

# Endometriosis: the bloggers' tales

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## BACKGROUND

To bridge the gap – that's what my brief for the Journal has always been. To create understanding between reproductive health professionals and health service consumers – to help the former appreciate the needs of the latter. This is why I often base my columns directly on the experiences of end-users: women patients with cervical cancer, teenage students needing sex education, purchasing customers using pharmaceutical services, being recent examples.

But when the Journal Editor recently tasked me with writing about endometriosis (Box 1), I found myself unexpectedly log-jammed. Despite the fact that over 170 million women worldwide suffer, I knew no one with the condition. I didn't even know anyone who knew anyone with the condition. And the devoted user-organisations couldn't deliver me the numbers of globally-based, first-hand accounts that I ideally needed.

And then, I had a Eureka moment: blogs. A Google trawl threw up nearly 3 million hits, which I narrowed down to 70 blogs written by women with endometriosis, chronicling insights, realisations and emotions that allowed me a glimpse into the experience. Which is why, dear reader, you are privy to a first: for the first time the Journal's Consumer Correspondent column is based entirely on bloggers' tales.

## PAIN

What struck me first as I began to read was the level of sheer agony described. Pelvic cramps, back ache, "the crippling abdominal pain that feels like a ninja star got lodged in my gut". And not just occasionally but constantly, chronically – yet unpredictably, making future planning impossible, job commitment uncertain, relationships erratic: "I am now an unreliable person ... and people don't believe me because I don't look like a sick person".

Then there's the bleeding – again not just for a few menstrual days but

constantly and heavily. "I have large clots ... the inside of the toilet was covered with splashes of blood." Add in bloating "I look like I am early in pregnancy some days". Also add in sleeplessness, night sweats, fatigue and tearfulness. Life between menarche and menopause becomes a daily struggle.

All of this even before the issue of infertility, for endometriosis may mean that bearing children is uncertain or impossible. The blogs tell a story familiar to those of us who work in reproductive health but a story that is no less heart-breaking for that. "I'm currently engaged in the biggest fight of my life ... trying to keep sight of my dream ... our [child]." Hopes are raised but dashed. Attempts are made but fail. Money is invested, but with no result. There is resistance, acceptance or the endgame choice of hysterectomy which, while ending symptoms, also ends hope. "I will never now hold my own baby."

## NEGATIVITY

It will come as no surprise that these physical symptoms also trigger emotional symptoms. There is sadness at the lack of life quality. "I have cried every day for several months ... people have asked me if I have allergies because my eyes are [so] swollen." There is depression. "The lights have been switched off in your life and won't come back on." There is anger. "How dare this happen. Why me ... why me?"

Sadly, much of this anger is aimed at medical science. There is huge frustration at the lack of understanding of endometriosis. "Most who practise medicine, especially the male population, can't even relate to [our] pain and discomfort." There is huge irritation about the lack of effective long-term treatment. "Medicine up till now has failed to provide [either] cure or side effect-free relief."

Also, those close to the endometriosis sufferer may add to the negativity. Some simply don't understand the problem, becoming frustrated at what many blogs

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**Box 1 Facts about endometriosis**

- ▶ Around 176 million women worldwide are thought to be affected by endometriosis.
- ▶ Endometriosis occurs when tissue that behaves like the endometrium is found outside the womb – commonly in the ovaries and in the peritoneum behind the uterus and around the upper vagina. Given no outlet, this tissue can cause inflammation, scarring and adhesions.
- ▶ The causes of endometriosis are unclear but may be down to retrograde menstruation, Müllerian tissue remnants, coelomic metaplasia or vasculogenesis.
- ▶ Although some women are symptom-free, common symptoms include painful periods, heavy periods and chronic pain in the lower abdomen, pelvis or lower back.
- ▶ Endometriosis can cause severe fertility problems either just by its presence or if it damages the Fallopian tubes or ovaries.
- ▶ There is no known curative treatment, but symptom management includes painkillers; hormonal treatments; ablation or surgery, support and counselling.
- ▶ Further information is available at <http://www.endometriosis.org>, a global forum listing all known endometriosis support worldwide; in the UK the main support body is <http://www.endometriosis-uk.org>.

describe as the ‘invisible illness’. Partners in particular become exasperated at the impact on their own life – the practical limitations, the emotional stresses, the lack of sexual activity – as described in a recent commentary article in this Journal,<sup>1</sup> the above mentioned high levels of pain often bring a full stop to intercourse. “While all of my friends are very sympathetic and supportive, I’ve never been with a guy who really got it.”

**POSITIVITY**

But let me not give the impression that these blogs are ‘misery memoirs’. On the contrary, the theme that runs through the overwhelming majority of the entries I read was that endometriosis bloggers are, above all, survivors.

Often the reason for survival is not reduction in symptoms, but sheer determination to look on the bright side, to remember the brief periods of relief, to keep calm and carry on. “Anything and everything I can find with a silver lining, I magnify it and give it attention.” “I have a deep desire not to let this disease cripple me or impact my life.”

And, sometimes there are results. Hormone treatments can help. Surgery can bring improvement. “So here I am, 2 months post-op and can safely say I am 90% pain free and feeling like superwoman.” Self-help in the form of exercise, diet change and

stress reduction can for some sufferers bring relief and, perhaps as importantly, an increased feeling of mastery. “I understood I had to think selfish and only take care of myself from the inside out ... Believe me, it can be done, step by step, one day at a time.”

Even the infertility struggle can have a happy ending. The ecstatic reports of successful conception: “I am carrying my daughter under my heart. There is no better feeling in the world”. The joyful chartings of adoption: “I marvel at how amazing it is that a childless couple can be matched with a family-less baby boy”. No matter that mother’s life will continue to be a constant physical struggle; baby makes it all worthwhile.

**SUPPORT**

Positive too are the wonderful reports of support the bloggers have received. Sometimes from those close: “I couldn’t have got through without my family, [my lover], and a handful of friends [you know who you are]”.

Sometimes, happily, support comes from the health community. I mentioned earlier the criticisms of medical ineffectiveness – but in equal measure, bloggers are grateful to medical staff. We professionals do try to understand what women are going through. Where we can’t help, we can at least commiserate. And sometimes, we can help: with pain relief, with surgery, and with fertility treatments. “My instinct was to pull her [my doctor] into my arms, and hug her deeply.” “I sometimes wonder what would have happened had I not stumbled across Professor X’s path, but then I look at my beautiful baby boy and realise that it was always meant to be.”

Also, the blog itself is a crucial form of support. Yes, one can argue that writing about suffering perpetuates the pain, but that certainly isn’t the impression I got. The blogs I viewed seemed to help their writers understand, gain insight, make links, feel less helpless. Writing about endometriosis gives one power over it.

And, other people reading what one has written about endometriosis gives one power too. The knowledge that one has communicated is a huge source of self-esteem and personal strength. “I have connected with so many other women with the disease and have helped others get diagnosed. I have learned that reaching out not only helps others, but enriches my [own] life.”

**LESSONS**

So what have I learned from these bloggers’ tales?

First, that the ‘endo-sisters’ community is full of strong, determined women living with a huge burden of suffering and still surviving and triumphing. All power to them.

Second, that there is much to be done in supporting these women. To research the condition more fully, to identify the causes more precisely, to find a cure more quickly, to manage symptoms more effectively – and

above all, to take the condition seriously and realise that it is life-destroying. All that is down to us health professionals.

And finally I learned that blogging itself is a hugely useful and empowering tool. I'm not suggesting that the next time an endometriosis patient presents in your consulting room that you necessarily suggest they write a blog about their condition. I am, however, suggesting that if they have that inclination, you support the idea fully!

And I am suggesting that whether or not your current caseload includes women with endometriosis, it is a salutary experience to do as I did. Google

'blog'... 'endometriosis'. Then read, digest and above all learn.

**Author's note** The quotations are taken from blogs written by women who suffer from endometriosis. My thanks to them and to all the bloggers whose work I read.

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## REFERENCE

- 1 Hummelshoj L, De Graaff A, Dunselman G, *et al.* Let's talk about sex and endometriosis. *J Fam Plann Reprod Health Care* 2014;40:8–10.