."

She explains: "Oestrogen makes the womb lining thicker and progesterone makes it thinner, so if someone visits the GP with endometriosis, they will be offered the pill [to manage symptoms]. However, many women cannot tolerate the synthetic progesterone the pill contains. Instead, they need real progesterone which tops up the hormone levels and helps with heavy bleeding and migraines. While doctors now prescribe real progesterone as part of hormone replacement therapy (HRT), they are less likely to offer it for endometriosis. The condition is not

fully understood by all GPs, and very few of them take a hormonal approach.

"No woman should run through terrible pain. Endometriosis has different stages, so if someone has pain for one or two days a month, it's likely that they won't be able to run on those days, but that other days might be fine." Jan concludes by asking where the idea came from that it's normal to have painful periods. "It should not be the case," she says. "If a mother understood straightaway that her daughter was in excruciating pain for two days a month because she had endometriosis, we would be able to diagnose it quickly and prevent it getting worse."

Symptom management

So what can women suffering from endometriosis do to help train and to minimise the symptoms?

According to Jan, maintaining a healthy diet that's not too carb heavy will help. A Mediterranean-style diet which includes fruits, vegetables and pulses is a good place to start.

It's also about listening to your body and in Philadelphia's case, this means resting when she needs to; not beating herself up about skipping a training session, but working with her condition. "Before surgery, I would wake up and not feel good, and then that would tip very quickly into

something more serious. I used to pass out in public sometimes but now that I know that my training threshold is 40 minutes because of lesions on my hips, I'm able to really listen to my body."

Before Philadelphia had her surgery, the endometriosis had literally stopped her in her tracks. She says: "I remember



Experts say no woman should suffer from painful periods

running the Overland Track in Tasmania, which is an 86K race. Four weeks after that, I just couldn't run at all. That led to chronic fatigue and then I didn't run for seven months. Then I got diagnosed with endometriosis, and two weeks later I got the surgery."

The scariest part of the journey to surgery for Philadelphia was thinking that they wouldn't find anything at all.

"I remember being told that if they found anything they'd extract it – it might be my ovaries, it might be my uterus – and then I panicked that they might not find anything at all. It was a huge relief afterwards." Following a five-week break after surgery, life



Gen up GET SUPPORT

Endometriosis can affect all areas of your life, including work, relationships and your mental and physical health. It's important to find out as much as you can about the disease...

The only definitive way to diagnose endometriosis is by a laparoscopy. This is an operation in which a camera (a laparoscope) is inserted into the pelvis via a small cut near the navel. This allows the surgeon to see the pelvic organs and any endometrial implants and cysts.

It's important to remember that endometriosis is not an infection, nor is it contagious. Some women also worry that it might be cancerous, but it's not.

Philadelphia, and healthcare professionals specialising in the field of endometriosis, all agree that the best way to raise awareness and help others is to speak out about it. We've seen this



happen with the menopause in recent years and women feel more informed about what's happening in their bodies and how to manage symptoms

Philadelphia talks openly about her condition and her battles with it throughout her training, and shares information when and where she can.

Endometriosis UK is encouraging those who suffer with endometriosis to complete The Endometriosis Health Profile (EHP-30) survey,

designed by Leeds Beckett University and University of Oxford to measure the wide range of effects that endometriosis has on women.

There are also many support groups across the UK that can help women suffering with endometriosis.

You can find out more about endometriosis, including other women's experiences of the condition, the online survey, and where to find support at [endometriosis-uk.org](https://www.endometriosis-uk.org)

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» was pretty sweet. Philadelphia remembers: "I got a dietician and came up with a plan. I told my physio too, so I had support from them, although I really couldn't find a GP who could help me. After reading up a lot on it, I decided that, while training for the Dragon's Back Race in 2023, I wanted a period again.

"Throughout training, my periods were really irregular but then I came on properly just before the race [without pain]. I remember crying [with relief], but I was also angry that I'd wasted so much time when I felt I couldn't do anything, and I was mad thinking of all the others who had missed out too."

A big regret for Philadelphia is not knowing about endometriosis earlier in life, and Jan Toledano believes that many women go for many years convincing themselves that their painful periods are normal. She says that if you're suffering, you should see a GP and suspect endometriosis – by catching it earlier there is still the chance to protect fertility and manage the symptoms.

Now, after her operation, Philadelphia is still running and learning to manage her symptoms while hoping to raise awareness of the condition and to speak out so other women are better informed. 🧡