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Time to put an end to the myths

TO MARK ENDOMETRIOSIS MONTH, ABI JACKSON HELPS BUST MISCONCEPTIONS AROUND THIS COMMON CONDITION

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ENDOMETRIOSIS is not uncommon – in fact, it’s believed to affect one in 10 women.



Yet it’s still widely misunderstood, and those affected can struggle for years before getting proper help.

Because it’s associated with the menstrual cycle (it occurs when cells similar to those that grow in the womb lining grow outside the womb too, resulting in inflammation, scar tissue or adhesions and blood-filled cysts/endometriomas), it’s often dismissed as being ‘just bad periods’.

But endometriosis is a medical condition which can have a huge impact. So, this Endometriosis Month, which runs through March, here are eight things everyone needs to know...

1. It’s not ‘just period pain’

A bit of cramping with your period is normal. But as Faye Farthing, campaigns and communications manager for Endometriosis UK, points out, one of the big myths around endometriosis is that people should “just get on with it” because it’s “just a bad period”. “Comments like this can be really damaging, not only to those experiencing the symptoms, but to society as a whole, as they are preventing people from seeking help and allowing taboos about menstrual health to continue,” adds Faye.

2. Symptoms can be complex “Endometriosis affects everyone differently. Whilst some may not experience many symptoms at all, for others, it can be debilitating,” says Faye.

“Common symptoms include pelvic pain, painful or irregular periods, pain during or after sex, painful bowel movements, pain when urinating, fatigue, and difficulty getting pregnant.”

3. A diagnosis can take years

“It takes – on average – a shocking eight years to diagnose endometriosis,” says Faye.

“A recent report in October 2020 by the All-Party Parliamentary Group (APPG) on Endometriosis of 10,000 patients, also found that prior to getting a diagnosis, 58% visited their GP more than 10 times; 43% visited doctors in hospital over five times; and 53% had to visit A&E.

“During this time, many will be misdiagnosed, and in some cases, even told it’s ‘in their head’. Not only can the disease worsen if left untreated, delayed diagnosis can have a huge impact on someone’s mental health, career and relationships.”

4. Disruptive periods aren’t normal Symptoms that render you housebound, unable to function or land you in A&E are not normal.

“If you are struggling to get a diagnosis – keep going,” says Faye.

“Keep a pain and symptoms diary, so you can share with your GP what symptoms you’re experiencing and how they’re impacting you.

“And you can always ask for a second opinion or see a different GP if you are dissatisfied.”

5. A suitable investigation is vital Being referred to a specialist is important, as endometriosis needs specific investigations to be confirmed. While ultrasounds and MRI scans can be useful, a “laparoscopy is the gold standard diagnostic test for endometriosis”, says women’s health expert Dr Nitu Bajekal MD FRCOG, a senior ObsGyn consultant and member of Plant Based Health Professionals.

“This is a keyhole procedure that allows the surgeon to perform a thorough assessment of the pelvis and confirm the diagnosis, take biopsies, and the endometriosis can also be treated at the same time by an experienced surgeon.”

6. There’s a psychological toll

“The mental health impact can be huge,” says Faye. “Years of fighting for a diagnosis, coupled with many of the symptoms already associated with poor mental health, such as chronic pelvic pain and infertility, is contributing to many of those with endometriosis also reporting poor mental health.

“There needs to be pathways in place so that those with the condition have access to support for both their physical and mental health.

“And endometriosis can be unpredictable – it can have a huge impact on people’s social lives and relationships.”

7. Treatment may involve surgery Managing endometriosis can vary from person to person and usually begins with the most conservative treatment options, such as pain relief and hormonal treatments, but surgery may be required.

“Surgery is definitely indicated in endometriosis for some, to relieve pain, improve fertility, treat cysts and release scar tissue,” says Dr Bajekal.

Again, this usually means a laparoscopy, where the surgeon can remove scar tissue/adhesions.

More complex cases may involve other organs such as the bladder and bowel, and some people may have radical surgery (removal of the ovaries and/or uterus), although this is a

last resort.

8. There is hope

Finding the right treatments for you can make a huge difference.

Dr Bajekal says lifestyle measures can also play an important role.

“There is always a place for making changes that can make a difference in the overall management of endometriosis, whether it helps with better control of menstrual or bowel symptoms, or quicker recovery from major surgery,” says Dr Bajekal.

She adds that there’s “growing evidence to suggest avoiding meat and eating a high fibre plant-based diet can help with symptoms. [And] acupuncture, breathing techniques, yoga and regular exercise can all help with pain management.”

These aren’t a replacement for appropriate medical interventions, but can play a part in supporting your health and sense of control over your wellbeing.

Endometriosis UK can also be a great source of support.

“If you also need someone to talk to, do reach out to our support services,” says Faye. “We run a helpline, online forum, and support groups across the UK (currently online), as well as a series of webinars.”

For more information, endometriosis-uk.org visit