

Advocating Against Pain: Philippa's Endometriosis Journey

For the seven in ten women with endometriosis who still struggle with unresolved pain despite being on treatment, education and self-advocacy are essential in finding the right treatment plan.

By D.F. McCourt

Philippa Bridge-Cook of Toronto began experiencing severe pain during menstruation at the age of 13. At the time, she assumed that it was just a normal part of being a young woman. As she got older, however, the pain got worse, changed in character, and lasted longer and longer each month. "At its worst, it wasn't just during my period," says Philippa. "I had significant pain two to three weeks out of every month. It was all through my pelvis, extending into my lower back. It felt like there were knives inside my bladder. I would get intestinal pain when I ate, and even chest pain."

For more than two decades, Philippa struggled in the face of excruciating pain and six consecutive miscarriages. She knew that something wasn't right, but no one could tell her what it was. It wasn't until she was 34 years old, after having obtained an undergraduate degree and PhD in genetics and molecular biology, that Philippa finally got an answer. She was diagnosed with endometriosis, a condition where tissue similar to the lining of the uterus implants abnormally outside of the uterus in the pelvic cavity or even further afield in the body, causing chronic pelvic pain, painful sex, and a range of other symptoms that can include fertility difficulties, which are estimated to affect roughly 30 to 40 percent of those with the condition.

The story of Philippa's long ordeal with undiagnosed endometriosis is an uncomfortably common one. One in ten women of reproductive age in Canada have endometriosis, and yet getting a proper diagnosis and treatment can be frustratingly difficult. "Usually women suffer in silence for years, thinking that the pain they're experiencing is normal and that they should just grin and bear it," says Dr. Jamie Kroft of Sunnybrook Hospital in Toronto, a specialist in the treatment of endometriosis. "A big part of the problem is that pain is subjective, and that living with pain has been normalized for many women."

Changing the treatment narrative

Despite diagnostic advancements, treating endometriosis remains complicated. "Our ability to diagnose and approach endometriosis has improved



Philippa Bridge-Cook photographed inside her home in Toronto, ON.

dramatically," says Dr. Sukhbir (Sony) Singh, a gynecologic surgeon at The Ottawa Hospital. "What we really needed were more options."

After receiving her diagnosis, Philippa underwent surgery. Though it helped with her fertility hardships, it did almost nothing to resolve her pain. Now a mother of three, Philippa's challenges became greater than ever before. "It was difficult to care for my children," she says. "I would have to get friends or family to come over and help me while I lay in bed and just tried to survive the pain. There wasn't much energy in my life for socializing. It was very isolating."

"Over the last 10 years, we've finally started to see new approaches to managing pain and novel medical options to manage endometriosis."

— Dr. Sony Singh

Philippa's story parallels that of many other women. Even among those with definitive endometriosis diagnoses, seven out of ten women are still living with unresolved pain despite being on treatment. Women with endometriosis must insist on the right to not just a treatment plan, but a treatment plan that works for them.

Fortunately, as understanding of endometriosis within the medical community has grown and new therapies have become available, women have begun to have a lot more options. "The key epiphany was that surgery alone, no matter how good the surgeon, is often not enough to manage chronic pain," says Dr. Singh. "Over the last 10 years, we've finally started to see new approaches to managing pain and novel medical options to manage endometriosis. Because each woman's situation is unique, the more options we have, the more we can personalize the approach for each patient. That's when you get really good outcomes."

Self-advocacy and finding the right treatment

Women diagnosed with endometriosis need the proper education and awareness to advocate for themselves and for the appropriate treatment for them. "Knowledge is power," says Dr. Singh. "The more that women know about their own reproductive and menstrual health, the better equipped they'll be to bring it up with their physician and to get access to the treatments that might benefit them. Empowering women to advocate for themselves and to talk openly about their reproductive health is very important."

"A doctor can't do a simple test to find out how much pain you're in or how it's affecting your life," Dr. Kroft adds. "Women need to feel confident talking about how severely their symptoms are impacting them."

In her vital work at The Endometriosis Network Canada, Philippa is now reinforcing these messages of self-advocacy. "It's not reasonable to say that this level of pain is something women should just have to put up with," she says. "The first thing is to vocalize your symptoms to your doctor. All of them. You have to believe in yourself and trust that you know what's going on with your body."

And Philippa happily uses herself as an example. After years of searching, she has found a treatment plan that lets her live the life she wants. For her, that regimen included a second surgery and finding the right medication. A combination of yoga, meditation, exercise, diet changes, and pelvic physiotherapy have also helped her manage her pain. "Now I have some days without any pain at all, which is amazing for me," she says. "I'm still managing symptoms and I still have bad days, but they're much fewer and farther between. Today, I feel like I can participate fully in all the parts of life I was missing out on."

If you have endometriosis and are still living with ongoing pain, consider speaking to your physician or a gynaecologist about the different treatment options available. If you're looking for additional resources, the SOGC is dedicated to providing the public with trusted information about endometriosis. Please visit www.yourperiod.ca/endometriosis to learn more.