

# ENDOLIFE

Digital magazine

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## PROF HANS TINNEBERG

Principles of  
endometriosis  
excision surgery

## DR ALINA DIMA

Endometriosis and  
fibromyalgia

## MR THOMAS BAINTON

Endometriosis and  
the risk of cancer

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for endometriosis

## DR JOSE EUGENIO-COLON

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endometriosis

## DR ABHISHEK MANGESHIKAR

Endometriosis of  
the diaphragm

## DR ANCA IONESCU

Chronic pain therapy

**Zahra  
McDonald**

*My endometriosis is  
constantly debilitating  
in every aspect of my life*



Using excision as primary treatment method, our centre is led by internationally renowned endometriosis specialist Dr Konstantinos Kyriakopoulos.

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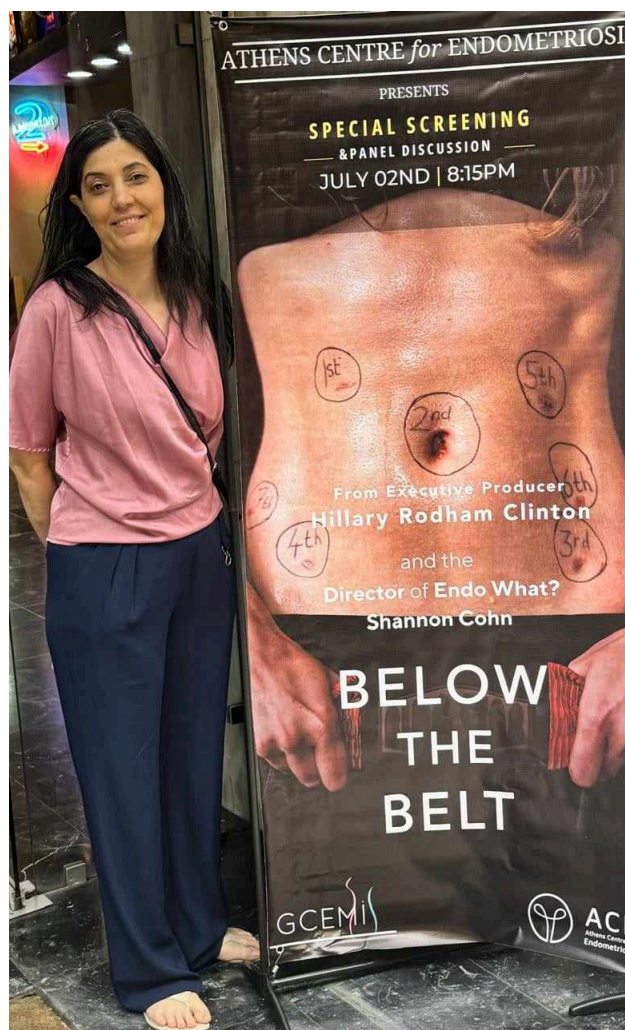
[endometriosis-surgery.gr](http://endometriosis-surgery.gr)

# The screening of Below the Belt, in Athens

Over these years that I know what endometriosis is, I have had the chance to learn a thing or two. As a social media person, job mainly, I am familiar with various events, projects or professional bodies that cover endometriosis and adenomyosis. One of them is the Endowhat project.

This July I flew to Athens from London with my husband to attend the screening of Below the Belt. Organised by Dr Konstantinos Kyriakopoulos from Athens Centre for Endometriosis, I played a small part as well. I was, if I can call myself so, a moderator of the after screening panel talk.

The screening started with drinks and snacks, with attendees from Greece but also patients of Dr Kyriakopoulos from abroad. Shannon Cohn and her family were present as well. I saw a few short clips from the documentary before, so I had a rough idea about what we will see. It goes without saying that it was very emotional to watch.



**Education is for sure one way of changing the world.**

Listening to the stories of 4 sufferers made me realise yet again the hard reality of many endometriosis sufferers. In March I was writing about my friend Brenda, the first person to tell me the word endometriosis, and her struggles with this disease. Brenda is from Chicago and old enough to be my mother (I am nearly 42), and her struggles are still lived by many sufferers, as seen in the documentary.

I sat in between my husband and a patient of Dr Kyriakopolous who herself had endometriosis since the age of 14 and it wasn't until the age of 46 when she had her first excision surgery. She cried for the duration of the screening.





The screening was without any doubt a success. And one that will hopefully improve care for women in Greece. Although not much has changed as someone from the documentary has said, slowly but steady things get better for endometriosis sufferers. We all left the location with hope and with plans. The panel discussion was also interested and highlighted many issues faced by endometriosis sufferers around the world.

As for this current issue of our magazine, you will find another great round of articles from doctors from many, many countries. I cant believe how fast the time flies. In we are in Septemeber, back to school for may of us, including for me, with a master at University Colleges of London. Fingers crosses, it will go well.

A big thank you to everyone who took part in this number. We have contributions from Germany, Romania, UK, India, USA, Holland, Australia, Malaysia, Israel and I believe Estonia. You can read about excision, complications of surgery, minimally invasive surgery, reocurrance and diagnosis and hormonal treatment. We have contributions on diet, IBS and fibromialgia as well, and assited human reproduction.

All articles will be uploaded to our website as well, and the magazine as well. You can also find us on Academia and Google books.

We are now at issue number 3 and in December will be our 4th issue and the last one for this year.

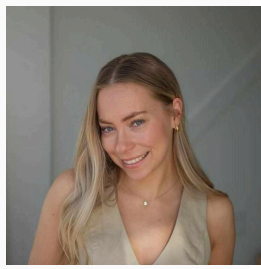
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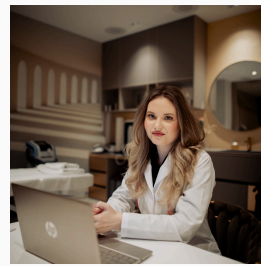
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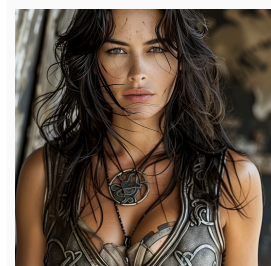
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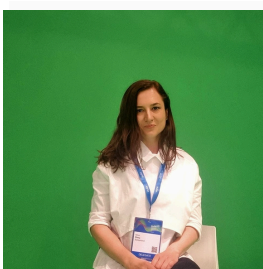
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**WHERE YOU CAN KEEP UP WITH OUR WORK AND  
NEWS ON OUR MAGAZINE:**



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EndoLife digital magazine is an educational non-for-profit project of People with Endometriosis Association. The magazine will be published regularly.

This current edition contains articles written by doctors, endometriosis advocates and healthcare practitioners.

**Concept:** Camelia Serban

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EndoLife magazine has taken all the necessary measures to ensure that all information provided herein are correct at the time of publication, however these do not substitute medical advice. The information provided herein is solely for educational purpose and not for diagnosing and/or treatment. EndoLife recommends seeing an endometriosis specialist if you suffer from endometriosis.





# Endometriosis of the diaphragm

**Dr Abhishek Mangeshikar**  
*Consultant gynecologist  
 and endometriosis robotic surgeon  
 The Indian Centre for Endometriosis*

**Statistics show diaphragm endometriosis to be rare. Based on your experience, how frequent it is?**

Diaphragmatic endometriosis is a rare and often under-recognized manifestation of endometriosis. In terms of statistics, it is estimated to occur in approximately 1-1.5% of all women with endometriosis, though some studies suggest it could be slightly higher due to the condition being underdiagnosed. The rarity is partly because diaphragmatic endometriosis is often asymptomatic or presents with non-specific symptoms, leading to it being overlooked or misdiagnosed.

In my practice, which involves a significant focus on advanced and atypical cases of endometriosis, I encounter diaphragmatic endometriosis more frequently than the general estimate would suggest. This is likely due to the referral nature of my practice, where I see patients who have complex or severe endometriosis.

Even with that, it still remains one of the rarer forms of endometriosis that I treat, with the majority of cases being diagnosed incidentally during laparoscopic surgery for pelvic endometriosis. We end up treating about one case every month of diaphragm or thoracic endo.

“ **The optimal management strategy for endometriosis of the diaphragm can vary, and a multidisciplinary approach involving thoracic surgeons may be necessary in more extensive cases.** ”





### **Can we diagnose diaphragmatic endometriosis via MRI, for example, and how accurate it is?**

Yes, diaphragmatic endometriosis can be diagnosed via imaging studies such as MRI, although the accuracy and reliability of these methods are generally lower compared to pelvic endometriosis.

MRI is a useful tool in the evaluation of diaphragmatic endometriosis, especially when there is a high suspicion based on clinical symptoms like cyclical thoracic or shoulder pain. However, the sensitivity and specificity of MRI in diagnosing diaphragmatic endometriosis are variable.

One of the challenges with MRI in this context is that diaphragmatic lesions can be small or subtle, making them difficult to detect. Additionally, the diaphragm is in constant motion due to respiration, which can further complicate the imaging. The lesions may not always be clearly distinguishable from other possible abnormalities in the diaphragm or surrounding tissues.

In my experience, while MRI can sometimes suggest the presence of diaphragmatic endometriosis, it is not definitive and is often used as a complementary tool rather than the sole diagnostic modality.

**Diaphragmatic endometriosis can occur independently without the presence of pelvic endometriosis, although it is more commonly seen in conjunction with pelvic disease. I've encountered cases where the abdominal diaphragm was completely clear, but the thoracic pleura had endometriosis.**

### **What happens when endometriosis grows or spreads into the thoracic cavity?**

When endometriosis spreads into the thoracic cavity, it can cause a range of symptoms and complications, often linked to the menstrual cycle. Key manifestations include:

- **Cyclic Thoracic Pain:** Sharp, chest or shoulder pain that worsens during menstruation.
- **Catamenial Pneumothorax:** Lung collapse during menstruation, often due to endometriotic lesions on the pleura or diaphragm.
- **Catamenial Hemothorax:** Bleeding into the pleural space, leading to chest pain and difficulty breathing.
- **Pleural Effusion:** Fluid accumulation around the lungs, causing shortness of breath and chest discomfort.
- **Lung Nodules and Hemoptysis:** Rare cases of endometriosis in lung tissue can cause coughing up blood during menstruation.

### **Fenestration or a hole in the diaphragm, how does it happen? And in terms of surgery how do you fix them? Do you need a mesh or you can use sutures?**

Fenestrations or holes in the diaphragm associated with endometriosis are thought to occur due to the chronic inflammatory process caused by the endometriotic lesions. These lesions can erode through the diaphragm, leading to the formation of defects or holes. The exact mechanism is not entirely understood, but it's believed that repeated cycles of bleeding and inflammation weaken the diaphragmatic tissue over time, causing it to thin and eventually form fenestrations.

### **Surgical Repair of Diaphragmatic Fenestrations**

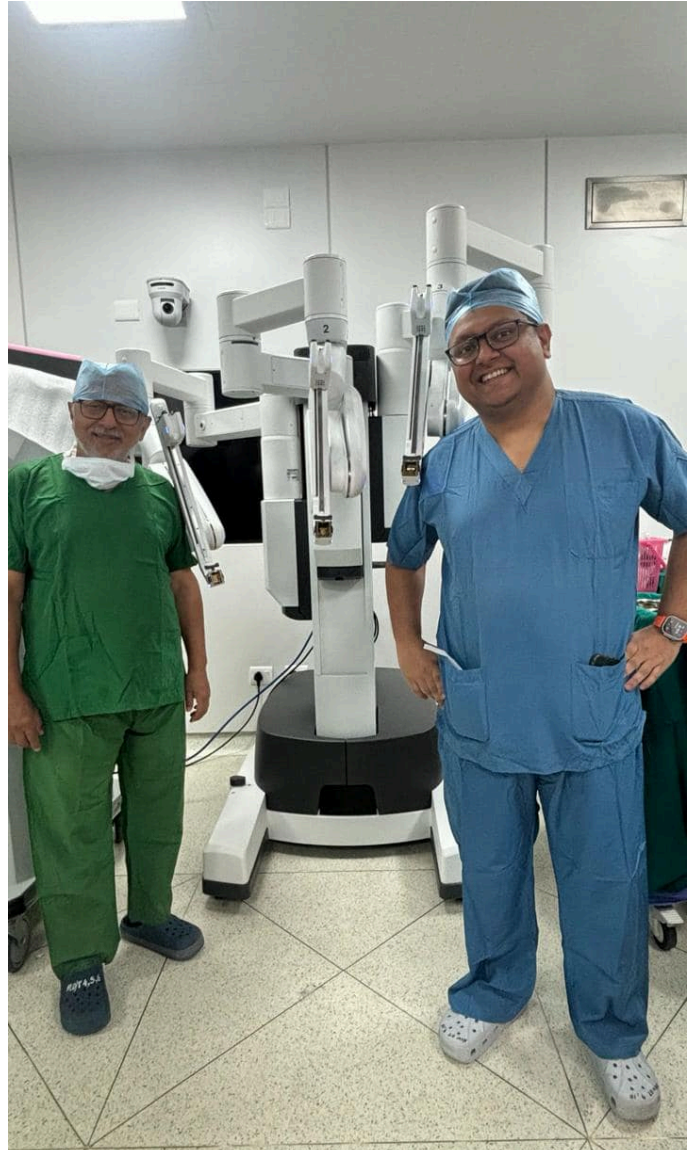
**Suturing:** In many cases, small diaphragmatic fenestrations can be repaired using direct suturing. The surgeon will approximate the edges of the defect and close it with non-absorbable sutures to ensure a strong and lasting repair.



**Mesh Repair:** For larger defects, or when the tissue quality is poor (e.g., due to extensive endometriosis or inflammation), a mesh may be required to reinforce the diaphragm. The mesh is usually made from a biocompatible material, such as polypropylene, and is placed over the defect, either on the abdominal or thoracic side of the diaphragm, and secured with sutures or tacks. Mesh repair is preferred when the defect is large, or there's concern that the tissue might not hold sutures well on its own.

#### Considerations in Surgical Repair

- **Location and Size:** The size and location of the fenestration play a crucial role in deciding whether sutures alone are sufficient or if mesh reinforcement is necessary.
- **Tissue Quality:** If the diaphragm is significantly weakened or thinned, mesh might be more appropriate to prevent recurrence of the defect.
- **Surgeon's Experience:** The choice between sutures and mesh can also depend on the surgeon's experience and preference, as well as the specifics of the patient's case.



**The goal in surgery is to restore the integrity of the diaphragm, prevent future complications (such as herniation of abdominal contents into the thoracic cavity), and alleviate any associated symptoms.**

#### *What types of lesions do we encounter on the diaphragm?*

When dealing with endometriosis on the diaphragm, several types of lesions can be encountered, each with distinct characteristics:

**Superficial Lesions:** These are small, flat lesions on the surface of the diaphragm. They may appear as black, blue, red, or white patches and are often similar in appearance to superficial pelvic endometriosis. These lesions are usually less invasive but can still cause significant symptoms due to the sensitivity of the diaphragm.



- **Nodular Lesions:** These are more raised, firm lesions that penetrate deeper into the diaphragmatic tissue. Nodular lesions are more likely to cause significant pain and are often associated with deeper invasion into the muscle layer of the diaphragm.
- **Fenestrations or Perforations:** These are actual holes or defects in the diaphragm, typically resulting from the erosion of the diaphragmatic tissue due to endometriosis. Fenestrations may vary in size and can lead to complications such as herniation of abdominal contents into the thoracic cavity.
- **Fibrotic or Scar Tissue:** Over time, endometriotic lesions can lead to fibrosis or the formation of scar tissue on the diaphragm. This can cause thickening of the diaphragmatic tissue and may contribute to pain and restricted movement of the diaphragm during breathing.
- **Pleural Lesions:** While technically on the thoracic side, pleural lesions can be seen in conjunction with diaphragmatic endometriosis. These lesions can cause pleuritic pain and may be associated with conditions like catamenial pneumothorax.
- **Hemorrhagic Lesions:** These are lesions that actively bleed, often during menstruation. They can cause localised bleeding on the diaphragm or into the pleural cavity, leading to symptoms like hemothorax.

***What are the most obvious symptoms of diaphragmatic endometriosis and how can we differentiate between thoracic endometriosis?***

Diaphragmatic and thoracic endometriosis can present with overlapping symptoms, but there are key differences that can help in distinguishing between the two:



**Symptoms of endometriosis of the diaphragm**



**Symptoms of thoracic endometriosis**

**Symptoms of Diaphragmatic Endometriosis:**

- **Cyclical Shoulder Pain:** One of the hallmark symptoms of diaphragmatic endometriosis is pain in the shoulder, often referred to the right side, which occurs cyclically in relation to the menstrual cycle. This is due to the proximity of the diaphragm to the phrenic nerve, which refers to pain in the shoulder.
- **Cyclical Upper Abdominal or Chest Pain:** Patients may experience upper abdominal or lower chest pain that worsens during menstruation. The pain is often sharp and may radiate to the back or sides.
- **Referred Pain:** Pain can also be referred to areas like the neck or collarbone due to diaphragmatic irritation.

**Symptoms of Thoracic Endometriosis:**

- **Catamenial Pneumothorax:** This is a classic symptom of thoracic endometriosis, where the patient experiences a collapsed lung during or just before menstruation. Symptoms include sudden chest pain, shortness of breath, and possibly cyanosis (bluish skin due to lack of oxygen).
- **Catamenial Hemothorax:** Thoracic endometriosis can also cause bleeding into the pleural cavity during menstruation, leading to chest pain, difficulty breathing, and sometimes a drop in blood pressure.
- **Cyclical Chest Pain:** Similar to diaphragmatic endometriosis, thoracic endometriosis can cause cyclical chest pain. However, this pain is typically more localised to the chest and may be associated with breathing difficulties.
- **Hemoptysis (Coughing up Blood):** In rare cases, thoracic endometriosis can cause blood to be coughed up during menstruation, especially if the lung parenchyma is involved.

**Differentiating Diaphragmatic from Thoracic Endometriosis:**

**Pain Location:** Shoulder pain is more indicative of diaphragmatic endometriosis, while chest pain and respiratory symptoms (like pneumothorax or hemothorax) are more suggestive of thoracic endometriosis.



- **Imaging Findings:** Imaging studies such as MRI or CT scans can help differentiate between the two by identifying the location of the lesions. Diaphragmatic lesions may show up on the diaphragm or the lower thoracic region, while thoracic lesions are more likely to appear in the pleura, lungs, or other thoracic structures.
- **Laparoscopic/Thoracoscopic Findings:** Direct visualization via laparoscopy (for diaphragmatic endometriosis) or thoracoscopy (for thoracic endometriosis) is the gold standard for differentiating these conditions. During these procedures, the surgeon can directly see the lesions and determine their exact location.

***Diaphragmatic endometriosis can be operated using laparoscopy and robotics? When is the robot most suitable?***

Robotic surgery is particularly advantageous for diaphragmatic endometriosis, especially when excising full-thickness lesions. It simplifies suturing during diaphragm reconstruction, making the repair process more precise and effective. Additionally, the robot's precision allows for careful stripping of the peritoneum in non-full-thickness lesions without opening the diaphragm, preserving its integrity. This level of control and accuracy is especially beneficial in complex cases where precise tissue handling is crucial.

***There are patients who had ablation done on their diaphragm, the reasoning was that ablation is better suited for superficial endometriosis. Can you excise superficial endometriosis of the diaphragm, or only ablation can be used?***

Superficial endo can be easily excised especially with the robot which is far more precise. Secondly excision is mandatory because sometimes a lesion that appears superficial can be quite deep.

**When ablation is used on superficial endometriosis, the disease is left behind and in time it will progress to deep endometriosis, causing holes in the diaphragm.**

***How is the recovery after surgery and what complications might arise?***

Recovery can differ significantly depending on whether the diaphragmatic endometriosis is excised via an abdominal or thoracoscopic approach.

**Recovery from Abdominal Excision**

Recovery from an abdominal approach is generally quicker, with most patients returning to normal activities within 2 to 4 weeks.

Potential complications include infection at the incision sites, adhesions, and, in rare cases, injury to abdominal organs. The risk of respiratory complications is lower compared to the thoracoscopic approach.

**Recovery from Thoracoscopic Excision (Chest Approach):**

Recovery from a thoracoscopic approach tends to be longer and more involved. Patients may need 4 to 6 weeks to fully recover, depending on the extent of the surgery.

There is a higher risk of respiratory complications, such as pneumothorax (collapsed lung), pleural effusion (fluid in the chest cavity), or atelectasis (partial lung collapse), due to the proximity of the surgery to the lungs. Patients may require chest tubes postoperatively to drain any excess fluid or air.



# Complications of laparoscopic surgery

**Mr Amer Raza**

*Consultant gynecologist and  
robotic endometriosis surgeon*



Laparoscopic surgery, also known as minimally invasive surgery, involves smaller incisions compared to traditional open surgery and is generally associated with a quicker recovery, earlier discharge and less postoperative pain. However, like any surgical procedure, it carries certain risks and potential complications. Here are the main complications associated with laparoscopic surgery:

**Injury to Organs:** There is a risk of accidental injury to organs, such as the intestines, bladder, liver, spleen, or blood vessels, particularly in complex or emergency cases. Injury to these organs may require conversion to an open surgical procedure or additional surgeries.

**Bleeding and Haemorrhage.** While laparoscopic surgery typically involves less blood loss than open surgery, there is still a risk of bleeding, especially if a blood vessel is accidentally cut or injured during the procedure.

Mr. Raza is a distinguished gynecologist and robotic surgeon at Cromwell Hospital in London. He is the Founder and CEO of the International Centre for Endometriosis, one of the largest centers dedicated to treating complex endometriosis. Mr. Raza is also a senior honorary lecturer at Imperial College and the principal investigator for several research projects focused on endometriosis diagnosis. Additionally, he serves as the Director of the Chelsea Centre for Minimal Invasive Gynaecology, which offers national and international courses in laparoscopic and hysteroscopic surgery.



**Infection.** Although the risk of infection is lower with laparoscopic surgery compared to open surgery, it can still occur at the site of the incision or internally.

**Hernia at the Incision Site.** A hernia can develop at the site of the small incision made for laparoscopic instruments. This complication is more common if the incision is larger than usual or if the patient has other risk factors like obesity or poor wound healing.

**Anaesthesia-Related Complications.** As with any surgery requiring general anaesthesia, there are risks associated with the anaesthesia itself, including allergic reactions, respiratory issues, and cardiovascular complications.

**Conversion to open surgery.** Sometimes, due to unexpected difficulties or complications, a laparoscopic surgery may need to be converted to an open procedure.

This can lead to a longer recovery period and increased risk of infection or other complications associated with open surgery.

**Nerve Injury.** There is a small risk of nerve injury, particularly in the abdominal wall as small Nerves cannot be seen.

**Deep Vein Thrombosis and Pulmonary Embolism.** As with any surgery, there is a risk of blood clots forming in the veins, particularly in the legs, which can lead to deep vein thrombosis or pulmonary embolism.

**Postoperative Pain and Discomfort.** While laparoscopic surgery is less invasive and usually causes less postoperative pain than open surgery, patients can still experience pain and discomfort from the incisions or the effects of insufflation.

## Serious Complications 2-3 in 1000 cases



### Adhesion Formation

Adhesions are bands of scar tissue that can form inside the abdomen after surgery, potentially leading to complications like bowel obstruction or chronic pain.



More serious complications like bowel perforation, organ damage, or significant vascular injury can occur, requiring immediate surgical intervention.

While these complications are potential risks, the overall safety profile of laparoscopic surgery is favourable, especially in comparison to traditional open surgery. The risk of complications varies depending on the specific procedure, the patient's health, and the surgeon's experience. It is important for patients to discuss these risks with their healthcare provider to understand the potential benefits and risks based on their individual case.



# Principles of endometriosis excision surgery

**Excision clearly means the complete removal of endometriosis. Ablation depends very much on the surgeon as well as the condition of the implant or tumor. In many cases small parts of endometriosis might be left behind so that a recurrence has to be taken into consideration.**

***Because endometriosis can involve various structures, with varying degrees of infiltration, endometriosis surgery is considered as one of the most challenging surgeries in gynaecology. It is one that not many surgeons do. With this in mind, what is the purpose of surgery in endometriosis?***

Unfortunately, medical therapy for endometriosis including endometriosis associated pain is only symptomatic and does not remove the endometriosis implants. Therefore surgery is still in many cases the only way to help stop the suffering of affected women.

***We know that excision is used in cancer, whereby a piece of tissue with margins is removed in order to fully remove the disease. In endometriosis, how is excision executed? Do we have a margin as well?***

Since fortunately endometriosis is **not a malignant** disease it is not necessary to have a safety margin. However, in a lot of cases endometriosis has no clear circumference and might even infiltrate the surrounding healthy tissue so that a wide excision is advised.

***What is the youngest and the oldest patient that you have operated on?***

The youngest patient was a young girl 16 years of age with a family history of endometriosis where her mother knew from the beginning of hearing her daughter complain of severe menstrual pain that this could be endometriosis.



**Hans-Rudolf Tinneberg**

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The oldest patient was clearly postmenopausal perhaps in her late 50ies or early 60ies. She had endometriosis before which was not completely removed and as she knew the symptoms came for final surgery.

***What is the principle of excision? Is it to avoid organ damages, or to save reproductive organs? Is it to remove the source of the pain?***

Probably the most important reasons or indications for endometriosis surgery is to remove the source of pain as this is sometimes debilitating for the women affected.





**Gateway Clinics GmbH, Amelia-Mary-Earhart Straße 17, Frankfurt am Main, Germany**

**Photo source:** courtesy of NSSU

Also, vital structures in the pelvis need to be protected from being damaged by endometriosis as for instance endometriosis can strangulate the ureter and thereby cause severe kidney problems including insufficiency of the kidney. Of course in those women that had not completed their family planning surgery might involve a compromise as maintenance of reproductive organs is of utmost importance.

***In endometriosis some says there is no cure, others say excision is the cure. When surgery is done and all the disease is removed, is that person cured, even if it is temporary? Or only if they no longer have symptoms?***

As menstruation is in most cases the reason for endometriosis, a woman in her reproductive age that wants to become pregnant and therefore menstruates regularly might have a stimulus for recurrence of endometriosis with every menstruation, even though the excision has been complete. So in principle, the disease was cured but due to a normal condition (i.e. menstruation) it was reignited.

***In some cases despite surgery being executed correctly, patients have little or no improvements. What can be the cause?***

This is the most difficult question as it might be that the initial diagnosis was not correct and the pain should be linked to other reasons than endometriosis. There are many differential diagnoses including psychological causes like post-traumatic disorders. Therefore, pre-surgical diagnosis must be executed very carefully as it is not easy.

***Given your experience, in patients that had 10 or more surgeries and they are still in pain, will another surgery help them or it won't bring them much improvement?***

This very much depends! Unfortunately, we see patients that had multiple incompetent surgeries where the disease was only removed superficially. In those cases a thorough diagnosis with excellent imaging and precise pain mapping following the description of the patient is absolutely mandatory in order to decide whether the patient will benefit from another surgery.

***Despite having surgery done correctly, or in some cases, by the same doctor, the results are different. Some patients have a higher symptom improvement, and others far less. What can be the reason?***





**First of all:** pain is quite subjective which might already explain the differences. In addition, especially in the case of several previous surgeries, side effects of these operations might be the reason for continuous pain or discomfort.



Endometriosis is a disease that involves several disciplines in addition to gynecology. Particularly in deep-infiltrating-endometriosis it is best if the surgeon is experienced in gynecology, bowel surgery as well as in urology. If the surgeon shies away from operating in a different discipline area than their own then incomplete removal of the diseased tissue is very common as we see in many cases of ablation.



***The pelvis has anatomical danger zones where there is a risk of damaging underlying structures. When it comes to ablation, they say that it cant be used in said zones due to damaging organs, hence why excision is better. What are the basic surgical principles employed in excision in order to fully remove the disease and avoid damage to these organs?***

As mentioned above excision means the complete removal of the disease. Even if endometriosis is close or involves important and vital structures or organs, excision needs to be performed in order to prevent further destruction of that particular region. This might involve that e.g. autonomous nerves can be destroyed causing bladder dysfunction. In ideal cases the pre-operative diagnosis is so precise that this instance can be suspected and needs to be discussed with the patient. Then it will be her decision whether the unhealthy tissue should be completely removed or parts should be left behind, possibly causing recurrence of the disease already after a short interval. I think it is only fair to the patient to explain not only the procedure but also the limitations of surgery.

***Do we have limitations in excision?***

If family planning is a vital issue, removal of endometriosis of any reproductive organ has to be performed extremely carefully, meaning that sometimes endometriotic tissue has to be left behind. For example ovarian endometriosis has to obey the ovarian reserve so that production of oocytes is still possible. Another example might be brain endometriosis (which fortunately is quite rare) where the surrounding tissue needs to be protected from radical surgery. In bladder endometriosis implants close to the trigon (i.e. where the ureters end in the bladder) must carefully be resected as otherwise innervation of the bladder might be compromised or even the function of the ureter could be impaired.

***“For me, having excision surgery meant getting my life back. After 20 years of pain, from a young age, impacting my education and career, and after several ablation and incomplete surgeries, I finally had correct surgery performed by Prof Hans Tinneberg. I can't tell the medical definition of excision, but I can tell what it meant for my long-lived suffering; the first time in years that I have no pain, despite having a complex surgery that needed a bowel resection. Grateful to the medical team and Prof Tinneberg for helping me live a life without pain”.***



**MARINA**  
ENDOMETRIOSIS  
PATIENT



# Recurrence in endometriosis

***There are various definitions of recurrence, so what exactly is recurrence of endometriosis?***

Recurrence of endometriosis refers to the reappearance of endometrial-like tissue after it has been completely surgically removed. This can manifest as new lesions or the regrowth of previously excised disease. True recurrence differs from persistence, which results when endometriosis is left behind and not actually fully excised. Recurrence may be clinically suspected based on symptoms and can be confirmed through imaging or surgical findings.

***Apart from surgery, are there any other risk factors that can lead to recurrence?***

Apart from incomplete surgery, some factors can contribute to the recurrence of endometriosis, including but not limited to the presence of other gynepathologies, such as adenomyosis and/or concomitant adhesion; higher stages of disease; lesion subtype such as the presence of bowel lesions; and whether pharmacological therapy is used postoperatively or not. It is critical to note that the recurrence or persistence of pain is not always synonymous with the presence of endometriosis; secondary pain generators may often be present.

***How do hormone medication work as a method of prevention for recurrence?***

Hormonal medication aims to suppress the stimulation of endometrial-like tissue and inhibit its growth during therapy. It is intended to treat endometriosis-associated pain and theoretically can suppress recurrence while used. Drugs to treat endometriosis-related pain include synthetic progestins, combined hormonal contraceptives, GnRH analogs, aromatase inhibitors, danazol, SERMs and SPRMs.



## Dr Jose Eugenio-Colon

Dr. Jose D. Eugenio-Colón of the Center for Endometriosis Care is one of the world's leading high-volume, Board-certified endometriosis surgeons and an Assistant Professor in the Department of ObGyn & Women's Health in the Division of Minimally Invasive Gynecologic Surgery at Saint Louis University School of Medicine. Dr. Eugenio is known throughout the international endometriosis community for his tireless Advocacy, sincere compassion, disease expertise and dedication to improving lives; he is a devoted physician whose commitment extends beyond his practice.

**Instagram: @DrEndometriosis**



While more recent publications indicate reduced reoperation rates for endometriosis in those who are treated with hormones in association with their surgery, a 2020 Cochrane Review exploring the effectiveness of hormonal suppression before, after or both before and after surgery for endometriosis determined that “the data was inconclusive.” Still, there is evidence that hormone suppression may help prevent postoperative recurrence, particularly endometriomas.

***What is the rate of recurrence in endometriosis after excision and for what period of time?***

*Recurrence rates after endometriosis surgery vary widely and are operator-dependent. Rates are heavily influenced by factors such as extent of disease and completeness of surgical excision. Rates have been previously reported between 20%-40% within 5 years; however, more current data published by dedicated centers of expertise indicates overall rates of recurrence of less than 10%.*



**There is no universal, definitive cure for endometriosis. Multidisciplinary treatments are directed at symptom management and meticulous removal of disease to reduce recurrence and persistence, with goals directed at alleviating symptoms and improving quality of life.**



***Is the presence of an endometrioma after surgery a sign of recurrence?***

Endometriomas have a high recurrence/persistence rate, and their presence after surgery can indicate both persistence or true recurrence of the disease.

***Why is the rate of recurrence higher in women under 25 years old or a bit older?***

While risk predictors remain under debate, younger patients may have higher recurrence rates due to increased hormonal activity, i.e., higher plasma estrogen levels, more aggressive disease and disease subtype may be associated with endometriosis recurrence. In contrast, still other data indicates that those in the 35 + age group are positively associated with recurrence when compared to non-endometriosis controls, driving home the importance of patient-centric care adapted to the individual in order to apply tailored therapies for every patient.

***What is the recurrence rate for bowel endometriosis based on the procedure done?***

While the recurrence rate after colorectal surgery for endometriosis may be as high as up to 50% at 5 years, as with all forms of the disease this may vary based on the skill of the surgeon and type of surgical intervention. For example, current data implies that the risk of recurrence is lower when segmental resection or disc excision is performed than when rectal shaving is performed.

***What are the signs of endometriosis returning?***

Clinical signs of endometriosis recurrence may be the same as or include those experienced at primary onset, i.e., pain (for example, persistent or new pelvic pain), changes in menstrual patterns, such as increased pain or heavy bleeding, recurrence of pain during or after sex, GI or urinary dysfunction/pain, bloating, fatigue and more. As with initial onset, timely diagnosis and effective intervention are key towards isolating and treating the diagnosis.



## Can some of these symptoms be caused by adhesions?

Yes, symptoms such as pelvic pain and discomfort during intercourse can also be caused by adhesions, which are scar tissues that can form after surgery or due to chronic inflammation. Adhesions can cause similar symptoms to endometriosis and complicate the diagnosis and management, as can a number of other conditions including but not limited to adenomyosis, for example.

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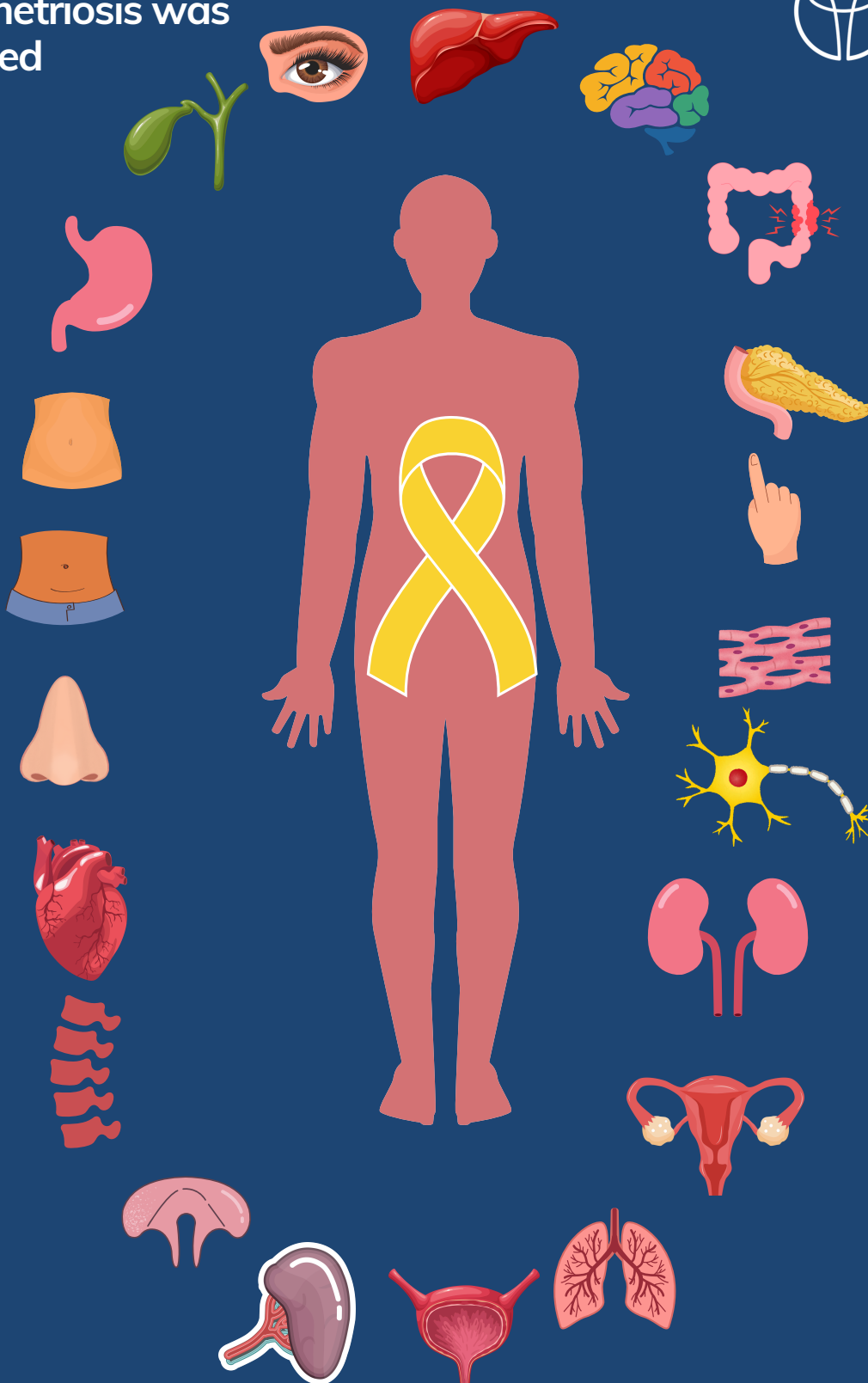
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some organs where  
endometriosis was  
reported



ACE  
Athens Centre for  
Endometriosis



Pericardial  
Somatic and vegetative nerves  
Spine  
Reproductive organs  
Kidney, Liver  
Bowel

Brain  
Eyelid, Nose  
Lungs, Diaphragm  
Gallbladder  
Stomach, Appendix

Belly button  
Finger  
Abdominal  
wall  
Muscles  
Spleen

# Endometriosis and fibromyalgia

***It appears that endometriosis sufferers have a higher risk of fibromyalgia. What is the connection between these two illnesses that can explain this risk?***

Like endometriosis, fibromyalgia is one of the major causes of chronic pain in women. In fibromyalgia pain syndrome is non-specific and frequently generalized throughout the body, accompanied by severe and apparently unexplained fatigue, sleep disorders and daytime sleepiness, increased anxiety and depression. In endometriosis, pain in the pelvic region, dyspareunia and dysmenorrhoea are described, all of which are frequently found during the menstrual cycle. Therefore, we have this clinical link between the two pathologies, chronic painful symptoms with a negative impact on the quality of life at young ages. Although the diagnosis of fibromyalgia is more frequent in people with endometriosis compared to the general population and we could thus say that there is a greater risk, this relationship is not known. One hypothesis would be that although they are not genetically transmitted diseases, there may be a common family predisposition. Moreover, neither of these two pathologies has a completely understood pathogenesis and therefore there are no preventive treatments.

***Is endometriosis a predisposing factor for certain autoimmune diseases?***

Yes, various population studies have shown that people who have endometriosis have an increased risk of associating other chronic diseases, including autoimmune diseases, compared to ones of the same age group who do not have this pathology. In addition, during screening laboratory determinations, it was observed that patients with endometriosis express more serum antibodies compared to the general population. Thus, autoimmune thyroiditis with hypothyroidism, atopic dermatitis, bronchial asthma, celiac disease are more common in people with endometriosis.



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Among the systemic autoimmune diseases, there are arguments for the association with endometriosis for systemic lupus erythematosus, rheumatoid arthritis, Sjogren's syndrome, and multiple sclerosis. For example, the risk of Sjogren's syndrome is increased especially in the first 5 years after the diagnosis of endometriosis.

**I think it would be important to mention that women with endometriosis who are also diagnosed with a systemic autoimmune disease generally have more advanced forms of the disease (stage IV) and more severe pain symptoms.**

### ***What symptoms do we encounter with fibromyalgia?***

People suffering from fibromyalgia generally describe a general discomfort, a feeling of permanent fatigue, accompanied by generalised musculoskeletal pain described "in the whole body", little or no response to classic analgesics. In addition, chronic headaches, sleep disorders or the impression of restless sleep, "brain fog" sensation, "blurred" thinking, as well as non-specific thinking and memory disorders may occur. In this context, of a chronic condition with physical symptoms and cognitive dysfunctions, anxiety and depression are frequently associated over time.

The clinical picture is pleomorphic, describing more than 200 systemic symptoms possibly associated with fibromyalgia. Fibromyalgia is also called the "invisible disease" because no specific diagnostic imaging or laboratory tests have yet been identified.

The diagnosis is based on a detailed medical history, careful clinical examination and the identification of complementary somatic symptoms. The clinical examination was standardised by marking some skin areas in specifically designated points (such as the area at the base of the skull, occiput, shoulder area, elbows or hips), which may be painful to palpation.

### ***If you have endometriosis and fibromyalgia, can fibromyalgia exacerbate endometriosis symptoms?***

Fibromyalgia pain is diffuse, usually affecting the entire body, it is not limited to or paced by the menstrual cycle periods, but is reproduced by the application of pressure specifically in the areas designated for evaluation, and this has nothing to do with endometriosis.

However, yes, fibromyalgia can amplify endometriosis symptoms, especially in people with advanced endometriosis lesions. People with deep, infiltrative endometriosis lesions are more likely to develop fibromyalgia compared to those with superficial or ovarian endometriomas. In a statistical analysis of predisposing factors for the physical component of quality of life scores, the association of fibromyalgia was statistically significantly associated with lower scores. In these cases, when the pain syndrome is pathologically amplified, there are neurogenic mechanisms that could explain the increased sensitivity.

An imbalance of nociceptors with a central sensitization mechanism. In fibromyalgia, persistent activation of type C nociceptive fibres produces a constant release of substance P, together with excitatory amino acids such as glutamate and aspartate. The prolonged and pathological release of such neurotransmitters causes people suffering from fibromyalgia to respond negatively to lower levels of painful stimuli (hyperalgesia) or even to present pain to stimuli that are normally benign (allodynia).





***Endometriosis, in many cases, has a cyclical character, it is somehow hormone-dependent. Do we also find these aspects in fibromyalgia?***

Indeed, fibromyalgia also has some characteristics that can be classified as cyclical and hormone-dependent, but the connection is not as obvious or well characterized as for endometriosis. In endometriosis, the symptoms are paced by the menstrual cycle, which suggests the important role of estrogen hormones. Although we do not find the same ratio in fibromyalgia, many patients describe an aggravation of symptoms with the hormonal changes associated with menstruation, pregnancy or menopause.

Sometimes the symptoms of fibromyalgia begin after events that severely affect the general state of health, such as various traumas, other diseases or even psychiatric conditions. Multiple hormonal imbalances, some with cyclical variability, have been blamed for aggravating the systemic pain syndrome in fibromyalgia. Namely, serotonin and/or dopamine (low level can be correlated with sleep disorders, depressive states and increased sensitivity to pain), cortisol (abnormal level can contribute to chronic asthenia), growth hormone (decreased due to sleep disorders can accentuate the feeling of muscle weakness), estrogens (fibromyalgia being a pathology with a clear female predominance), substance P (the increased level can explain the increased sensitivity to pain).

***In addition to widespread pain, fibromyalgia also causes tender points. What are these points and how can we know if they are caused by endometriosis or fibromyalgia?***

The quantified areas of sensitivity to be able to appreciate the diagnosis of fibromyalgia, such as the region at the base of the skull, shoulders, elbows or hips, and which can be painful to touch, also help to define the generalized character of the pain through the simultaneous presence of painful points in different regions of the body. Among the areas of sensitivity characteristic of fibromyalgia, four are in the pelvic region, namely at the buttock level and the greater trochanter of the thigh bilaterally, they can be associated with lumbar pain, and these symptoms can be difficult to differentiate from those of endometriosis.

Separately, the chronic lumbar pain observed in endometriosis could be explained by nerve compressions, the increase in local prostaglandin levels, and the presence of chronic inflammation. Related to fibromyalgia, patients with endometriosis may experience chronic pelvic pain and/or lumbar pain unresponsive to surgical or hormonal treatment.

Endometriosis lesions are probably present in these situations, which become a trigger for myofascial dysfunction. Endometriosis lesions can facilitate the remodeling of neural networks, which contributes to the sensitization and generation of myofascial trigger points. Sacroiliitis is the inflammation of the sacroiliac joint that causes pain in the lower back and in the gluteal region, which can also be difficult to differentiate from endometriosis.





***Diet appears to play a role in managing endometriosis symptoms. Is there a special diet for fibromyalgia?***

It has been observed that major lifestyle changes can have a positive role in controlling fibromyalgia pain. Patients' access to materials with educational information can subsequently improve the quality of life, by integrating specific complementary activities into the daily program. An adapted diet, but only together with a healthy lifestyle and adapted to the specific needs associated with fibromyalgia, can significantly improve systemic musculoskeletal symptoms. There are still no clinical studies available that have clearly demonstrated the usefulness of the diet generically called "anti-inflammatory diet", but it seems that a diet with fruits and vegetables, with fish rich in omega-3 fats, nuts and seeds is beneficial. There are arguments that a vegetarian or vegan diet rich in antioxidants can improve the quality of life of people with fibromyalgia. Also, reducing the amount of trans fats and refined sweets is proposed as a solution to improve the feeling of chronic fatigue.

It is recommended to correct vitamin (vitamin D, B complex) or mineral (iron, calcium, magnesium) deficiencies when they are identified. Permanent administration is not recommended, but laboratory testing and correction of existing deficits may be important. In the case of fibromyalgia, products with food additives such as aspartame or sodium glutamate can exacerbate symptoms, especially physical asthenia and neurocognitive deficits. Only for people with fibromyalgia who associate celiac disease with gluten sensitivity, a gluten-free diet could improve not only digestive symptoms, but also systemic ones, including fibromyofascial pain.

***In endometriosis there are certain pain crises, called flare-ups, and are sometimes caused by stress, fatigue. Do we see them in fibromyalgia and if so, how can we manage them?***

Since the etiopathogenesis of fibromyalgia is not known, we do not yet have any specific etiological treatment.

In fibromyalgia, management strategies that involve lifestyle changes, physical exercises, and the use of drugs from the classes of antidepressants or anticonvulsants are very important.

**Unfortunately, we are not yet talking about curative treatment of fibromyalgia, but only amelioration or remission of the symptoms. The treatment induces the improvement of symptoms and entry into remission, periods with greatly reduced symptoms that can be followed, generally with a sudden onset, of new episodes with severe, intense pain called "flare ups".**

These episodes of activity and pain intensification can be triggered by factors such as stress or excessive physical activity. The treatment of painful exacerbations from fibromyalgia requires individually adapted strategies, the identification of coexisting pathologies being very important. Sometimes an effective treatment of them, such as in this case the treatment of endometriosis, also contributes to the relief of fibromyalgia pain.



# Robotic vs laparoscopy in endometriosis surgery

***What is deep endometriosis and where do we find it most frequently? Do deep lesions play a role in how surgery is conducted?***

Deep infiltrating endometriosis (DIE) refers to endometriotic implants that penetrate more than 5 mm into underlying tissues. The most common locations for DIE include the rectovaginal septum, which is frequently affected between the rectum and vagina; the uterosacral ligaments, which are fibrous bands connecting the uterus to the sacrum; the rectum and sigmoid colon, where bowel involvement is common and often leads to significant gastrointestinal symptoms; and the bladder, where involvement can cause urinary issues. Other affected locations may include the pelvic sidewalls and ureters.

DIE significantly influences surgical strategy. Preoperative planning with detailed imaging, such as MRI and TVUS, is crucial for mapping lesions accurately. A multidisciplinary approach is often necessary, involving gynecologists, colorectal surgeons, and urologists. The complexity of the condition requires advanced surgical techniques, such as bowel resection or bladder repair, depending on the extent and location of the disease.

***What is the main goal of endometriosis surgery and what does it require? More specifically, do you need advanced surgical skills, do you need to know pelvic anatomy quite well?***

The primary goal of endometriosis surgery is to alleviate pain, improve quality of life, and enhance fertility if desired. Specific objectives include the thorough excision of all identifiable endometriotic tissue, the restoration of normal anatomy by correcting distortions caused by adhesions, and the reduction of pain and other endometriosis-related symptoms.



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To achieve these objectives, the surgery demands advanced surgical skills, particularly in minimally invasive techniques. An expert knowledge of pelvic anatomy is crucial to ensure precise and safe procedures. Additionally, effective multidisciplinary coordination among specialists is essential when managing extensive disease, enabling comprehensive care and optimized patient outcomes.

***Some of the pro arguments for the use of the robot in endometriosis surgery is better visualisation. If that is the case, is it correct to assume that in laparoscopy disease is left behind due to a poorer visibility?***

Robotic systems offer high-definition 3D visualization, which can enhance the identification and removal of lesions. However, the notion that laparoscopy inherently leaves disease behind due to poorer visibility is more nuanced. While laparoscopy has traditionally been 2D, modern advanced laparoscopic systems also provide high-definition 3D imaging, enabling skilled surgeons to perform effective surgeries. Studies indicate that, when performed by experienced surgeons, the outcomes of both robotic and laparoscopic surgeries are comparable, underscoring the importance of surgical expertise over the specific technology used.

***In terms of technicalities, what are the differences between laparoscopy and robotic surgery? Do you use the same number of incisions, the same tools?***

In terms of incisions, laparoscopy typically involves 3-5 small incisions, whereas robotic surgery uses a similar number of incisions that may vary in size and placement due to the setup of robotic arms. Regarding instruments, laparoscopy employs rigid instruments directly controlled by the surgeon, while robotic surgery uses wristed instruments operated from a console, providing superior dexterity.

Visualization and ergonomics also differ between the two methods. Laparoscopy offers 2D or 3D visualization with direct manual control by the surgeon. In contrast, robotic surgery provides enhanced 3D visualization and superior ergonomics, which can significantly reduce surgeon fatigue.

***Given the organs and the nerves that are in the pelvis, all stuck in a small space, is laparoscopy hard to learn?***

The learning curve for laparoscopy is indeed challenging due to several factors. The confined pelvic space requires precise navigation, making spatial limitations a significant hurdle. Mastering the use of rigid instruments with inverted movement control adds another layer of complexity. Additionally, surgeons must adjust to operating with 2D visuals, although modern 3D systems have improved this aspect.

**Keyhole surgery introduce several challenges, such as restricted access that limits maneuverability and can complicate excision procedures. However, modern advancements in laparoscopic and robotic tools have alleviated many of these difficulties, making precise excision increasingly feasible. Nonetheless, the skill and experience of the surgeon remain critical in ensuring effective disease removal. The enhanced and high-definition vision provided by modern scopes greatly facilitates the identification and excision of endometriotic implants.**





**Robotic surgery represents a significant advancement, particularly beneficial in complex cases of deep infiltrating endometriosis due to its superior visualization and instrument dexterity. It is especially advantageous in situations involving extensive adhesions and multiple organ involvement, where precision is paramount.**

***The difference in benefits for the patient between open and keyhole surgery are massive. In terms of removing the actual disease, in open and keyhole surgery, how does it work?***

In open surgery, the ability to directly visualize and access the surgical area provides tactile feedback, facilitating thorough excision. Conversely, keyhole surgery offers enhanced 3D visualization, especially in robotic systems, and is minimally invasive, resulting in reduced recovery times and lower postoperative morbidity. When performed by skilled surgeons using advanced tools, keyhole surgery can achieve efficacy comparable to open surgery, while also reaping the benefits associated with decreased surgical trauma.

**When multiple specialties are involved in surgery, coordination is crucial to ensure comprehensive disease removal. Combining robotic and laparoscopic modalities, where one surgeon uses robotic tools and another employs laparoscopy, can be highly effective. This approach, however, requires careful planning of incision strategies to provide optimal access for each modality, ensuring the best outcomes for the patient.**

***What's the difference between laparoscopic and robotic surgery?***

In terms of control, laparoscopy relies on direct manual manipulation accompanied by tactile feedback, while robotic surgery is performed remotely from a console. The visualization technology also differs laparoscopy provides 2D or 3D views, whereas robotic surgery offers an enhanced 3D, high-definition perspective.

Regarding dexterity, laparoscopy is constrained by rigid instruments, while robotic surgery allows for superior precision through the use of wristed instruments. In laparoscopy, the camera is typically managed by an assistant, whereas in robotic surgery, the surgeon has direct control over the camera.

***Is the reach better in robotic surgery and given that in laparoscopy the tools are managed by the surgeon's hands, is the tremor reduced?***

In robotic surgery, the use of wristed instruments provides superior reach compared to the more limited range of motion in laparoscopy. Additionally, robotic surgery has the advantage of filtering out hand tremors, thereby offering greater precision. In contrast, laparoscopy relies on the surgeon's steady hand technique to achieve accurate results.

***Who is the most suitable candidate for robotic surgery?***

Ideal candidates for robotic surgery are those with complex, deep infiltrating endometriosis, where precision is paramount. Patients with multiple organ involvement, requiring delicate dissection, also benefit significantly from this approach. Additionally, individuals with difficult anatomy, where enhanced visualization and precise instrument control are crucial, are well-suited for robotic surgery.

***We know the benefits of robotic surgery vs laparoscopy. Or about the disadvantage of robotic surgery over standard laparoscopic surgery?***

Robotic surgery entails several disadvantages compared to laparoscopy. The high initial and ongoing costs for equipment and maintenance can be prohibitive, limiting accessibility in many healthcare settings. Additionally, there is a steep learning curve; surgeons require specialized training to become proficient. Initial procedures may take longer, although operational time tends to decrease with experience.



Art by Mike Baker



# A Father's Journey: Advocating for Endometriosis Awareness

Mike Baker

 EndoDad76



**M**y journey into the world of endometriosis advocacy began one night after I literally broke inside.

My daughter was having a terrible flare-up, and there was nothing I could do to help her. I couldn't take her pain away, and I was devastated. After she finally fell asleep, I found myself online, desperately searching for an outlet or some way that I could make a difference.

In my search, I stumbled upon some AI tools and began experimenting with them. What emerged were beautiful images of warrior goddesses. This was how we, as a family, see all of you EndoWarriors. We see you fighting battles every day. You are amazing, you are so strong, but I know that when you are down, you can't always see that warrior within yourself. My goal was to create these warrior images for people with endometriosis so that on the hardest days, they could look at those images and remember their strength.

The response was incredible. These images resonated deeply with many and opened doors for me to connect with people across the world. Through this journey, my wife and daughter have had the chance to meet many others who share their struggles. They've connected, shared their stories, and found a community of support and understanding.

Living with endometriosis is a daily battle, filled with pain, uncertainty, and the relentless quest for understanding and relief. Witnessing the struggles of my wife and daughter ignited a passion in me to make a difference, not just for them but for everyone affected by this often misunderstood and overlooked condition. This passion led to the creation of my social media page, @EndoDad76.

**Through @EndoDad76, I aim to provide daily doses of empathy, support, and information to those affected by endometriosis. My posts are inspired by the daily realities of living with endometriosis, from the physical pain to the emotional toll it takes. I share stories, tips for managing symptoms, and words of encouragement, all from the perspective of a father and husband who deeply cares about the well-being of those suffering.**

My advocacy work is rooted in a simple but profound belief: every person with endometriosis deserves to be heard, understood, and supported. This condition affects millions worldwide, yet it often remains in the shadows, misunderstood, and misdiagnosed. By sharing my family's journey, I hope to shine a light on the realities of endometriosis and foster a community of support and solidarity.

One of the most rewarding aspects of this journey has been connecting with others who share similar experiences. The messages of gratitude and solidarity from people around the world reinforce the importance of what we're doing. Each story shared, each message of support, and each new follower is a step towards greater awareness and understanding.

As the CEO of a large healthcare organization, I am working to train our providers to catch endometriosis earlier. Catching it at the primary care level means we can diagnose it faster and begin treatment sooner, which can significantly improve the quality of life for those affected.

Looking ahead, I am excited about the future of endometriosis advocacy. With continued awareness, research, and community support, we can improve the lives of those affected by this condition. My wife and daughter are my daily inspirations, and their strength fuels my dedication to this cause.

To everyone reading this, know that you are not alone. There is a community of support and understanding out there, and together, we can face the challenges of endometriosis with courage and compassion. Thank you for allowing me to share my story, and I look forward to continuing this journey with all of you.

Be sure to follow me @EndoDad76 on Instagram. I'd love to hear your story or make you a custom warrior image of your own.



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# New study: Endometriosis and the risk of cancer

***A study published a couple of months ago found out that women with endometriosis have a higher risk of developing certain types of cancer. Needless to say that it caused worries among many patients.***

## **Mr Thomas Bainton** Consultant gynecologist

The population cohort study concluded that the risk of ovarian cancer was higher in endometriosis patients who suffer from: ovarian endometrioma and deep infiltrating endometriosis, compared to the ones without endometriosis.

The researchers found that in women with deep infiltrating endometriosis the risk of developing ovarian cancer overall was around 18.8 times higher, and in women with deep infiltrating endometriosis along with ovarian endometrioma was about 13-fold higher.

Endometriosis patients were over seven times more at risk of developing type 1 ovarian cancer, which included cancer types like endometrioid, clear cell, and mucinous. They were also 2.7 times more at risk of developing type II ovarian cancer, which can be more aggressive.



Mr Thomas Bainton is a consultant gynecologist surgeon and research doctor with a special interest in endometriosis, working at Chelsea and Westminster Hospital in London. Advocating for a faster and better diagnosis, Mr Bainton is passionate about raising awareness. Recognising the severe impact of endometriosis, and wanting to contribute to improving care, he is undertaking specialist research at Imperial College.



***What are your thoughts regarding this new study that showed an increase in ovarian cancer risk in people with endometriosis?***

We have known for quite some time that there is an increased risk of ovarian cancer with endometriosis. Whenever we're talking about risk, we need to think about both the absolute risk and then the relative risk. We've understood that people with endometriosis do have an increased risk of cancer for a long time. The numbers change a bit, but they still remain incredibly low. We've understood that people with endometriosis do have an increased risk of cancer.

The cancer that we've longest perhaps associated with endometriosis and known that has significantly increased the risk relative to other forms of ovarian cancers in the context of endometriosis is clear cell. Many clear cell cancers come with someone with a history of endometriosis, particularly ovarian endometrioma.

There is also an increased risk of endometrioid carcinoma. We've known for quite some time that's an increased risk because endometriosis by nature has similar tissues to the endometrium growing outside the womb.

What this study has shown, and it has shown very well with a large number of people, is the risks, in this cohort at least, were slightly higher than we previously thought. And additionally it's broken down by type of endometriosis and type of cancer that people subsequently go on to develop. The study broke down what type of endometriosis led to particular types of cancer in later life. It showed that women with superficial peritoneal endometriosis, which is the most common form, didn't have such a significant risk of developing ovarian cancer. Women with ovarian endometriomas are at a higher risk. And women with deep invasive disease had a higher risk still.

***Have you ever had a patient with endometriosis and ovarian cancer?***

Yes, I have and sadly, more than one. I think any doctor who has a significant endometriosis practice, who sees a lot of women particularly with deep disease and endometriomas likely has.

There's abdominal bloating, there can be complications such as ascites, where you've got an accumulation of fluid within your pelvis and even bleeding, which can be concerning for cancer in the initial stages of investigation, which can be incredibly scary. Much of the time we are able to reassure women that these symptoms and any concerning blood tests, such as raised CA125, are due to endometriosis rather than anything more sinister.

**Most of the time when we have a kind of scare about cancer, we're actually able to reassure the patient and we can say quite confidently on the basis of usually the MRI that no, this isn't cancer, we're not concerned about that. But we still need to treat your endometriosis and there are lots of different ways of doing that. Sometimes however, and this is the extraordinary minority, we aren't able to reassure people quite so much in the initial stages.**





Sadly, in this example, the patient was a young woman who hadn't had children yet - wanted future fertility, and the initial surgery was to get a very good biopsy of the area that appeared concerning on the basis of her MRI rather than proceeding directly to excision surgery until we confirmed the diagnosis. We got a very good biopsy of the cyst and were able to look at it under the microscope in the laboratory to confirm whether it was what we thought it was.

Prior to the surgery, our estimation was that there was about 20% chances this was actually cancer. Very sadly for her, it came up to be ovarian cancer.

This lady then subsequently after counseling, had an option just to remove the ovary, but actually given the very small but not insignificant risk of recurrence, she chose to have complete surgery which was removal of both ovaries, both fallopian tubes and the womb. On histopathology the cancer was confined to the ovaries, so we would have expected that cancer to be cured by surgery, but she did need a series of chemotherapy and she is under continued follow-up.

I have also seen patients who sadly have had cancer in endometriosis that was outside the womb, after hysterectomy. I've seen older patients who had significant deposits of endometriosis when they were much younger and had malignant changes later on, but they're treated in a very specific way, often needing chemotherapy, and it's quite a complex surgery due to the position of the endometriosis.

But these are usually women in later life who are postmenopausal, in whom the risk of cancer is higher.

***Even though the numbers themselves should not scare people, because the risk of ovarian cancer is still low in comparison with other types of cancer, people do tend to panic when such studies come up. How do you talk to your patients about this and what do you recommend people with endometriosis to do to ease this wave of panic?***

I think it's important to separate what we call the absolute risk, which is the overall risk of developing ovarian cancer and the relative risk. The absolute risk remains significantly low. The vast majority of women with endometriosis will never go on to develop ovarian cancer, and will not ever go near it.

And importantly, with all sorts of risks, you need to look not only at the risk factor which is introduced by endometriosis, but the other risk factors some might have for cancer. The most significant being a family history. If there's a very strong family history of ovarian or breast cancer, then consider being tested for genetic changes like the BRCA gene.



If you don't have any other risk factors for ovarian cancer apart from endometriosis, your overall risk remains incredibly low, particularly if you don't have deep disease or ovarian endometrioma. So actually if your risk is higher with endometriosis, if you were to have other risks, then the risk approaches back towards a sort of baseline.

***Would you recommend removing everything through surgery to protect against cancer, if the person with endometriosis already gave birth or has an alternative way of conceiving?***

We're talking about removing all visible endometriosis, which will be the deep disease in terms of what we see in surgery and on MRI and draining and removing the endometriomas. That's the mainstay surgical of treatment for women who are in pain.

When we're treating an ovarian endometrioma, then the amount of surgery we do to the ovary has to be tempered against the future wishes for fertility. If someone is 20 and hasn't had any children yet, then we need to be a little bit more conservative with the endometrioma because if we do remove every single little bit of endometriosis, we can actually cause collateral damage to the ovary, so we are often more conservative. But even with an aggressive approach, removing every little bit of endometriosis, there is a risk of recurrence with endometriosis.

I think if someone is in their 30s and their only risk factor for ovarian cancer is endometriosis, whether it is ovarian disease or deep disease, then the disease needs to be treated, but not necessarily by removing the ovaries, which is not appropriate for most women.

The downside of removing the ovaries is an earlier menopause. If you remove the ovaries then you instantly go through the menopause, and we know that an earlier menopause gives you higher risks of different conditions in later life.

Not just the obvious ones that we commonly think about, like thinning of the bones, but cognitive decline. You also have a significantly higher chance of dying from heart disease, especially if you don't have oestrogen hormone replacement therapy (HRT). And we know that HRT is a little more complicated in women with endometriosis because you can not always be 100% sure you've removed absolutely everything, which can require progesterone HRT even when women have had a hysterectomy.

The decision is one to be made on a very personal basis. If that risk is 40% as it can be in BRCA mutations there's absolutely no question, it's a very sensible thing to do. If it's just a case of having endometriosis, if it's not affecting the ovary, then removing the ovary may not be sensible. If you are having a hysterectomy we always remove the fallopian tubes at the same time because the fallopian tubes are potentially where the origin of many ovarian cancers actually is. Particularly the high grade serous cancer, which is one this study showed is associated with endometriosis.

**Having the fallopian tubes removed would definitely be done if you have a hysterectomy even if the ovaries weren't being removed. If you are over 40-45 and you're having a hysterectomy, so you're definitely not going to have any more children, then there is an argument about having the ovaries removed as well. It's a discussion we have with patients, even if they don't have a statistically increased risk of ovarian cancer, that we may now be able to have with more evidence in those with severe endometriosis regarding their overall risk of cancer development.**



If you're significantly over 45 or approaching the age of the menopause (the average is 51) so the ovaries will go into slow down regardless, then should we remove the ovaries just as a prophylactic? You will of course go through the menopause immediately, which might be one or two years earlier, but we'll reduce your risk of developing ovarian cancer in later life which can be a pretty devastating disease.

**I don't think that removing everyone's ovaries at a younger age, would be a sensible thing to do. That would be far more likely to introduce additional risks in later life with the extra burden that an early menopause gives you and potentially the extra risk that a longer HRT gives you.**

***How do you think this new study will impact the endometriosis community (both patients and doctors/researchers)?***

Firstly, I think it's going to precipitate a lot of in depth consultations, but on a very personalized level. What is that person's specific risk of ovarian cancer, where is she in terms of journey for treatment, is surgery even on the cards anyway? Remember that not all endometriosis cases actually need surgery. It could be managed medically, managed symptomatically, and then thinking about how we keep an eye on it with surveillance, with ultrasounds, with MRIs and with CA125s in some cases.

We don't know all the answers at the moment so I think that treating it on a very personalized level is the right approach to begin with. Some people will be on fence regarding surgery for endometriosis, because there are huge downsides to surgery. One thing I tell all my patients is that you'll feel worse before you feel better. The surgery is a big thing to recover from. But with additional considerations regarding lifetime ovarian cancer risk in the context of endometriosis, a few more might choose surgery on the overall balance of risk and benefits.

If the endometriosis is suppressed for a longer period of time with medical management, for example with the combined contraceptive pill taken a longer period of time back to back, you have a lower risk of ovarian cancer. The contraceptive pill can lower your risk of developing ovarian cancer because it stops ovulation and cumulative damage to the ovary. So people might be more inclined to stay on long term medical treatment, start medical treatment earlier and have a longer period of treatment when they're not wishing for fertility.

The imperative is to keep a close eye on endometriosis, treat it earlier, treat it potentially a little bit more aggressively for some given that we know the cancer is a risk but most of all, personalized care for someone's specific and overall risk according their wishes after a comprehensive discussion of the evidence and where treatment fits in with their overall lives and aspirations.



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# Endometriosis and irritable bowel syndrome

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Endometriosis, a frequent disease, one of the most painful conditions that affects the quality of life, extremely complex and unfortunately underdiagnosed all over the world, can affect 1 in 10 females and is prevalent as type 2 diabetes II.

Literature data states that the diagnosis of endometriosis can be delayed for approximately 12 years, due to confusion with other conditions, and a well known fact is that patients with endometriosis are misdiagnosed over the years. One of the conditions that endometriosis is often diagnosed is irritable bowel syndrome. A study done by a group of researchers from the University of Queensland highlighted that endometriosis and irritable bowel syndrome have the same genetic risk factors, which explains the large number of people who suffer from both conditions.

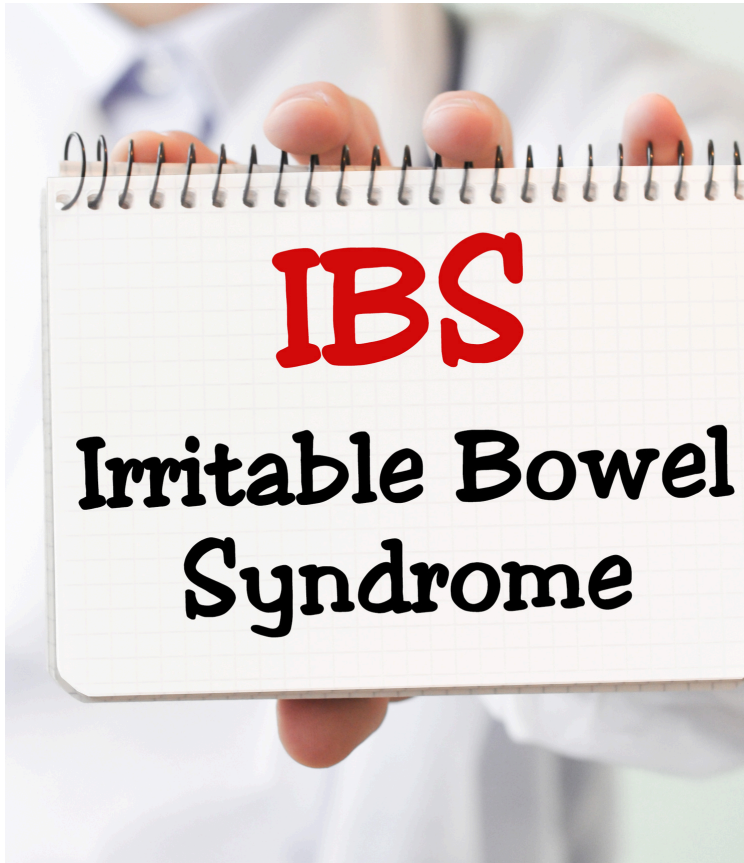
Women with endometriosis are twice as likely to also suffer from irritable bowel syndrome, compared to those who do not suffer from endometriosis; in addition, they have a 1.4 times higher risk of being diagnosed with gastroesophageal reflux disease.

Also, endometriosis and irritable bowel syndrome are associated, with gastrointestinal symptoms being present in both conditions. Quite often patients turn to the gastroenterologist specialist for pain in the lower abdominal floor, excessive flatulence (endo belly) and sometimes aggravated transit disorders during menstruation.

However, the 2 conditions can appear together, especially since visceral hypersensitivity is the key element in both cases.

**Recent sources in the literature show that it is difficult to differentiate the source of the pain, which leads to confusion and misdiagnosis, with years of delay in treatment, during which time endometriosis evolves into severe forms.**





Even if the symptoms may coincide, the difference lies in the frequency and intensity of the pain: a patient with irritable bowel syndrome may have pain several times a week, over several months, while in the case of a patient with colorectal endometriosis, the pain intense occurs during the menstrual cycle.

In most cases endometriosis can be confused with irritable bowel syndrome, with patients presenting: constipation, excessive bloating, gas, rectal tenesmus, pain in the lower abdominal floor with radiation to the back, diffuse abdominal pain, rectal bleeding during menstruation.

Although rare, intestinal endometriosis can cause intestinal occlusion in young patients of reproductive age, who can present to the emergency room with: nausea, vomiting, colic abdominal pain and abdominal distention. Involvement of the terminal ileum is even rarer, but must be considered in the differential diagnosis of intestinal occlusion in fertile women.

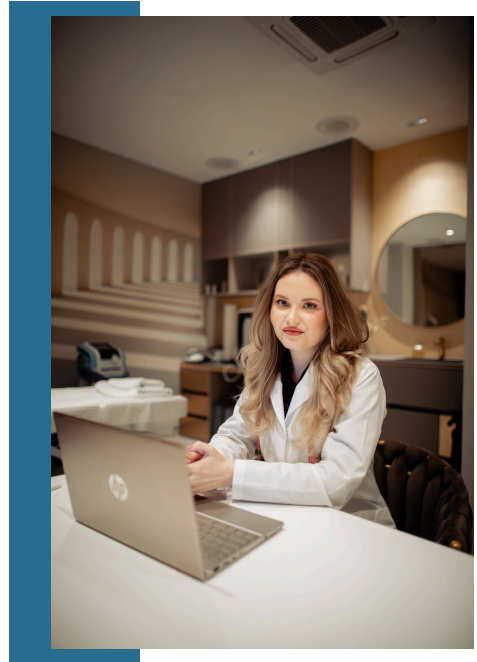
The diagnosis of this condition is multidisciplinary, tracking the location of the endometriotic nodules, their size and multifocality, so as to decide the optimal treatment solution.





# Diet impact on inflammation in endometriosis

**Beatrix Barbulov**  
Nutritionist-dietician



Inflammation plays a central role in the pathogenesis of endometriosis, contributing to the onset and exacerbation of symptoms. In this context, medical nutritional therapy can have a significant impact on the control of inflammation, thus providing a potential therapeutic benefit for patients with endometriosis.

Inflammation is a physiological response of the body to stress factors, infections or tissue damage. In endometriosis, chronic inflammation is caused by the presence of ectopic tissue, which releases pro-inflammatory cytokines. These substances stimulate angiogenesis and cell proliferation, creating a vicious cycle of chronic inflammation, pain and disease progression. In particular, cytokines such as IL-6, TNF- $\alpha$  and prostaglandins are involved in the pathological mechanisms of endometriosis, exacerbating inflammation and associated symptoms.

## **Dietary factors affecting inflammation**

There is conclusive evidence that diet can influence levels of systemic inflammation, thus having a strong impact on symptomatology in endometriosis.

Diet can be a pro-inflammatory or anti-inflammatory factor, depending on its composition. Thus, there are specific nutrients that can modulate inflammatory responses through different biochemical pathways.

## **The components of the pro-inflammatory diet**

A pro-inflammatory diet is characterized by a high consumption of saturated fat, refined sugars, simple carbohydrates and ultra-processed foods.

Saturated fat, found in red meat and full-fat dairy products, promotes the production of pro-inflammatory eicosanoids such as prostaglandin series 2 (PGE<sub>2</sub>).

Excessive consumption of sugars and processed foods increases insulin levels and oxidative stress, amplifying inflammation. Also, an unbalanced ratio between Omega-6 and Omega-3 fatty acids, in favor of Omega-6, can intensify inflammation by promoting the synthesis of pro-inflammatory leukotrienes and prostaglandins. An anti-inflammatory diet is rich in antioxidants, fiber, Omega-3 fatty acids and phytonutrients.



Fruits (especially berries), vegetables, nuts, seeds and fatty fish are important sources of nutrients that can help reduce inflammation.

Omega-3 fatty acids, present in fatty fish (salmon, sardines), have anti-inflammatory properties by inhibiting the synthesis of pro-inflammatory eicosanoids and favoring the synthesis of DHA and EPA, molecules with anti-inflammatory effects.

Also, polyphenols in fruits and vegetables (eg, resveratrol in grapes and quercetin in onions) act as natural inhibitors of pro-inflammatory cytokines, thereby reducing systemic inflammation.

**For patients with endometriosis, a holistic approach that includes both dietary interventions and other lifestyle changes can help effectively manage inflammation and relieve unpleasant symptoms.**

- Regular consumption of foods rich in omega-3 fatty acids, which are essential for reducing inflammation and are found in fatty fish (salmon, sardines, mackerel), flax seeds, chia and walnuts. It is recommended to eat two servings of fatty fish per week or to integrate Omega-3 (fish oil) supplements under the supervision of a doctor or dietitian.
- Increasing the intake of fibers because they can contribute to balancing hormones by decreasing the reabsorption of estrogen at the intestinal level. Good sources of fiber include vegetables (especially cruciferous vegetables), fruits, legumes (lentils, chickpeas, beans) and whole grains. A minimum intake of 25-30g of fiber per day is recommended to support digestive health and reduce inflammation.
- Limiting the consumption of processed foods, even if many of them can be part of categories such as gluten free or lactose free as are frequently recommended in this pathology.
- Eating fermented foods and probiotics because a healthy gut microbiome is essential for reducing inflammation and regulating intestinal transit. Fermented foods such as goat yogurt, kefir (depending on tolerance), sauerkraut and kimchi contain probiotics that support the balance of intestinal flora. Probiotic supplements can also be helpful, but should be chosen carefully, preferably under the guidance of a specialist.
- For some patients with endometriosis, the Low FODMAP diet may be suitable for a certain period, followed under the guidance of a specialized dietitian.
- Avoiding alcohol and excess caffeine.
- Reducing stress and increasing sleep quality: Chronic stress and poor quality sleep increase cortisol levels and promote inflammation. Practices such as meditation, yoga, breathing techniques, and a sleep routine can help manage stress and reduce systemic inflammation.
- Moderate physical exercises practiced regularly. Moderate physical activity (walking, swimming, yoga) has anti-inflammatory effects and can relieve pelvic pain associated with endometriosis. High-intensity exercise (HIIT for example) can increase inflammation in some people, so it's important to tailor your exercise program to individual tolerance and experience.



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My endometriosis is constantly debilitating, in every aspect of my life

**Zahra McDonald**  
*endometriosis advocate*  
 Australia

***They say that endometriosis is a disease that mainly affects fertile women. In one of your interviews you said you have been told for 10 years that your symptoms are not real. How old are you now and when did your symptoms start?***

Firstly I'd like to start by saying endometriosis is not a reproductive disease despite common misconceptions. Endometriosis can affect any organ in the body, and any gender but is extremely common in women, affecting 1 in 7 people who menstruate. So regardless of the presence of reproductive organs people can still have endometriosis and hysterectomy will not cure it.

***Many women are told that being in pain during periods and so on is part of being a woman. Sometimes these comments come from close friends or family members. Have you been told the same?***

Yes, constantly throughout my life I have been told this. By family, friends and numerous doctors. It's extremely concerning that painful periods are so normalised in society even amongst medical professionals, when in fact there is nothing normal about a period being painful.

***“I bled for 1 year every day until I saw a doctor. I went to so many doctors about it and it was brushed off every time.”***



**“Personally my symptoms started at the age of 13/14 and I didn’t get diagnosed until last year. I am now 23 years old”.**





“ *In my later years of schooling my periods and constant pain really affected me. My periods were extremely heavy, lasted 2 weeks long and occurred every 2 weeks. I was in constant pain and anxiety. Stressing about when I’d next make it to the bathroom before I bleed through my uniform, trying to hide the enormous pads and tampons I’d need to use, and then taking several different tablets to try and manage the pain. Every time I mentioned how bad my periods were to my school friends they could never relate to me, so it was very isolating.* ”





***You said in your interview for Daily Mail that 2 years ago you bled for 1 year every day until you saw a doctor. I personally can't imagine how hard it must have been for you. What was the impact on your wellbeing?***

It impacted every aspect of my life, from relationships, to work, to uni. I was constantly stressed, in pain and anxious. I went to so many doctors about it and it was brushed off every time.

***When did you first hear of endometriosis and that you might have it?***

I first heard about endometriosis on tiktok funnily enough, but I brushed it off as every test I had had told me everything was normal. Little did I know endometriosis rarely shows on any tests including ultrasounds and MRIs. I then heard about it at work from a colleague of mine who was about to have surgery to find out if she had endometriosis. When then discussed our similar symptoms and she referred me to go see the same gynaecologist as her.

***What is endometriosis for you and how is your life with endometriosis?***

For me endometriosis is an extremely cruel and debilitating disease. It has negatively impacted my life in countless ways. Most of all how little is known about it and how little research has been done on it. When I first got diagnosed with endometriosis it was a roller coaster of emotions. I was so happy I finally had an answer to my decade of pain and symptoms but was also extremely upset that there was so cure, any "real" treatment and no known cause.

***From your own experience, is endometriosis a disability?***

Yes it is definitely a disability. The way that endometriosis lesions can attack any organ in the body can be extremely debilitating. I've seen a lot of women who use walking on sticks or wheelchairs due to the extent of the endometriosis. Even those without mobility aids still struggle to function daily.

**Personally when my endometriosis is at its worst, it is very disabling. Sometimes I struggle to sit or stand without extreme pain.**





***What changes do we need to make so people with endometriosis won't suffer as much?***

There is an enormous amount of effort that is needed to be made to help those with endometriosis. Medical bills, appointments and medications are extremely expensive. And it costs \$10,000 a year for someone with endometriosis. Something needs to be done about the medical costs. The research surrounding endometriosis is extremely poor. There are still no known cause and there is no cure.



***Majority of medical journals have the wrong definitions and the wrong medical information making it extremely hard for doctors to give the appropriate treatment.***



***Let's talk about advocating. What is Endo with Zahra and what made you create this account?***

When I started preparing myself for my surgery I started searching about endometriosis and other people's experiences. I had never really had a surgery and was extremely nervous, but to my surprise found very little information. I then went to tiktok and saw others' experiences and again found hardly any information or raw experiences with the surgery etc.

I then decided that I wanted to document my journey entirely because if I was looking for it I guarantee others were. I then started making daily blogs after my surgery recovery and had an enormous amount of messages, comments and engagement with my videos.

It made me realise how important these videos were for everyone, and all of the kind messages motivated me more to do something about this disease. I already had a small following on TikTok but didn't want to bombard my entire account with endometriosis content so I decided to make an endometriosis only Instagram page. I love drawing and I wanted to be able to post images as well as videos which led me to Instagram. Since making @endoitwithzahra it has grown incredibly fast, and the support from others has been huge. I have followers from every continent and I receive so many messages daily. I've featured two news articles, a podcast, and now this magazine.

***Sometimes social media can be quite upsetting; hate comments, lots of work, sad stories and so on. How do you make sure that such things do not affect you?***

I've been posting on social media for a few years now and I've come to learn how to make it work with my mental health. There is a lot of hate on social media but luckily I rarely receive any. If I do, it's from uneducated people. I did find when I started posting that I was consuming a lot of negative content that was quite depressing around endometriosis. I try to post more content than I consume, but I also try to make some light-hearted content as well. I truly enjoy posting and creating videos and drawings, and I love to educate others about endometriosis. All the positive messages that I get daily from young women or older women thanking me for my content truly inspires me to continue posting.



# Medical hormonal treatment for endometriosis

Endometriosis appears to be menstruation cycle, estrogen- dependent condition. Hence the first line treatment where endometriosis is suspected prior surgical confirmation and treatment, or in cases after surgical intervention due persistent of recurrent disease, is currently hormonal suppression of menstrual cycle. These are drugs that suppress ovarian activity or act directly on steroid receptors and enzymes found in the endometriosis lesions.

These drugs include combined oral contraceptives (COCs), progestogens, anti-progestogens, gonadotrophin releasing hormone (GnRH) agonists, GnRH antagonists, danazol and aromatase inhibitors. All of them show compared to placebo significant reduction of pain. Until now there is no data supporting a superiority of one medical treatment over the other. Little is also known about effect on recurrence or disease progression. In clinical practice, unfortunately finding a good therapy is often 'trial and error' because the efficacy and side-effect are highly individual [1].

## Combined hormonal contraceptives (COC)

COCs are drugs that contain combination of estrogen and progestin. The combination treatment comes in form of pill but there is also a vaginal ring (Nuvaring) or patch (Evra) that consist of same hormones, but are delivered via vagina or skin respectively. The COCs stop ovulation as suppress the growth of endometrium and induce decidualization and atrophy of the lesions. They do not cure the disease, but do reduce the symptoms in 80% of cases [2]. The latest systematic review shows both COCs as progestin- only contraceptives significantly reduce menstruation pains, but also pelvic pain, pain during intercourse and improve quality of life. The preference is to use COCs continues to achieve situation of no bleeding, amenorrhea [1].



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This bases on studies that show significant improvement by continues use versus cyclical use of COCs for reducing menstruation pains and also endometrioma recurrence [3, 4]. There are few studies done about recurrence or growth of disease by use of hormonal medical treatment only. More studies are done looking at recurrence and pain reduction in women who receive before or /and after surgery medical treatment or not. There may be a reduction of disease recurrence in favor of postsurgical hormone therapy (COCs, GnRH agonists, danazol) compared to no postsurgical medical therapy [1, 5].



However these studies are low or very low quality of evidence and look at recurrence within 12 month period [6]. The COCs are safe and well-tolerate by most women. They also provide reliable contraception. The most frequently encountered problem however is unscheduled “breakthrough” bleeding or spotting.

### Progestogens en anti-progestogens

Progestagens induce decidualisation (an adaption of the uterus to enable implantation of the embryo) and atrophy of implants and decrease inflammation [7]. Progestogens come in form of tablet, intrauterine device (Levonorgestrel realizing intrauterine system LNG-IUS), depot injections or subcutis implants. While COCs are used as contraceptives, it is important to realize that not all progestogens are licensed to use as those. Literature review shows that both continuous progestogens and continuous gestrinone are effective therapies for the treatment of painful symptoms associated with endometriosis [1].

For example continuous norethisterone is as effective as combined oral contraceptives in improving endometriosis-associated pain and deep-infiltrating endometriosis to 70% satisfaction rate [8]. Dienogest has been found in several randomized controlled trials efficient treatment for endometriosis-associated pain, as has shown reducing endometriotic lesions [9] [10]. The same time progestogens are associated with increased cases of side effects that included weight gain, acne, oedema, headaches and cycle irregularity [11].

**Recurrence of symptoms as disease has been looked at post operative setting, however understandably huge heterogeneity due to various forms of endometriosis, differences in surgical interventions, and various treatment agencies with various regimes and follow up, makes it difficult to draw general conclusions.**

ESHRE has concluded that for symptom reduction clinicians should consider prescribing Levonorgestrel-releasing intrauterine system or COC as secondary prevention for painful periods [1]. This bases on the metanalysis where LNG-IUS was effective in decreasing the pain and/or disease recurrence rate with comparable effect COCs and danazol [12].

### Gonadotrophin releasing hormone agonists

GnRH agonists are modified versions of the hormones that naturally occurring and are in charge of controlling the ovarian release of hormones, hence the menstrual cycle. They stop the production of estrogen in the ovaries and place the body in an artificial menopausal state. This results in endometrial implants to become thinner and inactive, but it does not cure endometriosis.

Numerous clinical trials have shown that approximately 85% of women with endometriosis-associated pain treated with GnRH agonists have pain relief [11]. However, results suggest that a GnRH agonist is more effective than placebo but inferior to the LNG-IUS or oral danazol [11]. Due to possible adverse side effects by long term usage (>6 months) as reduction of bone mineral density, menopausal symptoms, it is advised to use “add back” therapy when using GnRHinj. Research suggests that it prevents bone loss and does not affect the efficacy [13]. In the review a subgroup analysis for GnRH agonist reported a significant decreased risk of disease recurrence compared to controls [5].

### Gonadotrophin releasing hormone antagonists

Elagolix is the first oral non-peptide GnRH antagonist available for the treatment of moderate to severe endometriosis-associated pain. Reseacht has shown statistically significant improvements in endometriosis-associated pain compared with placebo (75-78%) ; the higher dose also statistically significantly reduces dyspareuni (58-60%)[14].



Relugolix combination therapy (40 mg relugolix, 1 mg oestradiol, and 0.5 mg norethisterone acetate) has developed as a once-daily oral treatment for endometriosis-associated pain or symptomatic uterine fibroids. The latest randomized controlled trial have shown up to 95.3% reduction menstruation pains (NRS<1) and 70.5% reduction of non-menstrual pelvic pain (NRS<1) after 104 weeks of treatment. [15] Most common adverse effects that were observed were headache, nasopharyngitis and hot flush. Also, the bone mineral density loss was reported to be <1%.

## Discussion

It has been reported that around one-third of women treated with hormonal contraceptives do not respond to therapy.[16, 17] Hypothesis is that these patients may be who have pain contributors such as inflammation, peripheral an central sensitization, myofascial disorders and psychopathological conditions.[18] Highlighting the importance of endometriosis expertise centers were this could be recognized and treated. Also, it is still unknown whether the administration of oestrogens should be completely avoided or may be permitted in low dosages in women with symptomatic endometriosis; as the presence of a low-dose oestrogen component may represent an advantage in terms of bleeding control and therapy adherence.

The oestrogen threshold hypothesis posits that there is a therapeutically effective oestradiol range (30–45 pg/ml) at which signs and symptoms of endometriosis or fibroids improve while minimizing hypoestrogenic adverse effects. [19] There are also other potential therapeutics being investigated as selective progesterone and oestrogen receptor modulators (Mifepristone, Ulipristal, Bazedoxifene, Raloxifene). The medical hormonal treatment is safe and helps with symptom reduction but needs individualized approach when choosing and more future research.

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# Understanding Chronic Pelvic Pain: Causes, Diagnosis, and Recovery

**C**hronic pelvic pain (CPP) is a persistent pain in the lower abdomen or pelvic region that lasts for 3-6 months or longer.

It can be a complex condition with various causes and can affect both men and women, although it is more commonly reported in women. The pain can be constant or intermittent, may vary in intensity, and is unrelated to pregnancy.

There are many causes of chronic pelvic pain and these can range from gynecologic, musculoskeletal, gastrointestinal, urologic, neurologic, and psychologic factors.

- **Gynecological Issues:** Conditions such as endometriosis, adenomyosis, large fibroids, pelvic inflammatory disease (PID), or ovarian tumors.
- **Musculoskeletal Problems:** Issues with the pelvic floor muscles or joints in the lower back and hips can result in chronic pain
- **Urological Issues:** Problems with the bladder, such as interstitial cystitis, or other urinary tract issues can cause pain.
- **Gastrointestinal Issues:** Conditions like irritable bowel syndrome (IBS), constipation, or inflammatory bowel disease (IBD) can contribute to pelvic pain.
- **Neurological Causes:** Nerve damage or conditions like pudendal neuralgia or fibromyalgia can lead to chronic pain in the pelvic area.
- **Psychological Factors:** Stress, depression, and anxiety can contribute to the perception and severity of pain.

**Differentiating between the causes of CPP in women requires a thorough medical evaluation, as many conditions can present with similar symptoms. It is also important to note that many women have more than one cause for their CPP.**



## Jill Ingenito, DO, FACOG

In my practice I use a stepwise approach, and this starts with the pelvic pain assessment form. This form is from the International Pelvic Pain Society and is filled out in advance of the appointment by the patient and includes key questions that can give the physician insightful information about what may be at the root cause of the pain. I start by reviewing the form at the initial consultation and perform a physical exam, including an abdominal and pelvic exam, as well as the pelvic floor exam.



The pelvic exam includes a visual and manual examination of the pelvic organs & pelvic floor muscles. It can identify abnormalities such as masses, tenderness, or signs of infection. The pelvic floor exam can diagnose pelvic floor muscle dysfunction which is the number one cause for CPP for women of all ages. It is important to note that the pelvic floor exam is not performed by all gynaecologists. It is important to ask your physician if they are going to perform a pelvic floor exam, and what the findings of their exam are.

Imaging studies are also an important part of differentiating between different causes of pelvic pain. An ultrasound is often the first imaging modality used to evaluate CPP, and can identify ovarian cysts, uterine abnormalities, fibroids, fallopian tube disease, or endometriosis. It is important to point out that a normal ultrasound does not mean that you do not have endometriosis or adenomyosis.

Recovering after endometriosis surgery involves a combination of physical care, proper nutrition, and mental well-being. The number one thing you can do to prepare for and recover faster from your laparoscopic endometriosis surgery is pelvic floor physical therapy.

Pain management after surgery should include hot/cold therapy, NSAIDs and tylenol, as well as stronger pain medication, such as short term use of narcotics. Here are some additional tips I recommend for my patients to potentially speed up recovery and improve comfort:

- **Gradual Increase in Activity:** Start with gentle movements and gradually increase activity levels as you feel comfortable. Walking can help prevent blood clots, improve circulation, reduce inflammation and reduce the risk of adhesions. Avoid heavy lifting, strenuous activities, and abdominal exercises until 4 weeks after surgery.

You should also talk with your doctor about when to resume pelvic floor physical therapy.

- **Healthy Diet and Hydration:** Stick to anti-inflammatory foods and stay hydrated. You can divide your body weight in pounds in half, and that is approximately how much water you need to be drinking after surgery. This will aid in digestion and reduce constipation. Refrain from smoking and limit alcohol consumption.
- **Adequate Rest and Sleep:** Ensure you get plenty of rest and sleep to support your body's healing process. Create a comfortable sleeping environment and consider using pillows to support your abdomen.
- **Manage Gas and Bloating:** After laparoscopic surgery, gas used to inflate the abdomen can cause discomfort, especially in your right shoulder. Walking and gentle movements can help disperse the gas. Avoid carbonated drinks and gas-producing foods.

***Remember, recovery times can vary depending on the individual and the extent of the surgery. It's crucial to listen to your body and not rush the healing process.***

Adhesions after surgery can happen and may cause pelvic pain. Preventing adhesions after endometriosis surgery can be challenging, as they can form as part of the natural healing process. It is important to remember that not all adhesions cause pain. Adhesions can cause pain when organs stick together densely, nerves become entrapped, the tissue is under strain, or there are functional impairments like a bowel obstruction.





Diet can play a role in managing pelvic pain, particularly when the pain is associated with conditions like irritable bowel syndrome, interstitial cystitis, endometriosis, or inflammatory bowel disease. An anti-inflammatory diet rich in fruits, vegetables, whole grains, lean proteins, and healthy fats (such as omega-3 fatty acids from fish or flaxseeds) can help reduce inflammation in the body. If you have any associated bladder symptoms, then avoid all bladder irritants. Common irritants include caffeine, alcohol, spicy foods, acidic foods (like citrus and tomatoes), and artificial sweeteners.

Central sensitization is a condition where the central nervous system, which includes the brain and spinal cord, becomes hyper-responsive to stimuli. It can lead to an increased perception of pain and other sensory experiences. This heightened sensitivity can occur in response to chronic pain or inflammation, where normal stimuli that are typically not painful become painful (allodynia), and painful stimuli become more intense (hyperalgesia).

Central sensitization is associated with endometriosis due to persistent inflammation, and can cause pain to spread beyond the original site of injury or inflammation. For instance, pain may start in the pelvis but can spread to other areas such as the back or thighs.

In summary, chronic pelvic pain is persistent pain in the lower abdomen or pelvic region lasting for at 3-6 months or longer. CPP can stem from a variety of causes, including gynecological issues like endometriosis or fibroids, musculoskeletal problems like pelvic floor muscle dysfunction, urological conditions, gastrointestinal disorders, neurological causes, and psychological factors. Diagnosing the underlying causes requires a comprehensive medical evaluation, including detailed history, physical examination, imaging studies, and possibly specialised procedures like laparoscopy. Management may involve a multidisciplinary approach, including pain management, pelvic floor physical therapy, diet adjustments, and support systems. Post-surgery recovery strategies include gradual increase in activity, proper nutrition, adequate rest, and preventing adhesions. Central sensitization, a condition where the nervous system becomes hyper-responsive to stimuli, can amplify pain perception and complicate CPP, especially in cases involving persistent inflammation from conditions like endometriosis.

**Dr Jill Ingenito is an obstetrician-gynaecologist with over 16 years of experience. Passionate about patients education, Dr Ingenito runs the [@drpelvicpaindo](#) account on Instagram, where she shares useful content on many areas of endometriosis and chronic pelvic pain.**





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# Transvaginal scan in diagnosing endometriosis

## *How is endometriosis consultation conducted?*

An endometriosis consultation is a comprehensive process aimed at diagnosing, assessing, and managing the condition. The consultation typically involves multiple stages, each focusing on gathering information, performing examinations, and developing a treatment plan.

In our expertise center '**The Dutch Endometriosis Clinic**', we send a questionnaire involving questions about medical history, current complaints but also impact on quality of life (all aspects: work/relation/sexual/social etc). This preparation stimulates the patients to really think about her complaints and impact previous to her intake and provides information to us, health professionals, to actually understand complaints and daily impact.

The first consultation takes 60minutes. The first half is with a dedicated endometriosis nurse deepening the questionnaire. The second half of the consultation is with a dedicated endometriosis consultant, who will also perform physical examination. Depending on the age, previous (traumatic) experience and sexual activity this examination consists of abdominal palpation and inspection, pelvic examination and extensive transvaginal ultrasound (TVUS). Combining all this information results in a 93% of accurate diagnosis at the first appointment.

Once the initial examination and tests are completed, we will discuss the findings with the patient. If endometriosis is diagnosed, the stage and extent of the disease will be explained. Together with the patient we will conduct a personalized treatment plan.

## ***The diagnosis of endometriosis seems to be controversial. In some countries, they use surgery, in others they use imagining. What is the consensus of European organisations?***

In Europe, there has been a shift towards less invasive methods for diagnosing endometriosis, although surgical diagnosis remains a gold standard in certain situations. The ESHRE guideline recommends performing diagnostic laparoscopy in patients with negative imaging results or where empirical treatment was unsuccessful or inappropriate.



**Noor Paridaans, MD**  
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 co-founder and Board  
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**At the European Endometriosis Congress they talked about transvaginal scans being the first-line of examination in suspected cases. How accurate is it and what areas can be visualised?**

If performed by highly trained professionals, TVUS is a highly accurate and useful first-line diagnostic tool in detecting deep endometriosis, ovarian endometriosis or adenomyosis. Advances of ultrasound over MRI are also the option of tenderness guided imaging and showing the presence of adhesions between pelvic organs (sliding sign). Transvaginal scans are mostly limited to the pelvis. But uterus, ovaries, tubes, uterine ligaments, rectosigmoid, rectovaginal septum and bladder/lower part of ureters can be properly visualized.

**TVUS is relatively accurate for detecting bowel involvement, particularly when performed by a trained professional who specializes in endometriosis**

Studies have shown that TVUS can have a sensitivity of 79-98% and a specificity of 97-100% for diagnosing bowel endometriosis. It may be limited in detecting endometriosis in other parts of the bowel, such as the small intestine, or farther from the vaginal probe's reach.

**Superficial endometriosis is a form of endometriosis hard to diagnose. Is transvaginal scan suited for it?**

No, up until now it is not suitable. Although recent publications have shown that for some parts in the pelvis (posterior compartment/cul-de-sac) it is possible. But this remains complex. Currently there is no reliable imaging technique for diagnosing peritoneal endometriosis, other than laparoscopy.

**Some studies show that in the hands of appropriately trained clinicians, the transvaginal scan appears to be non-inferior to MRI in the diagnosis and assessment of deep infiltrating endometriosis. Can transvaginal scan replace the MRI?**

In the hands of appropriately trained clinicians, TVUS can often replace MRI in the diagnosis and assessment of deep infiltrating endometriosis. However, MRI retains its importance for more comprehensive evaluations, especially when TVUS results are inconclusive or when assessing areas beyond the reach of transvaginal scanning. In our center we use MRI not only for diagnostic purposes, but mainly for preoperative counseling and planning.

**What preparations are needed for the scan?**

In our expertise center we prefer women to have a full bladder previous to the first transvaginal scan for optimal visualization of the bladder. I know some centers use vaginal or rectal contrast during the exam. This might be experienced as uncomfortable and invasive, and this is the reason we do not use these preparations. If transvaginal ultrasound is inconclusive or suboptimal we would prefer to perform a MRI.

**Can you obtain the stage of endometriosis with a transvaginal scan?**

In our expertise center we use #Enzian classification for ultrasound, MRI and peri operative classification. We use a web based tool called the equsum to collect this data. After the scan we are able to inform the patient about the presence of adenomyosis/deep endometriosis and/or ovarian endometriosis.

rASRM classification uses 'stages' to describe extent of disease but we no longer try to use that term as we find it incomplete. Although worldwide health professionals are discussing to use the same classification, currently teams/centers are still using different systems.





***What aspects should be considered by doctors when they use transvaginal scan to look for endometriosis?***

Vaginal examination can be very painful. In women with a high burden/discomfort (adolescents, due to religion, painful examination, sexual abuse in the past, virgo intacta etc.) vaginal examination and thus transvaginal scanning should ideally be replaced by empirical treatment or MRI.

***What are the most specific signs of endometriosis on scan?***

This is a complex question as its answer is long! To summarize it I would say that it is organ or site specific.

For the ovaries this would mean groundglass appearance of cysts and for bowel or bladder nodules it would mean hypoechogenic areas. We also scan for adhesions resulting in reduced mobility of pelvic organs, with a lack of sliding between structures.

***Can adenomyosis be diagnosed with transvaginal scan?***

Transvaginal ultrasound is a useful and accessible tool for diagnosing adenomyosis. It can effectively identify the characteristic features of adenomyosis, particularly when performed by an experienced clinician. We use the MUSA criteria which involves 7 ultrasound features. Three-dimensional transvaginal scan has been reported to improve the diagnostic accuracy for adenomyosis.



# Assisted human reproduction techniques and endometriosis

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***A dilemma for patients and specialists: what is the best choice for an infertile endometriosis patient; hormonal medication, surgical intervention or AHR techniques?***

For an infertile patient with endometriosis, the decision on the therapeutic method is multifactorial, taking into account age, ovarian reserve, the duration of infertility, endometriosis stage, symptoms, possible associated causes of infertility, and last but not least, their desire.

Studies and meta-analyses in recent years have analysed the effectiveness of surgery in increasing the chance of natural conception in patients with endometriosis. For the ones with with stage I/II rASRM endometriosis lesions, the current conclusion is that surgical intervention increases the pregnancy rate. For endometriosis cysts, operative laparoscopy can increase the chance of pregnancy naturally, although scientific evidence is lacking. As a surgical technique, laparoscopic cystectomy has the best results, compared to ablation. For deep endometriosis (involving the intestines), we have no evidence that surgery increases fertility, so it is an option mainly for symptomatic patients.

In order to evaluate the chances of getting pregnant naturally for patients who have undergone a surgical intervention, a scoring system called the Endometriosis Fertility Index (EFI) was developed in 2010.



**As a gynecologist with specialization in infertility and assisted human reproduction techniques, I know that from 20 infertile patients that enter my office, it is possible that up to 10 of them will have endometriosis. Because endometriosis is a pathology strongly intertwined with infertility: up to 50% of infertile women have endometriosis, and vice versa, 30-50% of women suffering from endometriosis are infertile.**



**The EFI score takes into account factors related to the patient (age, duration of infertility, history of previous pregnancies) and surgical factors (functioning of fallopian tubes and ovaries, endometriosis lesions, and the total score from the rASRM staging of endometriosis).**

This generates a score between 0 and 10, which can be used to advise women on their future reproductive options. The EFI has already been validated by dozens of subsequent studies.

If we talk about the usefulness of intrauterine insemination (IUI) in infertile patients with endometriosis, studies have shown that IUI with ovarian stimulation led to an increase in the birth rate compared to expectant management or IUI alone, for stage I or II rASRM. In the case of patients with advanced endometriosis, stage III or IV rASRM, the use of IUI with ovarian stimulation is debatable, as the benefits are unclear.

Most of the studies and meta-analyses carried out in the last 15 years evaluated in vitro fertilization (IVF) as effective in the case of infertile patients with endometriosis. The data we currently have have shown that endometriosis decreases the average number of oocytes collected per cycle, the implantation rate and the clinical pregnancy rate, and increases the cancellation rate of the stimulation cycle.

Some studies concluded that the negative effects increase with the severity of the disease. Thus, in patients with endometriosis stage I or II rASRM, the rates of clinical pregnancy and birth and the average number of oocytes collected per cycle were not statistically different compared to patients without endometriosis. But in patients with severe endometriosis, stage III or IV rASRM, the rates of birth and clinical pregnancy and the average number of harvested oocytes were significantly lower.

***What is the best ovarian stimulation protocol for endometriosis?***

There have been many studies over time that have evaluated various IVF protocols in women with endometriosis, in an attempt to find a protocol superior to the others. The current conclusion is that a specific IVF protocol cannot be recommended for patients with endometriosis. Both the protocol with GnRH antagonists and the one with GnRH agonists can be used, depending on the preferences of the doctor and the patient, because there are no differences in terms of clinical pregnancy and birth rates.

**The long protocol with GnRH agonists refers to 3-6 months of treatment in endometriosis patients, before the actual IVF cycle.**

Several studies published in the 1990s showed a higher clinical pregnancy rate for the ultra-long protocol, culminating in a 2006 systematic review that concluded that this protocol increases the chances of clinical pregnancy by more than 4 or in the case of patients with endometriosis.

But recent studies and systematic reviews (2019, 2020) contradicted these results and showed that the effects of the extended administration protocol of GnRH agonists are uncertain in terms of birth, clinical pregnancy and abortion rates, as well as the medium number of oocytes and embryos obtained. So currently, the ultra-long protocol is no longer recommended, due to the uncertain benefits.





***What are risks for patients with endometriosis when egg collection is done?***

When performing ovarian puncture on a patient with severe endometriosis lesions, you cannot help but think about the risk of bowel perforation due to unwanted adhesions, which could lead to the formation of ovarian or pelvic abscesses. From my experience, I can say that I have seen two cases of pelvic abscess following ovarian puncture, which led to strong antibiotic therapy and even surgery. A practical recommendation is the use of prophylactic antibiotic therapy for ovarian puncture of patients with endometriosis cysts.

Also regarding the risks of IVF in the case of patients with endometriosis, existing studies have shown that ovarian stimulation within IVF does not increase the risk of recurrences and does not worsen painful symptoms.



# Preparation of the uterus for frozen transfer

***For frozen transfer, what is the optimal preparation of the uterus?***

Regarding the uterus preparation types for for an embryo transfer with frozen embryos, we have no data showing the superiority of one over the other protocols in patients with endometriosis. Meaning that you can use any of the natural cycles, the modified natural cycle, the artificial cycle (with hormonal substitution) or the cycle with light ovarian stimulation, depending on the particularities of the respective couple.

However, I want to mention that even in the presence of endometriosis, cycles without hormone replacement medication have been preferred in recent years, due to recent meta-analyses that have shown an association between this medication and the increased risk of hypertensive pathology in the subsequent pregnancy (gestational hypertension, preeclampsia and eclampsia).



# Classification and staging of endometriosis



## Dr Alin Constantin

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Endometriosis is classified in several ways, depending on the location, extent and severity of the lesions, and the classification can be done using both non-invasive and invasive methods.

### **Invasive and non-invasive classification:**

- **Non-invasive methods:** Imaging can be used to evaluate endometriosis lesions, cysts and adhesions. For example, the **#ENZIAN classification** can be applied based on imaging findings to guide treatment planning.
- **Invasive methods:** Laparoscopy is considered the gold standard for the diagnosis and classification of endometriosis. Through surgery, lesions and adhesions are visualised directly, allowing an accurate assessment. Classifications such as the rASRM and EFI systems are based on direct surgical observations.

**#ENZIAN classification:** Updated and expanded, the #ENZIAN classification is no longer limited to deep infiltrative endometriosis (DIE), but also covers peritoneal lesions, adnexal adhesions (ovaries and fallopian tubes) and deep extrapelvic lesions, such as those involving the diaphragm or other organs outside the pelvis. The system divides the retroperitoneal region into three compartments (A, B, and C), and the severity is classified according to the size and depth of the lesions.

**rASRM (Revised American Society for Reproductive Medicine) classification:** This is the most widely used classification system for endometriosis and divides the disease into four stages, from minimal (I) to severe (IV), based on the size of the lesions and adhesions seen during laparoscopy.



**Endometriosis Fertility Index (EFI):** EFI is an assessment method that focuses on fertility, predicting the chances of pregnancy in women with endometriosis who have undergone surgery.

**AAGL classification (American Association of Gynecologic Laparoscopists):** Still in development, this system assigns scores to different locations and depths of lesions to quantify disease severity and surgical difficulty. It is intended to provide a more complete assessment of endometriosis in terms of pain, fertility and difficulty of surgery.

Each of these systems has advantages and limitations, and there is currently no universally accepted gold standard for classifying endometriosis. However, a combination of non-invasive and invasive methods, such as the use of imaging and surgery, helps to assess the disease as fully as possible and to individualize the treatment.

***In most cases, endometriosis is a painful disease. How can we explain the pain process or what are the factors that cause pain?***

The pain associated with endometriosis can be explained by a complex of mechanisms, involving inflammation, nerve changes and central sensitization.

## Chronic inflammation

Endometriosis lesions trigger an inflammatory reaction that includes increased levels of proinflammatory cytokines (IL-6, IL-8, TNF- $\alpha$ ) and prostaglandins (PGE2). They stimulate the nerve endings in the affected areas, leading to nerve sensitization and pain perception.

## Visceral and somatic pain

Depending on the location of the lesions, the pain can be visceral (spasmodic, diffuse) or somatic (sharp, punctate pain). The affected organs (uterus, urinary bladder, intestine) have different types of innervation, which explains the variations in the way pain is perceived.

## Nerve hypertrophy and hyperinnervation

Endometriotic lesions are frequently associated with a hyperinnervation of sensory fibers, especially in the peritoneum. An increase in nerve growth factor (NGF) is observed in the peritoneum of women with endometriosis, leading to neurogenic inflammation and acute sensitization of these nerve endings, contributing to chronic pain.

## Pressure on nerves and adhesions

Endometrial lesions can invade or compress nerves in the pelvis, such as the sacro-uterine nerves, causing severe pain. Also, the formation of adhesions between the pelvic organs can strain the nerve structures, amplifying the pain.

## Central sensitization

Untreated chronic pain leads to the development of central sensitization, where pain signals are amplified in the spinal cord and brain. This process can cause hyperalgesia (exaggerated perception of pain to minimal stimuli) and maintain pain even in the absence of obvious injury.

***We know that stage 1 or 2 endometriosis can hurt more than stage 4. How do we explain this phenomenon?***

The correlation between endometriosis stage and the location of the disease is limited, and the rASRM (Revised American Society for Reproductive Medicine) classification system has many limitations, especially when it comes to the correlation of symptoms with the stage of the disease. For example, in stage 4, intestinal damage is not always present, and the location of the disease is not described in detail by this system. The rASRM system does not fully account for the presence and severity of deep lesions, such as those affecting the uterosacral ligaments, bladder, vagina, or bowel.





Although obliterated cul-de-sac is evaluated in rASRM and indicates an advanced stage (stage 4), this does not always correctly cover the complexity of the disease, and many deep lesions remain insignificant in this system. For example, a patient with intestinal involvement but without obliteration of the cul-de-sac may be misclassified to a lower stage. Studies show that rASRM has a poor correlation with symptoms. Also, rASRM does not correlate well with disease location, making surgical planning and management of cases of deeply infiltrative endometriosis difficult.

### ***What is the Enzian score and how does it help the patient?***

The **#ENZIAN classification** is a comprehensive system for describing endometriosis, used both in non-invasive diagnosis (by imaging such as MRI or transvaginal ultrasound) and in surgical evaluations. It was created to overcome the limitations of previous systems, such as rASRM, by providing a detailed assessment of endometriosis, especially for cases of deep infiltrative endometriosis (DE), but also to include peritoneal, ovarian lesions and adnexal adhesions.

### **The advantages of the #ENZIAN system**

**Detailed and accurate description of the location of the lesions:** ENZIAN divides the pelvis into compartments (A for the rectovaginal space, B for the uterosacral ligaments, C for the rectum), providing a clear description of the lesions in each area. It also includes other locations such as the bladder, ureters or bowel, providing a complete map of endometriosis.

**Extension of the classification:** The #ENZIAN System can assess deep lesions, and can also cover peritoneal endometriosis and ovarian endometriomas, including the size and severity of these lesions, making it applicable to all types of endometriosis. This is a great advantage over the rASRM system, which does not describe adhesions or lesions outside the peritoneal cavity.

**Pre- and post-operative use:** The classification can be applied both in non-invasive diagnosis (imaging) and in surgery, providing a continuity in the description of the disease throughout the entire treatment process. Thus, it allows a better correlation between the preoperative stages and the actual surgery.

**Usefulness in surgical planning:** By providing a clear picture of the size and location of lesions, the #ENZIAN classification is of great help in planning surgical interventions. Studies have shown that this classification correlates well with the complexity of surgical procedures and can guide the medical team in choosing the correct approach.

By including more anatomical and clinical factors, the #ENZIAN system is considered a significant improvement over other classifications, helping patients by providing a more accurate and personalized assessment of the disease.

### ***What is the accuracy of imaging modalities for disease staging?***

The accuracy of imaging modalities for the staging of endometriosis largely depends on the level of training and experience of the doctor, but also on the type of technique used. In general, transvaginal ultrasound and MRI are most useful for detecting deep endometriosis each with specific advantages and limitations.

**Transvaginal ultrasound:** The accuracy of TVS depends on the doctor's experience and is recommended as a first-line method due to its availability and low cost. TVS is highly effective for detecting DE in the rectum and bladder, with high sensitivity and specificity. However, TVS is less accurate in predicting sigmoid lesions due to limited visibility.

**MRI:** MRI provides a detailed image and is useful for more difficult locations such as the rectosigmoid, uterosacral ligaments and bladder, with high accuracy (over 90% in many cases). MRI is often preferred for preoperative staging of deep endometriosis, especially for complex cases.



# Awareness around the world, each one teach one

**Surita Mogan**  
 President  
 Endometriosis Association of Malaysia  
 (MyEndosis)



***Endometriosis poses difficulties to many women, however, asian-african women seem to have it worse. From your experience, why these differences in care?***

In my view, the disparities in the treatment and experience of Endometriosis among Asian and African women and their Western counterparts can be attributed to a variety of factors, including stigma and awareness. Within certain Asian and African societies, subjects pertaining to menstruation health and reproductive disease may be regarded as taboo. Such cultural stigma can hinder women from seeking assistance or simply engaging in open discussions about their problems. The cultural differences in the perception and expression of pain can lead to underreporting symptoms. Women of Asian and African descent may downplay their symptoms in order to conform to cultural standards that avoid expressing grievances about personal distress.

Moreover, research on Asian and African women is severely lacking. The existing body of endometriosis research has concentrated chiefly on Caucasian women, which may result in prejudices when attempting to comprehend the presentation of the disease in women of Asian and African origin.

***Many of the changes around the world come from patients. You are one of them. What is your story with endometriosis?***

In the 1990s, I was often told that the the menstrual pain I experienced in my teenage years should be part of my life as a young girl. People around me, especially female family members, ignored my painful periods, constantly telling me that I should bear the pain like everyone else. I was in so much pain that I constantly vomited and had uncomfortable bowel movements all the time. As the years went by, I started to slowly notice that my pain increased in intensity, and it affected my daily routine to the point that I was unable to be productive.





**I suffered silently, in pain most of the time before, during and even after my period. I was even told by a general practitioner that I have a low tolerance for pain. I had to consume lots of painkillers to function normally. I was in bad shape physically and mentally.**



Since being diagnosed, I went through repeated surgeries, faced considerable challenges in conceiving and was constantly on pain and hormonal medication to manage my condition. I was told early on that I might not be able to conceive naturally. After my first surgery, I was given GnRh for six months. After I completed this medication, I got pregnant naturally. However, my baby passed away when I was seven months pregnant. No answers were given, and I went into depression after that. However, I did not lose hope. I conceived again in the year 2004 and year 2010. Both my daughter and son were preterm babies, as I am unable to carry them full term.

***What was the impact of endometriosis on your career?***

My unbearable pain and excessive bleeding affected my career prospects as I was always on medical leave. My employers truly believed that I was making up my pain to avoid my job responsibilities. I was deemed lazy and weak. At times, I forced myself to go to work, although I was in pain. I took large amount of painkillers to mask and hide my pain. I developed a strong reliance on painkillers. Naturally, there are instances when painkillers are ineffective, so I am not totally dedicated to my line of work.

***Endometriosis Association of Malaysia is a charity that you have founded. What made you take this road and how hard it is as an organisation to receive funds?***

Frustrated with the unfair judgment on women with endometriosis, MyEndosis was established in the year 2014. The primary objective of MyEndosis is to offer emotional assistance and accurate information to women afflicted with endometriosis in Malaysia. The most significant role of our movement in Malaysia is to highlight to our society the long-term damage endometriosis does to a woman's physical and mental health.



Of course, funding was never easy to obtain when we initially started the association. As the years went by, we gained the trust of our community, who believed in our drive to end misinformation on endometriosis. We at MyEndosis tend to collaborate with supportive healthcare professionals and health facilities to organise events, and this has made it possible for us to receive funding.

***Do you think that endometriosis should be classified as a disability?***

The categorisation of endometriosis as a disability is a subject of continuous discussion among healthcare practitioners, legislators, and public interest organisations. The decision to classify a condition as a disability typically depends on how significantly it affects an individual's ability to perform daily activities and maintain a normal quality of life.

Identifying endometriosis as a potential disability for specific individuals could facilitate the promotion of essential workplace adjustments, such as flexible working schedules or the option to work remotely during episodes of worsening symptoms. Furthermore, it could facilitate the implementation of adaptations in educational environments, enabling impacted students to get the essential assistance to handle their pain adequately at school and universities.

However, I think there is also a concern about the potential negative impact of labelling, which might affect an individual's self-image and how others perceive them. So, we have to be careful about labelling someone as disabled.

***Tell us a bit about your charity activity.***

MyEndosis's primary objective is to assist those impacted by endometriosis by increasing awareness and lobbying for improved care and research. We organise seminars, workshops, and information sessions to educate the general public, healthcare professionals, and policymakers on endometriosis.

We utilise platforms like Facebook and Instagram to spread awareness, share stories, and provide updates on advocacy efforts.

We offer peer support from:

- Website (myendosis.org)
- Facebook page (Endomarch Malaysia)
- Facebook group (MyEndosis)
- MyEndosis YouTube channel.
- MyEndosis Instagram
- Email (endomarch.malaysia@gmail.com)

We engage in partnerships with healthcare professionals, hospitals, and other organisations to enhance the efficiency of treatment processes. We disseminate promotional brochures and other resources that offer knowledge on managing endometriosis, accessible therapeutic interventions, and the experience of living with the disease.

These measures are crucial for improving the quality of life for individuals impacted by endometriosis, raising awareness of the condition, and promoting transformative changes in healthcare systems to better meet the requirements of patients.

***If there were to be a national/international endometriosis care plan, what are the first issues you think that should be addressed?***

I believe there is a need to address disparities about endometriosis among the public and healthcare providers, enhancing healthcare infrastructure and advocating for policy changes that ensure better access to care for all women, regardless of their ethnic or socioeconomic background. Understanding and addressing these multifaceted issues is crucial for improving the care and outcomes for all women with endometriosis, particularly those in underserved populations.





# Chronic pain management

***Dr Anca Ionescu***  
*Consultant reumatology*  
*Pain therapy specialist*  
*Integrated Pain Therapy Centre*  
*Nord Hospital, Romania*

**Chronic pain affects up to 24% global female population aged between 18 and 50 years old. Its prevalence is similar to migraine headaches, asthma, and chronic back pain and has a poor prognosis.**

Chronic pelvic pain is defined as a cyclic or non-cyclic pain in the lower abdomen, genital organs, perineum, sacro-coccygeal area lasting for more than 6 months, aggravated or not by menstruation, urination, bowel movement or sexual activity. It is unrelated to pregnancy and is considered a form of chronic regional pain syndrome, as most of the patients have a low pain threshold resulting in central sensitisation.

Chronic pelvic pain can have an initial source in many organ systems, like:

- gynaecological (ex. endometriosis, pelvic congestion syndrome, pelvic inflammatory disease, adenomyosis, hydrosalpinx, pelvic adhesion disease, post tubal ligation syndrome, recurrent ovarian cysts);
- gastrointestinal (ex. irritable bowel syndrome, inflammatory bowel disease, coeliac disease, long-standing abdominal hernias, colorectal cancer);
- urological (ex. urethral syndrome, chronic prostatitis, chronic recurrent cystitis, interstitial cystitis, radiation cystitis, bladder cancer);
- neurological (nerve lesions or entrapments – ex. pudendalgia; spinal cord injury, peripheral neuropathy);
- musculoskeletal (ex. pelvic girdle pain, levator syndrome, coccydynia, pelvic floor tension myalgia, piriformis syndrome, gluteus maximus syndrome, ischiogluteal bursitis, obturator internus syndrome, osteitis pubis, sacroiliac joint dysfunction).



It is well known that there are several biopsychosocial factors associated with chronic pelvic pain, like anxiety, depression, or traumatic experiences (adulthood and childhood sexual abuse). Many the patients with long-standing pain can get a secondary deep myofascial pelvic syndrome, thus requiring an even more complex management than usual.

Given all these possible etiologies, it is important that the chronic pelvic pain patient is evaluated and treated by a multidisciplinary team – gynaecologist, urologist, gastroenterologist, neurologist, rheumatologist, physical therapy specialist.

## There is no standard protocol for the assessment of the chronic pelvic pain patient.

Firstly, it is important to check for red flags: postcoital bleeding, postmenopausal bleeding, unexplained weight loss, pelvic mass, haematuria and rule out acute abdomen and potential malignancy. That's why every pelvic pain patient should initially be evaluated by a gynaecologist/urologist and a general surgeon/gastroenterologist/proctologist and then referred to a pain practitioner for procedures or physical therapy specialist for rehabilitation.

During the initial assessment of a chronic pelvic pain patient it is also important to collect as many information as possible about the patient's symptoms, for example:

- localisation of pain (deep/superficial; well localised/widespread);
- characterisation of pain (how it feels like – cramping/burning/stabbing/ sharp/dull; intensity, duration) , alleviating and precipitating factors (association with menses, urination, sexual activity, bowel movements, certain movements or positions).

- prior treatments,
- associated symptoms (gastrointestinal, sexual, menstrual, neurological).

The physical examination is the most problematic when it comes to assessing the chronic pelvic pain patient because it should involve at least a gynaecological, an abdominal and a musculoskeletal exam, hence, the need for a multidisciplinary team for this type of chronic pain patient.

The workup, depending on symptoms, can involve blood and urine tests, ultrasound, X-ray, MRI or CT scans, or in some cases, urodynamic testing, anoscopy/rectoscopy/colonoscopy, anorectal manometry.

After establishing a diagnosis, some cases may have good outcomes with systemic medication, other may benefit from surgery with good results but other cases may be referred to a pain practitioner.



In my experience, most of the patients address a pain specialist after trying many treatments with no (long term) results. They may have or may have not received a diagnosis for their long-standing symptoms. Some of them have undergone surgery that didn't help. Others' pain started after surgery or other pelvic procedures. The pain therapy specialist can help with identifying the cause of pain and/or treating it using minimally invasive procedures. Unfortunately, treating the source of pain doesn't always mean making the pain disappear. This can be due to a complex neurological phenomenon called central sensitisation, which can be addressed separately via non-invasive therapies.

The minimally invasive procedures can have diagnostic, prognostic or therapeutic role. They may only bring partial relief of pain in some patients, depending on the intensity, duration of pain and associated pathology. They are mainly indicated when conservative treatment fails and are contraindicated in patients with bleeding diathesis or infections.

Most of the pain procedures are done with needles that can be introduced almost anywhere in the musculoskeletal system (spine - epidural space, muscles, joints, around joints, around nerves). These needles are inserted under local anaesthesia, with ultrasound or X-ray guidance. These procedures can be injections of different agents (local anaesthetics, corticosteroids, regenerative agents, neurolytic agents, botulinum toxin), nerve stimulation, pulsed radiofrequency, radiofrequency ablation, cryoablation.

Each procedure and each agent injected has its own indications and for each and every case the procedure is chosen depending on the patient's diagnosis (or most likely diagnosis) and their disease history. Some patients may need more than one procedure to get long time relief. Most of the patients need combined therapies (procedures, medication, rehabilitation, psychotherapy) to get long term pain relief and a good quality of life, hence, once again, the need for a multidisciplinary team or collaboration for the management of chronic pelvic pain.



## Integrated Pain Therapy Centre at Nord Hospital

When conservative treatment does not work, and the patient is still in pain then pain therapy can be an option. An integrated and complete system of evaluation and a therapeutic plan are offered to patients.

Pain therapy is a medical branch that brings together, under the same umbrella, doctors from different medical specialties, all prepared to treat the common symptom called PAIN.

Pain therapy means to correctly identify the causes and then treating them to permanently eliminate the source of persistent pain.

[www.nord.ro](http://www.nord.ro)



# EndoCure, innovation to improve endometriosis diagnosis

**T**echnology and health goes hand in hand and innovation is a way of improving service users experience. Endometriosis is one of the most impactful disease; both on one's self and the society, with diagnosis being very hard to make.

***In general, technology, creating equipment and devices is quite challenging. Given the importance of medical devices, this might be even harder. So, what attracted you to the medical technology world?***

As for the technological part, I was attracted to those fields already as a child, being in a scientific class.

I am a biomedical engineer, of the first cohort that was opened in the Technion a few decades ago. It was important for me from the first moment to have a career in the medical device field, to do something good and impactful, to save people's lives. Looking for a job while pregnant with my first child did not stop me from insisting on my path.

***How would you describe FemTech?***

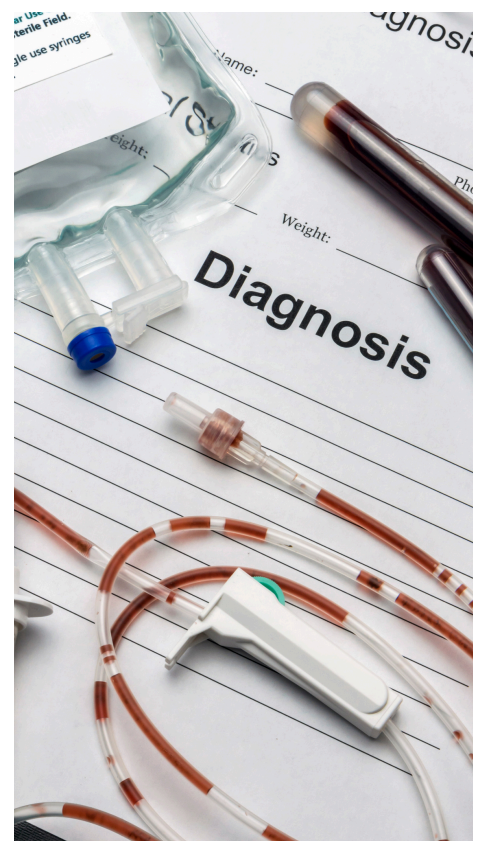
For me, FemTech is my way of expressing feminism at its best. Devoting my days and (nights) to improve women's health is the most meaningful thing I can do with my skills.

***Endometriosis and technology, what is the connection between them two?***

Endometriosis is a forgotten disease. For decades there were no advancements in this very difficult condition diagnosis and treatment. In general, medicine cannot advance much without technology, the same goes for endometriosis and women's health in general. Technology brings new tools for the physicians, allowing them to provide better care for the patients.

**Hadas Ziso**  
**CEO**  
**EndoCure**

I have four degrees, so obviously I like to learn – happy for every day I learn something new. I have a BSc and MSc in Biomedical Engineering, a PhD in Medical Robotics, and an MBA.





**EndoCure, what it is new about it?**

Endometriosis, a chronic condition impacting 10% of reproductive-age women, poses a significant challenge due to the limitations of current diagnostic tools. Approximately 75% of the patients experience misdiagnosis. The existing inadequate imaging capabilities not only extend the diagnostic period to 11 years but also leave the patients in an ongoing vicious cycle of poor diagnosis, trial-and-error based treatment, recurrence, and progression of this chronic debilitating condition.

Addressing this critical gap, EndoCure's solution is an advanced system for the detection, mapping, and staging of lesions by robotic AI-powered ultrasound imaging. By streaming high-resolution data from a standard ultrasound, we process it to DICOM and use AI to easily detect even 1mm lesions. Our solution represents a transformative leap forward in not only the diagnosis and management of endometriosis but also in surgical planning. It stands alone as the premiere solution offering a comprehensive lesion map to facilitate personalized treatment.

**We use AI in computer vision to detect very small endometriosis lesions, invisible to date. As there is no correlation between lesion dimension and symptoms, detecting those small lesions is crucial for diagnosis and disease management.**

**Our AI-powered software could also compare the lesion map before and after treatment and monitor the condition throughout the patient's lives.**

**Is your product available or is it still developing?**

We have completed a very successful POC in preclinical trials, detecting lesions that were invisible to date. We plan to have our First-in-Human clinical study in Jan 2025.

**Name 3 main benefits of EndoCure compared to what we have now available in terms of diagnosis.**

Today, unfortunately, definitive diagnosis is performed by a laparoscopic surgery. New methods for the diagnosis of endometriosis rely on biomarkers, like Ziwig's Endotest, which provide a binary answer regarding the presence of endometriosis. However, our market validation suggests that this approach does not provide sufficient information for physicians to plan treatment and follow-up accurately. While it may have some significance for patients, it does not provide disease sub-types and stage, thus it is not a comprehensive disease management tool. Therefore, we anticipate that patients will undergo an in-vitro test and subsequently utilize our imaging system for further evaluation.

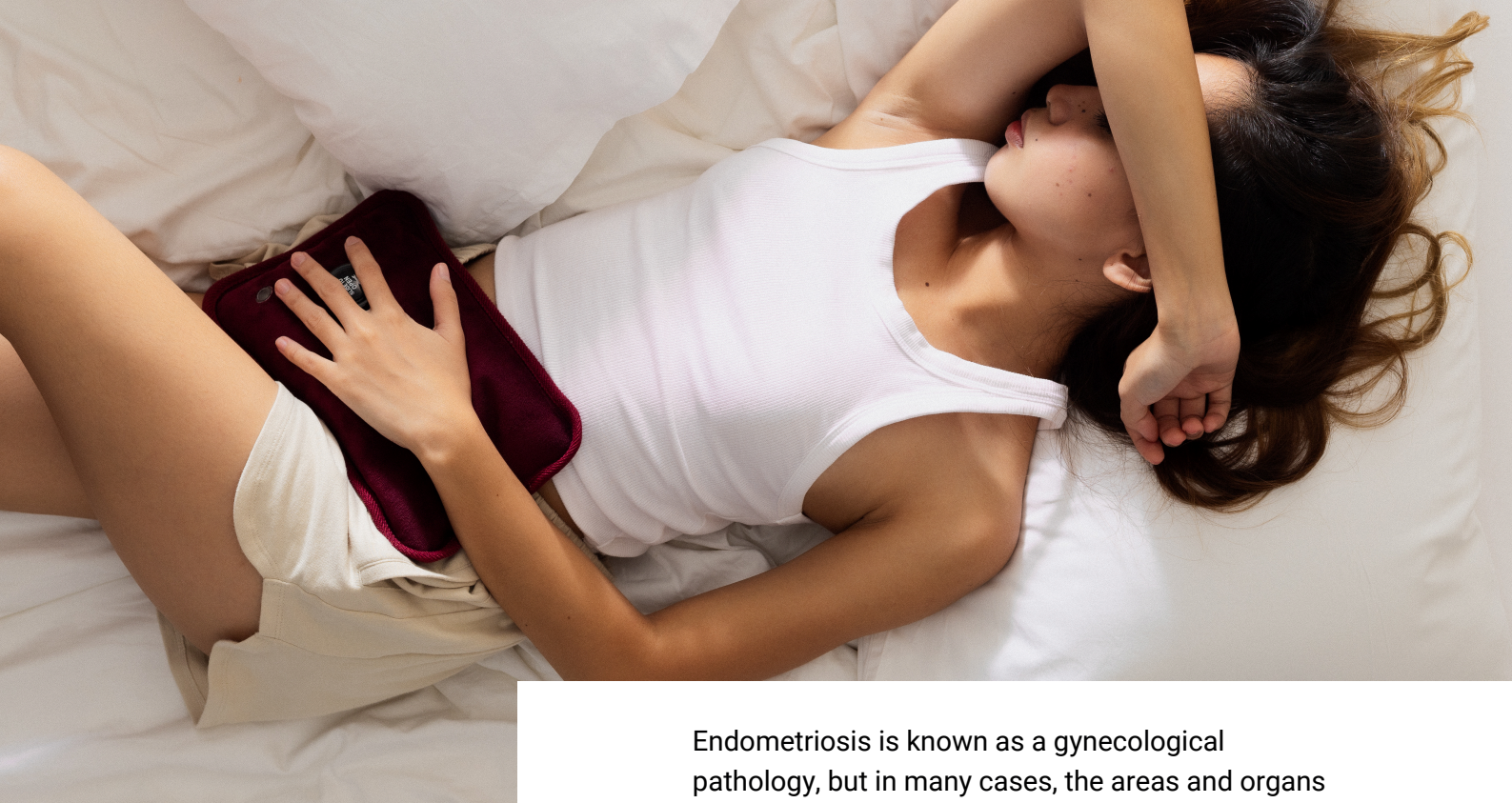
**Our solution is fast, comprehensive, affordable and accessible, providing a tool for complete disease management.**

**Is it a worldwide product?**

Of course. Our go-to-market strategy begins in the US, followed by Europe and the rest of the world.



# Endometriosis is a whole-body disease



Endometriosis is known as a gynecological pathology, but in many cases, the areas and organs affected by this disease are, in fact, extragenital. Endometriosis lesions come in different shapes and colors and can be found anywhere in the human body. The pelvis is the area most affected by endometriosis, but the abdomino-thoracic area can also be frequently affected.

Statistics show that endometriosis affects one in ten women, but due to misdiagnosis and other factors, the exact prevalence of endometriosis is unknown. In countries with a developed economy there is a diagnostic delay between 8-10 years. Endometriosis can affect the peritoneum of the pelvic organs, the ligaments, the bottom of the pouch of Douglas, the intestines, the urinary tract, the appendix, the ovaries, the fallopian tubes, the external surface of the uterus, the nervous system, but also organs in the upper abdomen, such as the diaphragm, lungs, kidneys, etc. The latter are classified as rare forms of endometriosis.

Dr Camran Nezhat, one of the most well-known specialists in endometriosis says that endometriosis is a disease of the whole body, a serious disease that over time can lead to severe complications if left untreated. Dr Nezhat also says that for centuries, the symptoms of endometriosis were and are considered to be normal menstrual cramps and pain that every woman complains about.

# ENDORO-ONLINE

**ENDOMETRIOSIS, ADENOMYOSIS AND  
FIBROIDS**



**ENGLISH ROMANIAN**

Information from various medical  
sources

Endometriosis

Adenomyosis

Fibroids

Infertility

JULY 2025

ISSUE 05

# **ASSOCIATION OF PEOPLE WITH ENDOMETRIOSIS**

**HELPING TO CONSTRUCT A BETTER WORLD**

