



PAINFUL PERIODS?

UNABLE TO CONCEIVE?
ENDOMETRIOSIS?



Hilfe & Unterstützung
bei ungewollter Kinderlosigkeit





THE MANY FACES OF ENDOMETRIOSIS

- **PROFESSOR SYLVIA MECHSNER, HEAD OF THE ENDOMETRIOSIS CENTRE AT BERLIN'S CHARITÉ HOSPITAL**

Endometriosis needs to finally be taken seriously! It is unacceptable that women keep trying to talk about their symptoms, yet their friends and gynaecologists say and do nothing. Or just downplay the whole thing, saying 'period pain is normal', 'don't make such a fuss' or 'we all go through it!'. Don't let statements like these get you down. Don't resign yourself to the situation and don't doubt yourself. You are definitely not just imagining it all.



- **LOLA WEIPPERT, HOST**

All the symptoms I had, all the insane pain ... I have quite a high pain threshold, but when I have my period, you may as well write me off. There's no chance of me being able to do my job without taking painkillers. That's why I knew I had to get it checked. Because the fact that it was getting worse and worse was making me really scared. I didn't know what was going on. In my opinion, the most important thing is to find an expert and insist that they examine you properly and take you seriously.

- **ANNA ADAMYAN, INFLUENCER AND AUTHOR**

Endometriosis is a benign but chronic illness in which tissue similar to the tissue lining the uterus grows outside the uterus in the abdomen. It sounds complicated, and unfortunately it is. Endometriosis appears as masses, growths or even cysts, which can appear almost anywhere. It's really cruel, because it doesn't even stop at our reproductive organs, which can unfortunately lead to infertility or difficulties conceiving naturally. None of this sounds overly pleasant, but today I am very pleased to say I have made friends with my endometriosis. I have accepted it and integrated it into my life, even though it's not always easy.





- **ELLA THEBEE, INFLUENCER**

For a really long time, I thought I was just a wuss, that everyone else was able to handle it so easily. I remember one time at school when my teacher said, 'When I have my period, I don't just spend the day at home, so you just have to harden up a bit.' And I thought, okay, what's wrong with me? I remember situations when I collapsed in class, when I hyperventilated. My parents very often had to pick me up from school early and I would spend the rest of the day in bed.

- **ANJA MORITZ, MANAGING DIRECTOR OF ENDOMETRIOSE-VEREINIGUNG DEUTSCHLAND E. V. (GERMAN ENDOMETRIOSIS ASSOCIATION)**

One of the impacts endometriosis can have is involuntary childlessness. Apart from the pain, this is another very burdening symptom for people wanting to have children. If someone is eager to have children and this does not happen, it can be one of the most painful life experiences ever. Ideally, they will seek advice and support at a fertility clinic specialising in endometriosis. Everyone's pregnancy path here is unique, which is why a one-on-one consultation is required. Even women whose organic diagnostic findings appear hopeless can still fall pregnant naturally.



- **MAITE, BEAUTICIAN, MOTHER OF ONE-YEAR-OLD TWINS**

When my gynaecologist told me I had endometriosis, I had never heard of the disease. The diagnosis was a shock, because the doctor then said it would be difficult for me to conceive naturally. After further examinations, my husband and I soon decided we didn't want to wait any longer and that we wanted to try artificial insemination. We found a fertility clinic which explained everything to us in detail. The treatment was physically and emotionally draining, but it worked on the second attempt, only for us to unfortunately lose the child two weeks later. That was awful for me and my husband. Fortunately, friends and family lifted us up and encouraged us to keep trying. It took another two tries for me to get pregnant again – this time with twins! Today, they're a year old and definitely keep us on our toes, but we cannot imagine life without them!

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Symbol for digital content via augmented reality.



THE GYNAECOLOGICAL CHAMAELEON

FACTS AND FIGURES

- **Around two million women** in Germany have endometriosis – that's ten per cent of the sexually mature female population.
- Endometriosis is **the second most common gynaecological disease**.
- It takes on average **ten years** for a woman to be diagnosed with endometriosis and to start receiving treatment.
- **Around 95 per cent of all women** with endometriosis suffer from dysmenorrhoea, i.e. severe pain and other complaints during menstruation.
- Endometriosis is a factor in around **50 per cent of cases** in which women wanting to have children are unable to conceive.
- Endometriosis has **major impacts on the economy**, as the women affected miss lots of days of work or are less productive, and the medical treatment is expensive and complex.

Sources:

- Guideline on diagnosing and treating endometriosis, 2020 (015/045)
- www.endometriose-sef.de/patienteninformationen/was-ist-endometriose
- www.endometriose-vereinigung.de/was-ist-endometriose.html

WHAT IS ENDOMETRIOSIS?

Endometriosis is a hormonal disease in which tissue similar to the uterine mucosa appears in parts of the body where it doesn't belong. The places where this tissue appears and grows are called endometriosis lesions. These are typically found in the abdomen and ovaries, but can also appear in the gut, bladder and, in rarer cases, the skin, diaphragm or lungs. Endometriosis often also causes adhesions in the abdomen which results in, for example, the uterus not sitting freely or the fallopian tubes getting blocked.

Cells can then build up in the uterus' muscular wall, causing adenomyosis. Many of the disease's symptoms appear cyclically, i.e. tying in with periods.

Endometriosis lesions are benign and are therefore usually not harmful, meaning the cells do not grow in an uncontrollable manner the way they do with cancers. But the effects can still be extreme, ranging from terribly severe period pain to infertility.

WHAT ARE THE TYPICAL SYMPTOMS?

Endometriosis is known as the 'gynaecological chameleon', because it can take many forms and thus have very varying symptoms. Pain is one of the main ones. It can occur cyclically or be irregular/permanent.

Typical symptoms are

- severe period pain, sometimes with nausea, vomiting, diarrhoea, a tendency to collapse
- lower abdominal pain, e.g. before menstruation or around ovulation
- pain and/or difficulty urinating
- pain and/or difficulty emptying bowels
- pain during sex
- back and/or shoulder pain
- pain radiating into the legs
- bloating ('endo belly')
- (Cyclical) bleeding from areas such as the gut, bladder, belly button, lungs (coughing up blood)
- limited fertility, infertility
- pain around C-section scar
- bladder problems
- gut problems (e.g. constipation, diarrhoea, pencil-thin stools)
- stomach problems
- pain in the side
- headaches, even migraines
- dizziness
- fatigue



THE DIAGNOSIS

When women present with symptoms indicative of endometriosis, doctors have several ways of diagnosing it.

The first step is always to speak with the patient in detail about her systems. Then comes the physical examination, first with the speculum, an instrument used to detect visible endometriosis lesions, and then internal and external palpation. An ultrasound should definitely also be performed, either vaginally or rectally. This is the only way to properly detect the lesions; abdominal ultrasounds are not accurate enough. As endometriosis can also affect the kidneys in some cases, these should also be looked at in the ultrasound. If endometriosis is suspected in the gut, further ultrasounds and a colonoscopy should be performed.

But the only way to be totally sure is to perform a laparoscopy, a procedure conducted under general anaesthesia, in which a camera and sometimes also other instruments are used to make tiny incisions in the abdomen.

WHERE IS THE RIGHT PLACE TO GO?

While endometriosis is a gynaecological disease, the wide variety of symptoms means patients also present at other types of practices, such as GP clinics, gastroenterology clinics (gastrointestinal tract) and urology clinics (kidneys and bladder). Doctors specialising in other fields often do not associate the symptoms with endometriosis – which is another reason for the long time women often have to wait for a correct diagnosis. But even gynaecologists need a lot of time and experience to diagnose endometriosis. So it is definitely a good idea for patients themselves to mention the fact that they suspect endometriosis. Some gynaecological practices advertise themselves as specialising in endometriosis. You can also go straight to an endometriosis centre or, if you want to have children, a fertility clinic. These places will be able to offer you good advice. Contact details can be found on page 8.

SANNA'S STORY

Soon after I got my period for the first time, my gynaecologist prescribed me the pill for my acne, and I ended up taking it for fifteen years. I eventually noticed it wasn't doing me any good; I was having bad side effects. After trying different versions of the pill, I finally stopped taking it for good. My first period after stopping it was horrendous. I had never experienced such pain! I went straight to the gynaecologist, but she said it was normal and all part of it.

I managed to get through the next few months by taking painkillers, until I collapsed at work. I was taken by ambulance to the emergency department, where I was diagnosed with an ovarian cyst. During the surgery to remove it, the doctors were surprised to find my entire abdomen was full of endometriosis! No wonder the pain continued even after the cyst had been removed. I then went straight to a clinic specialising in endometriosis.

Unfortunately, I still don't know exactly how to proceed. Hormone treatments cause me such bad side effects that I've decided against using them. I'm currently doing very well with relaxation exercises, yoga and over-the-counter painkillers, which I take as soon as I can feel my period coming on. But I'm still definitely not very functional on those days, and I am often not even able to work.



Then there's the fertility aspect. I'd actually like to wait a bit longer before having children, but I'm 33. Even without endometriosis, the biological clock for us women is ticking. For me, the pressure is doubled, because I know that endometriosis can make conception more difficult.

Being in contact with other women who have the same issue has helped me a lot. We 'Endo Sisters' interact and encourage each other on Instagram.



ENDOMETRIOSIS – NOW WHAT?

TREATMENT OPTIONS

Endometriosis is a chronic illness with no cure. But there are several options available that can relieve symptoms. These always depend on what the individual's main symptoms are, and whether they want to have children or not. This question is important, because endometriosis is a hormonal disease and can be treated with hormones, but only if the patient has no pressing desire to have children. If this is the case, surgery is often advisable, as this can remove any adhesions and check whether the fallopian tubes are blocked – an initial step towards successful pregnancy.

HORMONE TREATMENT

Taking the contraceptive pill, also known simply as 'the pill', stops the natural cycle. This also renders the endometriosis inactive, and sometimes even causes it to regress. Many women experience no pain when on the pill.

SURGERY

Surgery for endometriosis usually takes the form of a laparoscopy, during which a camera and surgical instruments are inserted into the abdomen via small incisions in the stomach. This enables endometriosis lesions and adhesions to be removed and the fallopian tubes to be flushed out. Some women find the surgery cures their pain, while others experience little benefit at all. It is important to note that, in the vast majority of cases, endometriosis does return after surgery.

PAIN TREATMENT

The earlier painkillers are taken, the better their effect. That is why it is not a good idea to wait until the pain becomes unbearable. Untreated pain can also get worse and become chronic over time, and by then very few treatments can help. It is imperative to tell your doctor what you take and how much you take, so that they can explain the risks and alternatives.

LIVING A GOOD LIFE – WITH ENDOMETRIOSIS

Endometriosis is a chronic disease, which is why patients need to learn to live with it. This not only means consulting doctors for advice and treatment, but also knowing how to deal with your own body. In addition to painkillers, for example, exercise, sport and a diet can also have a big influence on wellbeing. Things like regular pelvic-floor stretches, relaxation techniques, physiotherapy, osteotherapy and acupuncture have proven beneficial for many pain patients.

As inflammatory processes play a role in endometriosis, an anti-inflammatory diet is also recommended. This means little, if any, meat or dairy, and largely avoiding sugar and gluten. You can also seek advice on taking micronutrients.

Rehabilitation treatments, e.g. after surgery, are another good idea. It is also very important to note that seeking psychological support can be very helpful in enabling you to live a good life despite all the difficulties. Get help – psychotherapy is covered by all health funds.





ENDOMETRIOSIS AND FERTILITY



Interview with Dr Mohamed Gamal Ibrahim, specialist in gynaecology, obstetrics and reproductive medicine. He is an expert in endometriosis and fertility treatment, and heads the 'Team Kinderwunsch Oldenburg' fertility centre. He holds accreditation from the ESHRE (European Society of Human Reproduction and Embryology), the largest specialist society for reproductive medicine.

Dr Ibrahim, how often do you see patients with endometriosis at the fertility clinic?

Around 50 per cent of women with fertility problems have endometriosis. Sometimes it's us who end up diagnosing it. Either the patients have had no infertility symptoms and have come to us because they cannot get pregnant, or they have had pain/symptoms before but endometriosis was never diagnosed.

Can a woman get pregnant even if she has endometriosis?

The clear answer is: yes! Women with endometriosis can get pregnant, even naturally. Whether that is possible in each individual case depends on the stage/severity of the endometriosis.

A classification known as the Endometriosis Fertility Index was established in 2010. To determine this index, you need to closely examine which organs are affected by the endometriosis, and to what extent. The woman's age and the length of time for which she has been infertile are also factored in. It is then possible to estimate the likelihood of pregnancy over the next three years.

But it is very important here not to forget the men! Both partners always need to be examined in cases of infertility.

What treatment options are available for patients with endometriosis who want to have children?

If they want to have children, hormone treatment (contraceptive pill, IUD/hormonal injections) is not an option, because these inhibit ovulation and thus the possibility of getting pregnant. In these cases, we need to find a different way of controlling the pain. In some instances, surgery performed by an endometriosis specialist is recommended. This can gently remove endometriosis lesions and adhesions, while also checking for fallopian-tube blockages. The exact procedure is discussed individually with the patient. An operation can take just one hour, or ten, depending on where and how widespread the endometriosis lesions are. And surgery is not a miracle cure. Some women find they stop experiencing pain afterwards, while others notice the pain returns after a while or notice no change at all. In certain cases, surgery can be helpful in improving fertility.

If natural conception is not possible and the patient opts for fertility treatment, who bears the costs for this?

Patients should first consult their health fund. There is legislation establishing the minimum expenses these funds need to pay. The German federal 'Infertility Assistance and Support' initiative also provides information on this at www.informationsportal-kinderwunsch.de, where you can additionally check whether you are eligible for a federal or state grant for fertility treatment.

Finally: What message do you have for women regarding endometriosis?

If you have pain and/or are having trouble conceiving, see a gynaecologist immediately! Actively discuss your symptoms and the possibility of endometriosis with them. In many cases, even women with endometriosis can have successful pregnancies. But it does take time and patience.



RECOMMENDED LINKS – FIND SUPPORT HERE!

www.endometriose-vereinigung.de

Website of the Endometriose-Vereinigung Deutschland e. V. (German Endometriosis Association) providing help with doctor searches, advisory services and self-help groups, extensive information and infomaterial available to order.

www.endometriose-sef.de

Website of the Stiftung Endometriose-Forschung (Endometriosis Research Foundation).

www.euroendometriosis.com

Website of the European Endometriosis League.

www.nakos.de

Website of the National Contact and Information Centre providing suggestions and support for self-help groups. You can find self-help groups for many different issues here.

www.zeitbild.de/uni

Web portal Zeitbild UNI "Endo ... was???" with free-of-charge information and materials for students and teaching staff at universities and other higher education institutions.

RECOMMENDED READS



Prof. Dr. Sylvia Mechsner: Endometriose – die unterschätzte Krankheit, Munich 2021.

A comprehensive book with lots of medical expertise on diagnoses, treatment and self-help.

Martina Liel: Nicht ohne meine Wärmflasche. Leben mit Endometriose, Munich 2017.

The author herself is an endometriosis patient. In an addition to an academic perspective, she also describes her disease's impact on various other aspects of her daily life.

Martina Liel: Endometriose und Psyche. Ursachen, Auswirkungen und Bewältigungsstrategien, Munich 2021.

A book on the psychological stress experienced by endometriosis patients, possible coping strategies, and tips on regaining quality of life despite the disease.

Anna Wilken: In der Regel bin ich stark – Endometriose: Warum wir unsere Unterleibsschmerzen ernst nehmen müssen, Hamburg 2019.

The author herself has endometriosis. She provides medical and personal insights.

Anna Wilken: Na, wann ist es denn so weit? Kinderwunsch sieht bei jedem anders aus: Emotionen, Ursachen, Behandlungsmöglichkeiten, Munich 2021.

A book about fertility, causes of infertility, and treatment options, with lots of personal insights.

... PLUS:

On **Instagram**, women with endometriosis call themselves Endo Sisters, and interact using the hashtag **#endosisters**.

The **Endo app** is an accredited medical device that provides endometriosis patients with holistic support in the form of information, exercises and a symptom diary.

www.informationsportal-kinderwunsch.de

Is the online platform for the German federal 'Infertility Assistance and Support' initiative run by the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth on the topic of fertility. It provides detailed information on causes, treatment, advice and support. An internal search function makes it easy to find funding options. It also has lots of testimonials and expert discussions in the form of videos and podcasts.



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