Do you suffer from Endometriosis?
By Hannah Ebelthite
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When Lena Dunham was hospitalised after a ruptured ovarian cyst, it reminded us how serious endometriosis can be. The 29-year-old actress has talked openly about her health struggles with the chronic condition, yet so many women suffer in silence.

Endometriosis affects the reproductive health of approximately 1 in 10 of us, but according to experts, women are waiting an average of two years before seeing their GP about the tell-tale signs of difficult or painful periods. "My body (along with my amazing doctors) let me know, in no uncertain terms, that it's time to rest," wrote Dunham on her feed. "So many women with this disease literally don't have the option of time off and I won't take it for granted."

Endometriosis can leave you doubled up in agony every month. And that's not OK. Know the feeling? Here's what you need to know - and how to get the help you deserve.

**Vicious cycle**

Periods. They're a pain, right? That depends: how much of a pain are we talking about? A day or so when ibuprofen is your best friend - and you develop a brief but heady relationship with your hot water bottle? Or is your period so heavy it's potentially embarrassing and so painful that you can barely function? Does sex hurt? Do you bleed randomly in the middle of your cycle? This is not OK. What's even more concerning is that women are not seeking help. And this is definitely not OK, as the signs above could point to endometriosis, which affects one in ten women of reproductive age in the UK. The message behind Endometriosis UK's latest campaign, It's OK to talk. Period, is that pain is real and shouldn't be dismissed. "Women and girls are waiting an average of two years before seeing their GP about difficult or painful periods," says Helen North, the charity's CEO. "And with the average time to diagnosis still seven and a half years, that's too much unnecessary suffering."

**So what is endometriosis?**

Endometriosis is a condition where tissue from the walls of your womb or uterus (called endometrium) is found elsewhere in the abdominal cavity or body - outside of the womb. "So it can be found in or around the ovaries, Fallopian tubes, bladder and intestines," says Dr Andrew Horne, gynaecologist at the University of Edinburgh and spokesperson for the Wellbeing of Women charity. "The problem is, this tissue behaves exactly as normal endometrium does. So it swells in preparation to receive an egg, then bleeds (which would be your period). For cells outside the womb, the swelling and bleeding causes irritation and inflammation - and often horrendous pain. With nowhere to go, the blood stays in the pelvic cavity and forms what doctors call adhesions or lesions (scar tissue that binds organs together) and blood-filled cysts."

**What causes it?**

"We think retrograde menstruation (where pieces of womb tissue - that would normally be shed as your period - travel back through the Fallopian tubes into the abdominal cavity and stick there) is involved," says Dr Horne. But this happens to an extent in 90% of women, so why don't they all develop endometriosis? It may be an autoimmune condition (where your immune system mistakenly attacks healthy tissue) which triggers inflammation. Excess iron in the diet is another theory. "We know endometriosis is a hormone-dependent, inflammatory condition, so diet and lifestyle changes that work to balance hormones and limit inflammation may help, although more research is needed."

**Symptom checklist - If you have any of the following, see your GP:**

- Period pain that lasts more than two to three days
- Pain halfway through your cycle (during ovulation)
- Pain that affects your day-to-day activities
- Pain that can't be controlled by normal painkillers
- If you find having sex or using tampons painful
- Pain that radiates to your back or legs
- If you bleed heavily for more than three days
- If you have to change your pad or tampon more than every two hours or leak even when using double protection (flooding)
- If you have lots of darker blood at the beginning and end of your period
- If you have spotting during the month
- If you have pain when going to the loo
- Regular diarrhea
- Blood in your urine or stools
- You feel sick or tired all the time
- You have severe pelvic pain between periods

**What to say to your GP?**

So, you've decided to speak up. But you get to the surgery and panic: how can you explain it all in ten minutes? "The more information you can go armed with, the better," says North. Keep a monthly symptoms diary and: "Tell them when in your cycle you experience symptoms, for how long, how intense, how it makes you feel. And don't be afraid to say, I think it might be endometriosis, can you investigate? One of the reasons endometriosis can take so long to diagnose is because the symptoms cross over with those of other conditions, such as IBS or pelvic inflammatory disease (PID)," she adds.

**And then what?**

Your GP may refer you directly to a hospital gynaecologist for scans and further investigation. The only way to get a definitive diagnosis of endometriosis is via keyhole surgery. But as this is invasive, it's reasonable for your GP to ask you to try treatment first for six months to see if it makes a difference to your pain and bleeding. "The main problem we find is that doctors don't communicate well enough," says North. "If a treatment is suggested, ask what it's for, what condition the doctor suspects, if there might be side effects and if there's an alternative - amazingly, this essential information isn't always offered."

**What about the emotional effects?**

"Endometriosis can have a huge emotional as well as physical impact," says North. "There's a high level of depression among sufferers and it can affect careers, education, relationships, friendships and family life. It's hard for non-sufferers to understand how painful and debilitating it can be." That's where patient groups like Endometriosis UK come in. "Women may not feel their doctor or nurse has time to talk about issues like how to tell your employer what's wrong or how to access sex therapy. Patient groups have the experience and empathy to help, so give them a try," says North.
The treatment options

"Drug treatments for endometriosis include anti-inflammatory painkillers and hormonal medications. Hormone treatments work to block or reduce oestrogen production in the body. Some do this by putting the body in an artificial state of pregnancy (such as the combined contraceptive pill or patch used without a break, the Mirena coil or progestogens). Others (names to look out for are: GnRH analogues, testosterone derivatives and aromatase inhibitors) induce an artificial menopause," says Dr Horne. "Ultrasounds and MRI scans can also help to identify suspected areas of endometriosis. Diagnosis requires a laparoscopy - keyhole surgery through your belly button," explains Dr Horne. "A harmless gas inflates your pelvic area while the surgeon examines the organs inside using a tiny camera." If the surgeon finds adhesions, they should take a biopsy and will probably remove them right then using heat or lasers. "If the endometriosis is severe, you may need further surgery," says Dr Horne. "But it's a myth that treatment automatically involves removing the womb (a hysterectomy), or ovaries and tubes (oophorectomy). This is extremely rare." "We're starting to look at endometriosis more as a chronic (long-term) pain condition, rather than focusing on removing the adhesions," adds Dr Horne. "So there's research into what drugs might better help - antidepressants or anticonvulsants, for example. The Holy Graal of treatment is something that targets pain while also resolving lesions."

Getting the treatment you deserve

1 "If you don't feel your GP is listening, ask to see another doctor at the practice, register with another practice or go to a walk-in clinic," says North.
2 "Take your pain & symptoms diary and use the consultation questionnaire (both free from the Endometriosis UK website) to get the most from each appointment," says North.
3 "The European Society of Human Reproduction and Embryology (ESHRE) has published guidelines on the correct management of endometriosis," says Dr Horne. "You can read the patient version online and check the care you're receiving is in line with the 'gold standard'."
4 Your hospital may not have the best scanning equipment or most experienced radiographers. "So before having unnecessary abdominal surgery, it may be worth paying for a private scan using the latest transvaginal ultrasound scanners and dopplers (which measure blood flow)," says Bill Smith, head of ultrasound at London endometriosis specialists Clinical Diagnostics Services.
5 "The UK has some of the best endometriosis surgeons and specialist centres," says North. "The British Society for Gynaecological Endoscopy (BSGE) has a list of accredited endometriosis centres, so you can visit its website and ask your GP to refer you to the hospital of your choice. Not all hospitals choose to join the scheme, though, so that's not to say you won't find an excellent gynaecologist who's not on the list.

Help yourself

1 Because endometriosis is an inflammatory condition that responds and grows when exposed to oestrogen, the following complementary approach may help (and can be followed alongside conventional treatment).
2 "Common inflammatory foods to avoid are excess sugar, high-GI foods, yeast and dairy," says Dr Martin Galy, a doctor with a special interest in hormone disorders, and director of The Biorejuvenation Clinic in west London.
3 Follow a 'clean', organic diet. "By avoiding pesticides on fruit and veg or hormone disruptors in milk, meat and cosmetic products, for example, re-establishing hormone levels becomes easier," says Dr Galy.
4 Stress plays havoc with hormone levels. Dr Galy recommends looking at your sleep, work and lifestyle and trying stress-reducing techniques like CBT, meditation or yoga.
5 "Exercise can reduce stress, but the right type can also have a positive effect on hormones by improving insulin sensitivity," he says. "High-intensity interval training (HIIT), has been shown to have major benefits in controlling blood sugar levels through the production of growth hormone." 5 "Omega-3 essential fatty acids may have a role thanks to their natural anti-inflammatory action," says Dr Horne. Try Omega wise shots £9.45 verywisenutrition.co.uk. 6 B vitamins help the liver deal with excess oestrogen and also convert essential fatty acids into pain-relieving prostaglandins. Vitamin C helps immune response. Try Quest Mega B Complex Plus 1000mg Vitamin C £9.29 nutritioncentre.co.uk 7 Magnesium is a muscle relaxant that can ease monthly cramps. Try Wassen Magnesium-OK £4.72 boots.com

Fertility facts

Want the good news? Of those diagnosed with endometriosis, 70% go on to have children without problems - and most of the remaining 30% are able to do so with help. "A diagnosis of endometriosis does not mean infertility," says Dr Galy. "Once you're pregnant, symptoms are usually alleviated thanks to your progesterone levels, which rise ten to 20 fold. And many women report that their symptoms fail to return post-pregnancy. "I worried I'd never have children - now I'm a mum!" "I wasn't diagnosed with Endometriosis until I was 24," says Tara Gruszczak, 30, from Doncaster. "I thought my heavy and painful periods were normal. I only went to the doctor in my early twenties when I started to get a sharp pain on the left hand side of my abdomen. It was excruciating, sometimes I could barely stand. I was told it was a stomach ulcer, then that my liver was inflamed from drinking. Eventually I was sent to A&E with suspected appendicitis or ectopic pregnancy. Instead, they discovered a 12cm cyst on my left ovary. This was the first time endometriosis was mentioned. I'd never even heard of it and no one took the time to explain what it was or what it meant for me. Because I said I wanted to try for a baby, I wasn't given any hormonal treatment, so the symptoms continued. I'd long met my now-husband Paul and fortunately he was really understanding - at certain times of the month sex is too painful. Four years on, we visited a fertility clinic and a scan showed another cyst. And it was while removing this that the surgeon found extensive endometriosis scarring all over my ovaries. Having this lased away really improved my symptoms and just five days before we were due to start IVF, I discovered I was pregnant. Our beautiful son William, now 2, was born in December 2011. My advice to everyone suffering pelvic pain of any sort is not to sit back and take it. And don't be fobbed off. Ask to see a gynaecologist or for a second opinion - and if you're worried about fertility, insist on an early referral to a specialist. Above all, don't be frightened if you are diagnosed with endometriosis. Doctors may not always offer much information, but there's plenty available from patient organisations. Learning about the condition, that you're not alone and that there are things you can do yourself, is empowering."

For more information and advice
http://www.23md.co.uk/