

PRESS RELEASE

Contact: Emma Cox

Email: communications@endometriosis-uk.org

Phone: 020 7222 2781

Mobile: 07500 047424

Website: www.endometriosis-uk.org

It takes an average 7.5 years to get a diagnosis of endometriosis - it shouldn't

Endometriosis Awareness Month – March 2017

Despite costing the UK economy £8.2 billion annually, being the second most common gynaecological condition in the UK and affecting 1 in 10 women in the UK (1.5 million), it still takes shocking average of 7.5 years to get diagnosed with endometriosis.

Endometriosis UK is calling for shorter diagnosis time to ensure better health and life outcomes for women affected. There is no cure for endometriosis, and it can only be diagnosed through surgery (laparoscopy). But having a diagnosis enables women to:

- receive appropriate treatment, saving women from many years of living in constant pain;
- gain confidence, rather than being told they are 'making up' their symptoms which may not be believed;
- stay in work, by having a named medical condition that can be understood and managed;
- make informed choices about fertility issues (endometriosis doubles the risk of infertility in under 35s)
- reduce the impact on the NHS through decreased visits to GPs and unnecessary treatments.

"Despite it being 2017 we are letting down thousands of women who are ill yet cannot get a diagnosis; they may even be told they are making the symptoms up, impacting on their confidence and mental health when they are already suffering.

It is a challenging condition to diagnosis as there are a range of symptoms and these vary person to person. But with simple training with GPs and nurses and raised awareness with both healthcare professionals and the public, this could be overcome.

No-one should have to suffer for many years, possibly losing their job and chance to have children, because of endometriosis – yet heartbreakingly it happens all the time." says Emma Cox, Chief Executive of Endometriosis UK.

For example ...

Elizabeth was diagnosed aged 33 after 8 years of symptoms. Despite being hospitalised several times with severe, unexplained abdominal pain, endometriosis was never even mentioned. With the pain increasingly difficult to manage and impacting on her daily life, Elizabeth went to a GP and endometriosis was talked about for the first time - 8 years after initial symptoms. A laparoscopy diagnosed endometriosis, unfortunately also confirming that the severity of the disease meant Elizabeth would not be able to have children.

Symptoms

The classic symptoms of endometriosis are severe pain during or between periods; long, heavy and irregular periods; painful bowel movements; pain in the bladder and pain during or after sex. Extreme fatigue is very common, and fertility may be affected. Misdiagnosis is common, resulting in delays to accurate diagnosis, unnecessary tests and sometimes unnecessary surgery. All this can have a significant impact on a woman's wellbeing and ability to succeed in education or work.

Endometriosis UK's recommendations to improve endometriosis services:

- Training and awareness for GPs and nurses so they can recognise the symptoms, know when and how to refer to secondary care, and provide women with better support and information.
- All women to have access to an Endometriosis Specialist Centre, wherever they live in the UK.
- Referrals to specialists and British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres should be offered sooner to women with the condition.
- All women with a diagnosis of endometriosis should have access to a specialist nurse.

Other Awareness activities this month include:

A range of awareness raising activities can be found on our [website](#).

World Endometriosis March, 25th March – people all over the world will be marching together to raise awareness of endometriosis. Marches taking place in the UK: London, Manchester, Cardiff, Glasgow.

-ENDS-

For further media information please contact Emma at communications@endometriosis-uk.org or call on 020 7222 2781 or mobile: 07500 047424

Website: www.endometriosis-uk.org

We have a range of SPOKESPEOPLE who can talk to the leader, including a range of women with direct experience of endometriosis and healthcare professionals, as well as CASE STUDIES available.

Notes to editors

1. **Endometriosis UK** is the leading national charity dedicated to providing support and information for women who have the condition. We work to increase understanding of endometriosis through campaigning, awareness-raising initiatives and research. We offer a wide range of advice and support, including a helpline, information leaflets and local support groups. These services are run by volunteers, all of whom have been affected by the condition.
2. Endometriosis is a gynaecological condition where tissue similar to the lining of the womb grows in other areas of the body, most commonly in the pelvic region. This tissue responds to hormones in the same way as the lining of the womb but, with no outlet, it can cause inflammation, scarring and adhesions, leading to severe pain and many other symptoms.
3. A laparoscopy is the most common way to diagnose endometriosis. During a laparoscopy, a small telescope (laparoscope) is inserted into the abdomen to look directly at the internal tissue. Laparoscopies are always carried out under general anaesthetic. During a laparoscopy various procedures can be performed in order to destroy or remove the endometriosis, endometriotic cysts and release scar tissue (adhesions).
4. Painful or heavy periods can be a sign of:
 - **Fibroids** – 20-40% of women will suffer from these at some point during their reproductive years, but most can be treated through drugs or surgery. www.britishfibroidtrust.org.uk
 - **Endometriosis** – a common condition (1 in 10 women), associated with severe pelvic pain and infertility. Endometriosis is a chronic condition for which treatment can be difficult and may have to be repeated several times. www.endometriosis-uk.org
 - **Adenomyosis** – a similar condition to endometriosis where endometrial tissue grows within the wall of the uterus and responds to the hormonal changes each month causing severe pain. Prevalence is not known as diagnosis is difficult and symptoms are usually managed by hormonal treatments.
 - **Pelvic Inflammatory Disease** – a bacterial infection affecting the womb, fallopian tubes and ovaries (1 in 50 women will have this each year and of these only 1 in 4 is due to an STI). Treatment is usually through a course of antibiotics. <http://www.nhs.uk/conditions/Pelvic-inflammatory-disease>
5. An estimated 1 in 10 women in the UK suffer from endometriosis, with symptoms that include severe pain, heavy bleeding, pain during sex and the risk of becoming infertile. It can affect all women and girls of a childbearing age, regardless of race

or ethnicity. Approximately 176 million women and girls suffer from endometriosis worldwide.

6. Individual women can suffer a range of symptoms including severe and chronic period pain, heavy or irregular periods, fatigue and lack of energy, depression and feelings of isolation, pain on sexual intercourse and fertility problems.
7. There is no definitive cause for endometriosis and the only conclusive way to determine if a woman has endometriosis is through a laparoscopy, usually done under general anaesthetic.
8. Research by Endometriosis UK (Diagnosis Survey, 2015) shows that it typically takes 7.5 years for a correct diagnosis to be made. During this time women may suffer agonising pain each month which impacts on their lives, relationships and ability to work.
9. There is currently no cure. Treatments including drugs, surgery and complementary therapies can be used to help manage the pain, reduce the severity of symptoms and improve the quality of life for a woman living with the condition.
10. Endometriosis costs the UK approximately £8.2bn per annum in lost working time and healthcare costs. *Source: Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012; 27(5):1292-9.*
11. Endometriosis can double the risk of infertility in under 35s. *A prospective cohort study of endometriosis and subsequent risk of infertility. J. Prescott, L.V. Farland, D.K. Tobias, A.J. Gaskins, D. Spiegelman, J.E. Chavarro, J.W. Rich-Edwards, R.L. Barbier, S.A. Missmer. Hum Reprod (2016) 31 (7): 1475-1482.*