

Endometriosis: overlooked and mistreated

With thousands of women suffering from endometriosis, patients are striving for justice. Yet, three different European countries are at different stages of the fight.

It's just a part of being a woman, suck it up. Such comments probably many women have heard in their life when dealing with pain. Is pain even normal? With the medical field being based on men, many female chronic diseases are brushed under the carpet. One of them is endometriosis. Even being as common as diabetes and affecting one in 10 women, lack of research and advocacy has left many women in the darkness.

"It is not normal being in pain for 20 days every month and eating analgesics in order to have a life," says Mel Gorlich, a 26-year-old Czech patient, who was diagnosed with endometriosis by a laparoscopy. Now, she is volunteering at a patient organisation to raise awareness and help women with the same condition. Indeed, current treatments for endometriosis are painkillers, contraceptives, and surgery to remove endometrial tissue. However, there is no available cure for this disease.

Surprisingly, the ignorance surrounding endometriosis doesn't start at the doctor who might not know how to diagnose it. It starts with women themselves. Many endometriosis patients have not heard of the condition before their diagnosis, making it difficult to get a diagnosis, which can take up to 10 years.

Countries like Kosovo don't even have a support system for endometriosis patients and the exact number of women affected by this condition is unknown. Czech Republic has made some strides forwards with organisations such as ENDO Talks leading the way to awareness and justice. Trying to share best practices with doctors, being closer to patients and supporting the multidisciplinary treatment approach. Whereas the UK, slowly but surely, is developing a security net for women with endometriosis, however still women who suffer don't know what endometriosis is.

Lack of endometriosis awareness in Kosovo

Endometriosis is almost unknown to a lot of women in Kosovo, the youngest country in Europe, and there is no data on how many women are affected. While there is no taboo towards women's health in Kosovo, the same doesn't apply for endometriosis, says gynaecologist Trina Nushi. This is a result of a lack of awareness and the average time it takes to be diagnosed.

The diagnostic period is anywhere between three and 12 years, so when a woman is diagnosed, the disease is usually in the later stages "when chocolate cysts are already formed, and when patients experience unbearable pain caused or complain about infertility," she adds.

Nushi explains that symptoms vary and are usually related to other conditions such as anxiety, menstrual pain, and pain during intercourse. In the rare cases when patients are diagnosed, they may undergo a surgery, which does not guarantee a complete cure. "Surgical treatments that we use are usually laparoscopic interventions to find the lesions," she says.

Without accurate numbers of diagnosed women and awareness of this disease, patients with endometriosis lack support from the state, healthcare, or society. “The only support they get is the support from their own doctor. There are no endometriosis associations, which normally should assess and make a plan for handling endometriosis for both doctor and patient,” Nushi notes.

According to her, there is an immediate need to increase governmental and societal awareness around endometriosis. However, the change should first start with doctors, then patients.

“There is a lot of room for improvement starting from increasing awareness between doctors, starting from primary care all the way up to gynecologists. Then, all raising awareness amongst patients”. Until this happens, women in Kosovo continue to live with undiagnosable pain.

Czech Republic making strides for improved diagnostics

For over one year, ENDO Talks CZ, a new association led by women with endometriosis, has been running in Czech Republic. The organisation is aiming to decrease the diagnostic timeframe from 10 years to five and help doctors to have better legislative basis to offer quality care. To reach the goal, they are running projects to raise awareness for the wider public and offer support to newly diagnosed patients.

All of this is running in a perfect symbiosis between patients, doctors, and other specialists with only one goal - bring better quality of life to women with endometriosis in Czech Republic.

In Czech Republic, a country with more than 10 million inhabitants, has only 3 certified endo centres. Despite the geographical availability, the capacity is not enough for the number of Czech women suffering with endometriosis.

Insurance doesn't cover the complex care, resulting in hospitals not focusing on endometriosis, explains Misha Lebeda, founder, and CEO of ENDO Talks CZ, which is recognized by the Czech Ministry of Health.

“Endometriosis should be recognized as a serious disease such as cancer, because the surgery of endometriosis is analogical to oncological treatment,” says doctor Radek Chvátal from Hospital in Znojmo in Czech Republic and from Hospital of the Merciful Brothers Vienna, Austria.

ENDO Talks CZ is creating several projects such as photo exhibitions, concerts, workshops, panel debates, interviews with experts or animated videos for high school students to raise awareness of endometriosis.

Lebeda explains that a different message is needed for women who are dealing with infertility due to endometriosis, who are preparing for surgery or are just suffering from heavy and painful periods. “There is a wide range of target public we have to cover up,” she adds.

Earlier this year, ENDO Talks organised a march to raise awareness by chanting “painful period are not normal”. “It was pretty weird to shout in public messages about menstruation,” says a participant. “It is proof that menstruation is a real taboo.”

In this year’s 6th European Endometriosis Congress, international experts gathered to share their experience and knowledge about new treatment approaches and set new trends. Lebeda shares that two Czech doctors attended the congress as speakers, and ENDO Talks organisation started new collaborations on projects to continue raise awareness.

The UK still combats individual awareness.

Compared to other countries, the United Kingdom has taken some steps in raising awareness towards endometriosis. If the endometriosis presents as chronic and debilitating, it meets the definition of a disability under the 2010 Equality Act, and the employee can ask for reasonable adjustments from their employer. However, such conversations can be embarrassing for some people.

“That is one of the things we are trying to fight. It shouldn’t be any different to talk to your boss about your endometriosis than it is about asthma or diabetes,” says Rebecca Taylor, policy maker at Endo UK.

Yet, there are many other barriers in sight. It takes an average of eight years to be diagnosed with endometriosis, however there are several layers of barriers making the process this long, says Rebecca Taylor, policy maker at Endo UK.

However, the diagnostic dilemma is a small default why it takes almost a decade to figure out if you have endometriosis, says Dr Christian Becker, associate professor, and co-director of the endometriosis care centre at Oxford University. The first barrier is individual awareness of the disease as many aspects of women’s health are not included in school curriculum. “If you have never heard of endometriosis, you might not realise you have this condition,” Taylor says.

Often, women who get diagnosed with endometriosis hear about the condition for the first time, many times when trying to get pregnant and failing. This happened to Kerry Messenger, 41, who found out about the disease when going through IVF treatment. Suffering from severe stomach-aches since late teenage years, she wrote it off as bad periods and came to terms with it. Once, she even went to a hospital because of pain, but the doctors never looked into if it could be endometriosis.

Few years ago, during the process of IVF, doctors were checking if her fallopian tubes were blocked, and this is when they found out that Messenger had stage four endometriosis.

“If it wasn’t for my daughter, I would have never known,” she says. Messenger adds that she was glad once she got her diagnosis, as it explained any unanswered questions, however if there was proper school, maybe it wouldn’t have progressed to a late stage.

Second barrier is societal awareness. Often women get responses of “some women just get painful periods” or “it is a part of being a woman” after talking and sharing their experiences to their loved ones, says Taylor. After going through the same experience as a teenager, Messenger says this vicious cycle needs to end and will keep a close eye on her daughter's symptoms, as endometriosis can be hereditary.

Women across the world are suffering from undiagnosed pain in their abdomen, yet not much is being done to help them. While some countries in Europe have organisations, such as ENDO Talks or Endo UK, that can offer support for patients, others don't, leaving many patients in the unknown. Through pain, blood and tears, women of the world are striving for endometriosis awareness.