ENDOMETRIOSIS DIGITAL MAGAZINE

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ENDOLIFE

Association of People with Endometriosis

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“Handling nerves in surgery is not for the faint-hearted”

Endometriosis is not an harmless disease!

Seek specialist care if you suffer from endometriosis

CAMELIA SERBAN

I have attended the European Endometriosis Congress in Bucharest, Romania

Education is the most powerful weapon which you can use to change the world" – Nelson Mandela.

Hello and welcome to the second issue of our magazine. I would like to start by saying thank you to everyone who took part in this current issue and in the last one. In this issue you will find a lot of interesting articles that will hopefully be useful to many of you. For me the last couple of months have been busy but in a nice way and my recent adventure of "little Cami's world" was the Endometriosis European Congress.

Being a patient or a representative of patients' voices, regardless of the disease, can be challenging to say the least. Things can be more complicated when you are facing a disease that despite its high incidence and severe issues that might come with it gets less attention than what might be expected. Fighting a chronic disease, fighting for proper care can take a toll on one's life.

Changes are coming; slowly but steady

Endometriosis might not be a priority for many doctors or healthcare professionals, but for the ones that it is, I can say that they are truly invested in their roles. Over the 3 days that I have mingled and spoken with quite a few endometriosis specialists or gynaecologists, I saw nothing but a true desire to help us, a true interest in what can be done to improve care.

The **7th Endometriosis European Congress** was a purely scientific event with world renowned specialists taking the stage and sharing their experience with the participants. And they all have a common purpose: make this disease less complicated than it is. Participants were from many countries around the world and speakers came from Kenya, China, India and so on.

The last couple of weeks, as some might know, there were a lot of concerns amongst endometriosis sufferers due to the death of a well-known Kenyan endometriosis advocate. At the congress I bumped into Dr Joe Njagi, an endometriosis vetted specialist and we briefly discussed the sad case of Njambi Koikai. At the round table discussion on the last day of the congress, this case was also briefly mentioned.

Taking a peek at Mr Ertan Saridogan, University College London , award

A brave soul has gone from this world, fighting a severe form of endometriosis, and leaving behind a true legacy. Her story touched a lot of us and caused worries as well. It is with hope, as Dr Nijagi was saying, that governments will start looking at endometriosis and create national healthcare plans.

Endometriosis is a multidisciplinary disease and patients communities should be included

Treating endometriosis no doubt requires multidisciplinary treatment and the saying one size does not fit all, couldn't be more true. The congress talks touched many areas of endometriosis diagnosis and treatment, including impact on fertility.

Prof Hans Tenneberg from Germany holding a copy of my magazine.

From other surgical specialists to psychologists and nutritionists they all play an important role. Robotic surgery is becoming the new minimally invasive surgical method and other methods of diagnosis are in progress. One of them is a salivary test.

Although it was a fast–paced event with talks taking place at the same time, I had fun. It was the first medical event that I have gone to and I picked one of the biggest ones of the year. It did count that the congress was held in Romania where I am from, in my decision of attending. It was a great opportunity for networking and to share my work with others.

I have to say that everyone that I spoke with was very nice, kind and some of them made me laugh. For me, it was without any doubt a big thing. On my first day I bumped into Dr Harold Krentel and I told him “ I got lost”. I had a lovely chat with prof Hans Tinneberg who was impressed with my magazine. I gave him a copy of it and on the last day of the congress he showed it to the audience; thank you, sir.
I chatted with Mr Raza, with Dr Naem, with Mr Khazali, with Mr Tspeov and Dr Moawad.

On the first day, I went straight to Dr Keckstein who told me that years ago he did a surgery from Romania for some congress. Of course, I could not miss Prof Roman and many Romanian doctors. I also met Emma Cox briefly from Endometriosis UK and will be happy to engage with her soon.

What was my take away from attending this congress? We are on the right path, it might not be the best one for each country, but changes are coming. I saw true friendships between doctors, I saw a lot of brilliant young doctors willing to learn more about endometriosis. I have got many contact details and I have made plans for some new projects. I discovered that being part of two worlds and getting into the third one: Greece, can be fun.

Thank you to the organisers and to everyone that I spoke with. Together, we are making changes towards better understanding and dealing with endometriosis. Something that requires us to support each other and share our knowledge. It's a journey that needs partnership for a better world.

> **We need a world where diagnosis and treatment methods are made accesible, barriers to correct and timely diagnosis and care are broken, diversity is included and where every endometriosis patient has their voice heard.**

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FROM CONTENT

EndoLife Digital Magazine is linked to facebook page **Global Daily Endo News** and a website called **EndoDailyNews**
e-mail: contact@endoromania.org

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EndoLife digital magazine is an educational non-for-profit project of People with Endometriosis Association. This present edition of the magazine contains no paid publicity. The magazine will be published regularly.

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

Concept: Camelia Serban

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.

Help me win the battle with fibroids and endometriosis

Elena Dobre, Romania

Every donation matters and will encourage Elena to confidently continue on the path to recovery!
IBAN: RO94INGB0000999900097868
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Elena is one of the many women living with endometriosis who currently greatly needs financial assistance to undergo surgery. Besides suffering from deep endometriosis, Elena also has multiple uterine fibroids, further affecting her quality of life. Pain, bleeding, chronic fatigue, fertility issues, and many more have been part of her life for over 10 years, yet they haven't hindered her from maintaining joy in living and a smile on her face. These symptoms aren't just a cold list of words; they define her everyday life.

She has already undergone a classic myomectomy in 2012 and a biopsic and hemostatic curettage in 2023, but the battle is far from over. Many more fibroids have developed, causing bleeding and pain. Diagnosed with deep endometriosis in 2021, but experiencing unexplainable symptoms for many years, Elena found a doctor willing to perform robotic surgery to remove the fibroids and endometriosis lesions without removing the uterus, an option repeatedly suggested to her until now.

Robotic surgery is quite expensive, over 10,000 euros, which is why she has initiated a crowdfunding campaign to quickly raise the necessary funds.

Abdominal wall endometriosis

Emad Mikhail, MD, FACOG,FACS

- Associate Professor & Chief Division of Gynecologic Subspecialities
- Department of Obstetrics and Gynecology
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What is abdominal wall endometriosis? How does it occur?

Abdominal wall endometriosis is a disease where cells that are similar to the lining of the uterus migrate into the abdominal wall layers. We are not exactly sure how this happens but one of the most common theories is contamination in the endometrium like cells during C-Section delivery.

Can it be mistaken as hernia?

There are similar characteristics between abdominal wall endometriosis and a hernia one of these are that both diseases form an abdominal wall bulge. Both diseases are usually painful. On the other hand there are factors that differentiate between them including the timing of the pain whether or not it is cyclic in nature, other factors include the location and the consistency of the bulge.

One of the causes of abdominal endometrioma is believed to be contamination during c-section. What steps can be taken to avoid contamination?

That's right. One of the most common theories behind abdominal wall endometriosis development is contamination during C-section delivery. The incidence of C-sections is on the rise accounting for more than 30% of all deliveries in the US right now on the other hand the incidence of abdominal wall endometriosis is far rarer than that. The question is why certain patients develop abdomen endometriosis, while others do not since we don't understand that specifically developing a prophylactic measure to prevent contamination is hard.

> **Most patients with abdominal wall endometriosis do have pelvic endometriosis as well**

“Complications of surgery can be infection, pain, bleeding and incisional hernia formation”

What are the symptoms of endometriosis in the abdominal wall?

Most patients with abdominal wall endometriosis present with abdominal pain that is mostly cyclic in nature also abdominal mass or a bulge that is felt in the abdominal wall less commonly patients with umbilical endometriosis presents with cyclic bleeding from the umbilicus.

ABDOMINAL WALL ENDOMETRIOSIS HAS A REPORTED INCIDENCE OF 0.03–3.5% IN REPRODUCTIVE-AGED WOMEN

What other risk factors apart from c-section are? For example, can you have abdominal wall endometriosis after laparoscopy and laparotomy?

Most commonly abdominal wall endometriosis develop at the site of a previous C-section it can also develop at the site of previous abdominal incision including laparoscopy or laparotomy specifically in cases where an endometriosis surgery has been performed and or endometrioma has been retrieved through that incision. That is why most surgeons nowadays when they retrieve endometriosis tissue or endometrioma cyst wall they do it through a retrieval bag to avoid contamination.

Where do usually endometriosis lesions develop?

The most common site of endometriosis is the pelvic cavity. Extra pelvic endometriosis has become more prevalent I think because of our awareness of this disease and one of the most common sites of extra pelvic endometriosis is the abdominal wall endometriosis.

How is it diagnosed?

Clinical diagnosis is the goal is the standard; by history taking and physical examination. Abdominal ultrasound, CT scan, and MRI can also be very helpful in localising the lesion of endometriosis of the abdominal wall including its dimensions and its depth.

Can it be managed with medication?

Definitely patients can try medical treatment if they want to but usually in abdominal wall endometriosis it’s not successful in the long term and surgical excision is needed.

When surgery is indicated, how is it performed?

The most common modality for surgical excision is through a skin incision that is overlying the endometriosis lesion. In cases where the endometriosis nodule is deeper more towards the peritoneal side of that abdominal wall, a laparoscopic or robotic excision can be performed. It depends on the size of the nodule and the resultant defect in the fascial layer of the abdominal wall mesh can be used to reinforce a defect.

Tools used in surgery, how important they are?

Cindy Mosbrucker, MD and Trista Newville, DO
Pacific Endometriosis and Pelvic Surgery
in Gig Harbor, WA

What tools can be used in endometriosis surgery?

A surgeon needs to be able to identify all types of endometriosis ranging from subtle/juvenile to advanced/obvious disease. It's vital to visualise abnormal peritoneum which may cause pain or represent subtle endometriosis. Dr. Redwine termed the technique of visualisation of subtle endometriosis as "near contact laparoscopy." Some argue there is a lack of palpatory biofeedback, however, visually you can see if tissue is 'soft' or appears healthy. Drs. Redwine and Yocum detailed this further with criteria of normal peritoneum:

a. Peritoneal surface perfectly smooth with no texture irregularity or specular light reflections;
b. No abnormal vascular patterns;
c. Transparent peritoneum without associated colour;
d. No suggestion of subperitoneal cystic structures
e. No superficial fibrosis;

The next tool is a scope, either laparoscope or robotic scope, which allows for the "near contact laparoscopy". Laparotomy does not allow for the visualisation of the peritoneum less than 1 cm distance from the tissue (2). The robotic scope has 2 lenses which allow for a 3-dimensional view of the peritoneal surfaces.

Alongside the visualisation tools are the instruments and energy used for excision of endometriosis. Typically, a surgeon will use bipolar and monopolar energy sources or carbon dioxide lasers. However, they may also use sharp dissection. Sharp dissection does not typically use an energy source and is completed with scissors, which may also be used as a monopolar energy source for coagulation. The type of instruments used during surgery is largely dependent on the individual surgeon's experience and the technique they are proficient in exercising.

Are they the same for excision and ablation?

The Gold Standard treatment of endometriosis is excision. Excision of endometriosis may be carried out using the previously mentioned tools. Ablation of endometriosis is substandard and does not remove the disease from the roots. Ablation of endometriosis is typically performed using bipolar or monopolar energy sources or with carbon dioxide laser vaporization.

Is laser a tool to avoid in excision surgery?

If a surgeon is proficient in using the carbon dioxide laser for excision of endometriosis, then it doesn't need to be avoided. If the laser is being used for ablation of endometriosis, then it is substandard treatment

What complications can arise from these tools?

Complications from using these tools typically involve thermal spread, tissue trauma, bleeding, or poor surgical technique. The thermal spread depends on the type of instrument used, power setting, and amount of time applied to the tissue6. Adhesions may form, bleeding may occur, and damage to surrounding tissue (bowel, bladder, ureter, fallopian tubes, etc.) is possible. These may lead to complications including hematomas, abscesses, hospital re-admissions, need for additional surgeries, and increased pain.

Are there any areas such as bowel where only specific tools can be used?

Endometriosis of the bowel ranges from superficial disease to full-thickness disease and may involve the small bowel, large bowel, or appendix. The instruments used depend on the type, location, and extent of the disease but are generally the same as those used for pelvic surgery. Additional specialists may also be needed for segmental bowel resections. If a gynecologic surgeon does not perform appendectomies regularly, then a general surgeon should be included in the surgical plan. It is prudent to know each specialist's scope of practice and their abilities to perform surgery on the bowel specifically for endometriosis. Segmental resection is typically needed for small bowel disease or extensive large bowel disease. Partial thickness or small full-thickness bowel endometriosis may be excised using sharp dissection (scissors), monopolar cutting energy, and/or GI stapler for a discoid bowel resection.

Pacific Endometriosis and Pelvic Surgery

Dr Cindy Mosbrucker with her Endo Hero of the year nomination

How is the bleeding stopped?

Minimizing bleeding and maintaining hemostasis involves a global awareness of everything within the surgical field. It's important to have a thorough knowledge of pelvic anatomy, know the different tissue appearances, and know where and when bleeding may be encountered. Hemostasis is achieved using monopolar or bipolar cauterization or with suture depending on the location of the bleeding and surrounding tissue.

For deep endometriosis of the diaphragm what sutures can be used, if there are used?

Diaphragm endometriosis can be superficial or deep. Typically, superficial diaphragm lesions will cause pain under the shoulder blade but not cause shortness of breath, coughing up blood, or catamenial pneumothorax (dropped lung during menses) that full-thickness lesions will cause. We typically close full-thickness defects of the diaphragm with a delayed absorbable barbed suture that will hold its strength for about 4-6 weeks and then dissolve. Sometimes if the defect in the diaphragm is too large to close primarily then a patch needs to be used. Normally this would be a biological mesh made from pigskin or intestinal tissue vs PTFE or Gore-Tex.

On ovarian endometrioma what can be used?

Ovarian endometriosis is best treated with excision of the cyst wall and establishing a normal ovarian structure by closing the dead space left after the endometrioma is removed. This will also help to stop any bleeding. It is sometimes necessary to suspend/tie the ovary to the round ligament or temporarily suspend an ovary to the abdominal wall to prevent the ovary from sticking to the bowel, ureter, uterus, etc. It is substandard treatment to drain endometriomas, cauterize the bed, or incompletely remove the endometrioma. These actions may result in endometrioma reforming, peritonitis, adhesions, damage to fallopian tubes, reduction in ovarian reserve, and/or increased pain.

The removal of the endometrioma may be performed using the instruments mentioned in Part 1. Sutures used to reestablish normal ovarian structure will dissolve in about 2 weeks. We typically suspend the ovary to prevent the raw surface on the ovary from sticking to the raw surface on the sidewall left after the excision of endometriosis from this area. Patients who are unlikely to need IVF undergo a suspension to the round ligament, and those likely to need egg retrieval are better served with a temporary suspension via a suture through the abdominal wall which we remove at postoperative day 5.

References:

1. Redwine DB: Age-related evolution in color appearance of endometriosis. Fertil Steril 1987;48:1062–1063.
2. Redwine DB: Is 'microscopic' peritoneal endometriosis invisible? Fertil Steril 1988;50: 665–666.
3. Redwine DB, Yocom L: A serial section study of visually normal peritoneum in patients with endometriosis. Fertil Steril 1990;54:648–651.
4. Redwine DB: Laparoscopic excision of endometriosis by sharp dissection. In Laparoscopic Appearance of Endometriosis. Edited by DC Martin. Memphis, Resurge Press, 1990, pp 9-19.
5. Garry, Ray: The Effectiveness of Laparoscopic Excision of Endometriosis. Current Opinion in Obstetrics and Gynecology 16(4):p 299-303, August 2004.
6. Hefermehl HJ, et al. Lateral Temperature Spread of Monopolar, Bipolar, and Ultrasonic Instruments for Robotic-assisted Laparoscopic Surgery. BJU Int. 2014 Aug;114(2):245-52. doi: 10.1111/bju.12498. Epub 2014 Jan 22.
7. Malzoni M, Di Giovanni A, Exacoustos C, et al. Feasibility and Safety of Laparoscopic-Assisted Bowel Segmental Resection for Deep Infiltrating Endometriosis: A Retrospective Cohort Study With Description of Technique. J Minim Invasive Gynecol. 2015 Oct 8. pii: S1553-4650(15) 01604-0.

Thoracic endometriosis

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- Consultant Thoracic Surgeon at Oxford University Hospital
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Thoracic endometriosis is characterised by the growth of endometrial-like tissue in the chest cavity.

This tissue can affect various thoracic structures such as the lungs, the diaphragm, the airways, the pericardium and the pleura, leading to a range of symptoms and complications that pose diagnostic and management challenges. Previously considered rare, there's now mounting awareness that thoracic endometriosis may be under-diagnosed.

Symptoms indicative of thoracic endometriosis include chest pain, shortness of breath, coughing up blood, or recurring respiratory issues exacerbated during menstruation or ovulation, and also cyclical shoulder pain. These symptoms are often tied to hormonal fluctuations, triggering inflammation and pain in the thoracic region. Seeking medical advice for persistent or impactful symptoms is crucial for an accurate diagnosis and effective management.

Thoracic endometriosis syndrome (TES) encompasses various manifestations of the condition, such as:

- catamenial pneumothorax
- catamenial hemothorax
- hemoptysis
- pulmonary nodules.

These conditions often exhibit, but not necessarily, cyclical symptoms aligned with the menstrual cycle due to hormonal effects on thoracic endometrial-like tissue.

Complications of thoracic endometriosis, if untreated, can be severe. Catamenial pneumothorax, for instance, results from air accumulation in the pleural space, leading to lung collapse and breathing difficulties. Catamenial hemothorax involves blood accumulation in the pleural cavity, causing chest pain and respiratory distress. Hemoptysis arises from lung tissue irritation by endometrial-like deposits, resulting in coughing up blood. Pulmonary nodules, abnormal growths in lung tissue, can lead to further complications if they enlarge.

While pelvic endometriosis is more common, isolated thoracic endometriosis—without pelvic involvement—is rare yet possible, presenting distinct challenges in diagnosis and treatment. Healthcare providers should consider thoracic endometriosis in individuals with thoracic symptoms, even in the absence of pelvic endometriosis.

The four categories of thoracic endometriosis syndrome include:

Catamenial pneumothorax: recurrent lung collapse during menstruation due to endometrial-like tissue in the pleural cavity, leading to chest pain and breathing difficulties. Often associated with diaphragmatic involvement and fenestrations.

Catamenial haemothorax: menstrual bleeding accumulation in the pleural cavity causing chest pain, breathing difficulty, and anaemia.

Hemoptysis: coughing up blood due to lung and/or airway spots of endometrial-like tissue deposits.

Pulmonary nodules: abnormal growths in the lungs associated with thoracic endometriosis, necessitating further evaluation.

In summary, thoracic endometriosis presents complex challenges, necessitating early recognition of symptoms, understanding of thoracic manifestations, and awareness of potential complications. Healthcare providers play a crucial role in diagnosing and managing thoracic endometriosis to enhance quality of life and outcomes for affected individuals.

Dr Franceso Di Chiara
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MRI for the Diagnosis of Endometriosis

Dr. Wendaline VanBuren, MD
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Historically, endometriosis has been a clinical diagnosis with surgery being the gold standard in evaluation. However, unfortunately the disease is very complex, and may require a multifaceted approach to diagnosis and management. Most international medical societies now recommend imaging as part of the diagnostic evaluation. One of the key components to that diagnosis is the usage of MRI.

The frontline modality for evaluation of the gynaecological pelvis is ultrasound. Ultrasound is cost effective and generally accessible worldwide. Most routine pelvic ultrasound exams are not tailored for endometriosis assessment, but they will assess the ovaries for cysts called endometriomas and evaluate for other potential concerns.

A panel of experts from multiple Radiology and Gynecology specialists via the Society of Radiologists in Ultrasound recommends an “Augmented” pelvic ultrasound with a few additional maneuvers to detect direct and indirect signs of endometriosis. Included in the recommendations are clinical symptoms which are central to guiding care for those who should go on to expert level ultrasound or MRI. This type of ultrasound is essentially a triage tool that will empower physicians to advocate for their patients to receive advanced expert level imaging (1).

> **“An expert MRI or ultrasound exam may be decided upon based on the resources available in a particular country and/or physician experience”**

In this article we will discuss the utilization of MRI, which is an excellent diagnostic tool, but may not be as readily available depending on national resources. An MRI for Endometriosis is a special protocol that optimizes evaluation not just for the female pelvis, but also the disease itself. Both European and American Consensus guidelines recommend protocols using a small field of view and sequences tailored to evaluate for blood products (2).

Another critical aspect in most protocols is administering an anti-peristaltic agent for the bowel such as Glucagon or Buscopan to reduce artefact and allow for clear visualization. Bowel preparation and rectal gel may be recommended depending on practice preference.

Bowel invasion of Endometriosis is quite common, and delineation identified at MRI is very helpful in counselling and surgical planning. Gel administered into the vagina is often recommended and very useful in assessing vaginal invasion. The ureters may also be assessed if timed appropriately. Finally, intravenous Gadolinium contrast is often recommended for assessment of cancer, as well as evaluation of other findings which may be present (such as fibroids, polyps or other processes).

Endometriosis protocols to evaluate the pleura (surrounding the lungs), the diaphragm, the small bowel (called an MR Enterography) and the nerves all have uniquely tailored protocols.

MRI is the definitive modality of choice for extra-pelvic disease assessment as well as for anyone with concern for cancer, as all Endometriosis patients are at increased risk.

Endometriosis has three basic patterns: cysts in the ovaries called endometriomas which are well described on ultrasound and MRI. Superficial deposits are small lesions on the lining of the abdomen called the peritoneum. These types of deposits may be seen on MRI if they have blood products and can be described quite confidently, however this only represents likely 10-20% of superficial deposits.

If these lesions only have mild thickening without blood products, it is possible to suggest there could be superficial endometriosis, but the finding is non-specific.

There is limited data with regards to these types of lesions on MRI but in general this finding is well observed at surgery and while the knowledge of them is important, they do not change the surgical approach. The area that MRI really becomes outstanding is the identification of deep disease.

Deep endometriosis affects at least 20% of patients with Endometriosis and often results in increased surgical complexity and may require additional surgeons who specialize in the bowel, bladder, ureters, upper abdomen, nerves or chest.

Many patients have two or three of these patterns; and with advanced disease all 3 patterns are commonly observed (3).

Endometriosis is a disease of pattern identification. It is important to observe the individual sites of disease and describe detailed anatomy, but the overall appearance of the pelvis can also change (4).

While adhesions may not be directly observed at MRI, often times distortion of pelvic anatomy is present such as “kissing ovaries” when the ovaries touch each other and the uterus, a retroflexed uterus (folded backwards, pulled in by endometriosis), tilting of the uterus toward the pelvic side wall, obliteration of the posterior cul-de-sac and tethering of the rectum towards the uterus.

If these types of findings are observed on any imaging modality (ultrasound, MRI, CT) the possibility of endometriosis should be suggested as these patterns are very characteristic. Ultrasound may provide a powerful adjunct to MRI to perform dynamic maneuvers and assess for mobility.

MRI for endometriosis is a very important tool for assessment, particularly in those suspected of having advanced or deep disease. Patients may benefit from knowledge of the disease severity for operative planning or for follow-up in the case of medical or conservative management.

The training to read an MRI for Endometriosis requires dedicated effort, through case volume and specialized educational resources. There are tremendous strides in the adoption of dedicated protocols, education and reporting standards and MRI for Endometriosis is becoming increasingly available.

Young SW, Jha P, Chamie L, Rodgers S, Kho RM, Horrow MM, Glanc P, Feldman M, Groszmann Y, Khan Z, Young SL, Poder L, Burnett TL, Hu EM, Egan S, VanBuren W. Society of Radiologists in Ultrasound Consensus on Routine Pelvic US for Endometriosis. Radiology. 2024 Apr; 311 (1):e232191

2. Tong A, VanBuren WM, Chamie L, Feldman M, Hindman N, Huang C, Jha P, Kilcoyne A, Laifer-Narin S, Nicola R, Poder L, Sakala M, Shenoy-Bhangle AS, Taffel MT. Recommendations for MRI technique in the evaluation of pelvic endometriosis: consensus statement from the Society of Abdominal Radiology endometriosis disease-focused panel. Abdom Radiol (NY). 2020 Jun; 45 (6):1569-1586

3. Jha P, Sakala M, Chamie LP, Feldman M, Hindman N, Huang C, Kilcoyne A, Laifer-Narin S, Nicola R, Poder L, Shenoy-Bhangle A, Tong A, VanBuren W, Taffel MT. Endometriosis MRI lexicon: consensus statement from the society of abdominal radiology endometriosis disease-focused panel. Abdom Radiol (NY). 2020 Jun; 45 (6):1552-1568

4. Feldman MK, VanBuren WM, Barnard H, Taffel MT, Kho RM. Systematic interpretation and structured reporting for pelvic magnetic resonance imaging studies in patients with endometriosis: value added for improved patient care. Abdom Radiol (NY). 2020 Jun; 45 (6):1608-1622

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Dr. Mihail Banacu: "It is very important for a patient to realize that endometriosis is not a disease that can be cured, regardless of the treatment performed."

Endometriosis in young patients

From the point of view of symptomatology, depending on the stage of the disease that a patient has at the time of diagnosis, the most common symptoms include: menstrual pain, periovulatory pain, dyspareunia (pain during sexual intercourse), chronic pelvic pain, heavy bleeding , asthenia and last but not least, infertility. All these symptoms can lead to a decrease in the quality of life by limiting daily, family or work activities.

> **Endometriosis is a chronic, progressive disease that needs to be monitored more frequently through multiple checks.**

Not all patients with endometriosis have symptoms, but in all patients with endometriosis it is important to mention the cumulative impact by which it affects their lives; the risk of malignancy – although it happens rarely, it is twice than in the general population; at the same time, the association of metabolic and cardiovascular diseases is more common in these patients.

We believe that the etiopathogenesis of the disease is complex and incompletely understood, and originates from disturbances in hormonal synthesis and regulation, through changes in the neoformation of vessels and nerves in association with an aberrant inflammatory response; all this on a background of low hereditary or acquired immunity.

Thinking about how the environment can affect a patient with endometriosis, smoking, the modern diet that is based on processed foods, excessive consumption of red meat, excess dairy products, gluten, sugars can significantly contribute to the damage to the immune system and thus favor the occurrence or progression of the disease.

> the lack of physical activity and a balanced lifestyle certainly contributes to the increased incidence of the disease.

Endometriosis diagnosis

It is important to diagnose endometriosis as early as possible for a less invasive management. The recommendation is that the first consultation should be done with a gynecologist experienced in this disease. The limitations we encounter as doctors in the diagnosis of the disease are endometriosis in early stages where the lesions inside the abdomen are subtle and cannot be highlighted through consultation or imaging, being suggested only through symptoms; then extrapelvic lesions (small intestine, subcutaneous tissue, diaphragm, kidneys, sigmoid colon, etc.) are difficult to palpate and highlight during a gynecological consultation.

There is no standardized treatment strategy for a patient diagnosed with endometriosis. Each type of treatment (whether medicinal or surgical) will be individualized according to the stage of the disease of the patient, the presence of symptoms, how debilitating it is for the patient and, last but not least, the desire to get pregnant in the near future.

What we think is very important for a patient to realize is that endometriosis is not a disease that can be cured, regardless of the treatment performed. Symptoms can be alleviated, infertility can be combated in a fairly high percentage of cases, but unfortunately no curative treatment has been found until now.

Management methods

There are also a multitude of complementary treatment methods that patients can use, such as: acupuncture, physical therapy, lifestyle changes especially with regard to diet, osteopathic treatment, chiropractic symptom management, all these supplementing the treatment that the attending physician considers most appropriate for the patient.

The psycho-social aspects that a diagnosis of endometriosis will have on patients should never be neglected. They should be referred to specialist help if they feel they need it. There are psychologists and psychotherapists at the moment who work mainly with patients diagnosed with endometriosis and are prepared to help them understand their disease not only from a medical point of view, but also the implications it has in their daily life.

What do we want for our patients? On one hand, doctors awareness of the high frequency of these pathologies among all women and their referral to specialized doctors for a correct and complete diagnosis and then the large-scale access of patients to centers/multidisciplinary teams specialized in endometriosis. Until clinical trials reach a consensus on the causes and best treatment of endometriosis, the future of endometriosis treatment must be prevention and early detection.

Dr Ana SIERRA:The Life of a Female Endometriosis Excision Surgeon: Tackling the Nerves

We can argue that female surgeons are rare and for complex diseases such as endometriosis are even rarest.

For nerve surgery, you can probably count on one hand the number of females doing nerve surgery. Nerves, as many know, are important and carry important body functions. Tackling nerves issues requires high experience and knowledge. Among these few female surgeons that operate on nerves is Dr Ana Sierra from Doyenne Institute in Mexico. In this exclusive interview Dr Sierra talks about nerve surgery and the rigorous path to becoming a nerve specialist.

Navigating the Complex Area of Endometriosis Surgery

Endometriosis is a notoriously complex and often debilitating condition, affecting one in ten women worldwide. (although some statistics are even suggesting 1 in 7 in Mexico) For those of us who have dedicated our careers to excision surgery, particularly those specializing in nerve involvement, it is both a challenge and a calling. As one of the few female endometriosis excision surgeons globally—and lucky enough to have neuropelveology training—my journey has been marked by a lot of training, ongoing learning (not settling for the common answers), and an unwavering commitment to my patients; also lots of support from my friends and family.

The Rigorous Path to Becoming a Nerve Specialist

My training began with a standard medical degree, followed by a residency in gynaecology. However, to specialise in endometriosis and nerve surgery, I pursued additional Master´s in Anatomical landmarks, master´s in surgical management of deep endometriosis and Neuropelveology. These included hands-on training with experienced mentors, advanced courses in nerve dissection, and countless hours in the cadaveric lab and operating room honing my skills. Also, I had the opportunity to learn from other specialists that deal with patients with chronic pelvic pain on a daily basis, as I am part of a multidisciplinary team focused on the diagnosis and treatment of endometriosis based in Mexico City, Called Instituto Doyenne.

Dr Ana Sierra

“Handling nerves in surgery is not for the faint-hearted. It requires meticulous precision, extensive training, and a deep understanding of both the anatomy and the nuances of endometriosis”

There I can not only have some of the best endometriosis surgeons as part of my team but also learn from physical therapists about the muscles on the pelvic floor; how to explore them and what is the connection to the pain in endometriosis, as well as a Neurophysiologist that works with me during surgeries in order to preserve as much funcion of the nerves as possible.

Live Nerve Testing: A Cutting-Edge Technique

One of the most intriguing aspects of nerve surgery for endometriosis is the live nerve testing that we perform during operations. This technique involves stimulating the nerves intraoperatively to ensure they are functioning correctly. By doing so, we can map out the nerve pathways and avoid unnecessary damage. While this technique is not yet standard practice in all surgical centers, it is increasingly being adopted by leading institutions due to its effectiveness in preserving nerve function and improving patient outcomes.

> **Our job as doctors is to help them make the best decision empowered by information and the best pre-surgical diagnosis that we can provide.**

The Importance of Experience in Nerve Surgery

The consequences of nerve damage can be severe, leading to chronic pain, loss of function, and other complications. These complications can be diagnosed even before surgery, so we can actually tell the reality of the status of our patients and the chances of recovery. We can't promise something that we cannot back up. We only will offer the truth about their disease.

Diagnosing Endometriosis of the Nerves

Diagnosing endometriosis that involves the nerves is particularly challenging. It often requires a combination of detailed patient history, physical examinations, imaging studies and urodynamic studies.

Another important part of our team is the neurourologist that helps us diagnose our patients status of the micturition reflex before and one month after the surgery in order to see the improvement of the function of this very important reflex (as well as the defecation reflex.

Symptoms such as chronic pelvic pain, irradiation to the legs with or without loss of strength, cyclic sciatica (that becomes even more common with the passage of the years), pain during intercourse, being unable to empty your bladder or bowel, can indicate nerve involvement.

Endometriosis is a nerve centric disease that causes pain for 2 reasons: the inflammatory response releases cytokines that stimulate nerve growth that innervates the nodule, and the enhanced pelvic nociception can contribute to making it easier to transmit the signal of the pain. Also important is the nerve compression caused by the nodules that eventually start to damage the nerve and start losing its function.

Advanced imaging techniques like MRI with special appliances to the exact nerves of interest can help visualize the affected nerves, but often, the definitive diagnosis is made during surgery when the lesions can be directly observed and excised.
The decision of performing or not performing a surgery needs to depend on whether we are actually offering a chance to our patient in life improving. Sometimes the damage to the nerve is too intense and there isn't always something that can be done by surgery but we have other tools in order to help them achieve a life with less pain (and ideally no pain at all).

The Joy of Making a Difference

One of the most rewarding aspects of my job is seeing the transformation in my patients' lives. Many women come to me after years, or even decades, of suffering. Being able to provide relief and improve their quality of life is incredibly fulfilling. The gratitude and positive feedback from my patients reinforce why I chose this path and motivate me to continue advancing my skills and knowledge.

Empathy and Understanding as a Female Surgeon

As a female surgeon, I have a unique perspective on what my patients endure. The physical pain, emotional toll, and often the struggle to be taken seriously by healthcare providers are all aspects I deeply understand and empathise with. This empathy drives me to advocate for my patients, ensuring they receive the comprehensive care and support they need.

Tackling the Most Difficult Cases

One of the most challenging cases I have encountered involved a patient with extensive endometriosis affecting multiple pelvic nerves. The surgery required precise dissection around critical structures to remove the endometriosis while preserving nerve function. The complexity of the case and the stakes involved made it both a daunting and a defining moment in my career. Successfully navigating this surgery and seeing the patient's subsequent recovery was immensely gratifying. Having the support of my team during surgery made the difference (from skilled pelvic surgeons as Dr Cabrera, to our Neurophysiologist Dr Ponce, every surgery is a team effort).

Post-Surgery Care: The Road to Recovery

Before and After nerve surgery, patients require comprehensive care to aid their recovery. This often includes physiotherapy to restore function and mobility, pain management strategies, and sometimes additional treatments such as nerve blocks or neuromodulation.

Regular follow-up appointments are crucial to monitor progress and address any complications promptly. Multidisciplinary care involving physical therapists, pain specialists, and other healthcare providers is essential to ensure holistic recovery. Endometriosis is a systemic disease, we need to work as a team (patient with several doctors); sometimes the nerve damage is so extensive it can take up to 6-12 months in order for the brain to forget about the pain.

Nerve-Sparing Surgery: A Critical Approach

Nerve-sparing surgery is a technique aimed at removing endometriosis lesions while preserving the surrounding nerves. This approach minimises the risk of nerve damage and helps maintain normal function. It requires advanced surgical skills and a thorough understanding of pelvic anatomy. By carefully dissecting around the nerves and using techniques such as live neuromonitoring, minimising coagulating energy, we can achieve optimal outcomes for our patients, reducing pain and improving their quality of life.

Conclusion

Being a female endometriosis excision surgeon, especially one who specialises in nerve involvement, is a role that comes with immense responsibility and reward. Through rigorous training, ongoing learning, and a deep commitment to patient care, I strive to make a difference in the lives of women suffering from this challenging condition. Every successful surgery, every patient who finds relief, and every story of recovery is a testament to the importance of specialised, compassionate care in the fight against endometriosis.

Dr Joanna BUBAK: Unfortunately, in Poland, I observe the same trends as in other European countries. Endometriosis is still diagnosed too late.

ENDOMETRIOSIS DIAGNOSIS

How is endometriosis diagnosed?
Endometriosis presents with a variety of symptoms, which is why conducting a thorough medical interview is crucial for diagnosis. Gynaecologists should recognize both common and rare symptoms. For example, arm pain might indicate diaphragmatic endometriosis, while buttock pain radiating to the leg can suggest sciatic nerve involvement. Secondly, vaginal examination is essential, as endometriotic nodules in the pelvis can be palpated and sometimes even visible in the posterior fornix. Vaginal ultrasound, following standardised protocols like MUSA and IDEA, is typically the next step. All of the above-mentioned steps are often sufficient for diagnosing endometriosis.

Many endometriosis symptoms are found in other diseases as well. How can we differentiate between them?
Sometimes, the diagnosis of endometriosis might be difficult, as the symptoms might be nonspecific. In such cases, if gynaecological examinations and scans don't show abnormalities, the patient should be referred for other consultations. For example, a gastroenterologist might check a patient for SIBO or intestinal dysbiosis, a neurologist for fibromyalgia or sciatica, and an urologist for interstitial cystitis. The treatment of a patient with endometriosis and concomitant diseases should be holistic, involving doctors from various specialties working together.

How is a consultation for endometriosis conducted?
The consultation for endometriosis should resemble a routine gynaecological visit. It should be conducted with respect for the patient and careful listening to her symptoms. Because sometimes it might be difficult for a patient to discuss intimate details like passing stool or intercourse, the doctor should ask appropriate questions to aid in diagnosis. All steps of the vaginal examination as well as ultrasound should be explained by a doctor. It's also important to remember that touching an endometriotic nodule during examination might cause discomfort or pain, so communication between the patient and the doctor is crucial for such examinations.

What can be done when a patient has no visible endometriosis on scans, but they have symptoms?
Each patient with symptoms of endometriosis should be under the direct supervision of an endometriosis specialist. If current scans show no endometriosis, it doesn't definitively rule out the diagnosis. Some visible signs in scans might appear months or even years later after the onset of endometriosis. For this reason clinical examination as well as ultrasound scans should be repeated. There are also available noninvasive tests, such as checking salivary miRNA or serum BDNF, which might be helpful in such situations, but further large cohort studies and analyses are needed. In some cases, laparoscopy with excision of superficial lesions might be recommended.

When is the MRI indicated?
Protocols for diagnosing endometriosis might differ slightly between centers. Some specialists choose ultrasound scanning, while others prefer MRI exams. However, there are clear indications for performing MRI. The first one is extrapelvic endometriosis, such as diaphragmatic endometriosis. The second case includes patients with suspicion of small bowel endometriosis. MRI is also necessary when symptoms suggest nerve involvement, like sciatic endometriosis. In other cases, the diagnosis can be made based on either ultrasound or MRI, or both methods when deeper structures are involved.

> In schools, nobody mentions endometriosis, and even in medical universities, not much is said about this disease. However, I see some positive changes. During my last years in my practice, I encounter more younger women who come for their visits because they are aware of endometriosis.

Transvaginal scans: how accurate are they in diagnosing endometriosis?
Diagnostic accuracy for endometriosis varies according to different exams. That's why uniform criteria were created. Following the steps of the International Deep Endometriosis Analysis (IDEA), the sensitivity can reach 92%, but it depends on the localization of the endometriosis. The lowest sensitivity is found in the septum and vagina, while the highest is in the ovaries and rectum. MRI shows similar sensitivity, with results depending on nodule localization too.

In some countries the MRI is indicated as a way of diagnosing and in other parts they say surgery is the best option. Why the difference?
MRI, as well as ultrasound, is a complementary diagnostic method, meaning that some endometriotic lesions may not be detected during preoperative diagnosis. This particularly applies to nodules located in the small bowel or superficial lesions of the peritoneum. In such cases, surgery might be the best option for detection. However, the best practice is to perform any imaging test to plan the extent of the surgical procedure, explaining as well to the patient that it might change during surgery

In teenagers that are not sexually active, how can we diagnose endometriosis?
Adolescent endometriosis is a challenging problem. Studies show that before a final diagnosis, teenagers will visit at least three doctors. The diagnosis should start with a detailed medical and family history. The second step should be a pelvic examination. For teenagers who are not sexually active, transrectal sonography is recommended. However, from my daily practice, I would suggest preparing such a young person for this examination by explaining what to expect. Magnetic resonance is also a good option. Unfortunately, in some countries, the high costs make it less accessible.

Adenomyosis is a condition that is often diagnosed with endometriosis. Can ultrasound be used to diagnose adenomyosis?
Adenomyosis and endometriosis are closely related, as the pathophysiology is extremely similar. Both can also be diagnosed by ultrasound. The diagnosis of adenomyosis is systematised by MUSA (Morphological Uterus Sonographic Assessment) criteria, which describe direct and indirect features of adenomyosis.

Uterine fibrods; symptoms, diagnosis and treatment

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What are fibroids and what are their causes?
Uterine fibroid, also known as uterine myoma or leiomyoma, is a benign (non-cancerous) tumor that develops in the uterine muscle. This is the most common type of non-cancerous tumor in women during their reproductive years. Uterine fibroids can range in size from small nodules that cause no symptoms to large tumors that can cause serious complications.

The exact causes of uterine fibroids are not fully understood, but there are certain factors that can influence their development:

1. Hormonal:
2. Genetic:
3. Race:
4. Other environmental and lifestyle factors:

How many types of fibroids are there and which ones can cause complications?
There are several types of uterine fibroids, which are classified according to their location in the uterus and how they affect the structure of the uterus. The three main types are:

Subserous: Subserous fibroids grow on the outside of the uterus and develop towards the peritoneum, which is the outer layer of the uterus. These fibroids rarely cause symptoms and usually do not interfere with the normal functioning of the uterus.

> **Large subserous fibroids can put pressure on other surrounding organs and cause discomfort.**

Intramural: Intramural fibroids develop in the thickness of the uterine muscle and are the most common type of uterine fibroids. They can grow in size and cause symptoms such as increased menstrual pain and heavy menstrual bleeding.

Large intramural fibroids can affect the structure of the uterus and interfere with its ability to contract properly during pregnancy.

Submucosal: Submucosal fibroids develop under the uterine lining and can grow inside the uterine cavity. They can cause heavy menstrual bleeding, pelvic pain, and pregnancy complications, such as miscarriage or an increased risk of premature birth. Submucosal fibroids can also affect the ability of the uterus to support a pregnancy, causing difficulty in conception or repeated miscarriages.

Submucous fibroids are most likely to cause complications, especially if they are large or in a position that affects the structure of the uterus or interferes with its function. However, each type of uterine fibroid can cause problems depending on its size and location, and symptoms may occur that require medical treatment or surgery.

Being a condition of the uterus, how can it be diagnosed more accurately? Is biopsy recommended for diagnosis?

The diagnosis of uterine fibroids is made by ultrasound (2D or 3D) in the highest percentage. In certain circumstances, another type of imaging or interventional investigation is necessary to diagnose the relationships of this tumor formation with the tissues around it.

Medical imaging can be used to visualize the structure of the uterus and detect abnormalities. These images can provide detailed information about the size, location and characteristics of the tumor.

Hysteroscopy can be helpful in diagnosing and treating certain submucosal fibroids or other uterine abnormalities.

For uterine fibroids, biopsy is not always necessary because they are generally benign. However, if there is uncertainty about the diagnosis or in case of atypical symptoms, biopsy may be recommended to rule out other types of malignant fibroids (such as sarcoma).

In case of a pregnancy obtained with a fibromatous uterus what are the possible complications?

Pregnancy with a fibroid uterus can be associated with certain complications and risks, depending on the size, location and number of fibroids, as well as other specific characteristics of each case. Some of the complications may include:

Miscarriage: Fibroids can affect the implantation and development of the embryo in the uterus, increasing the risk of miscarriage, especially in the case of submucous fibroids that grow inside the uterine cavity.

Increased risk of premature birth: Fibroids can cause changes in the structure of the uterus and affect its ability to dilate properly during pregnancy, increasing the risk of premature birth.

Increased risk of abnormal fetal presentation: Large uterine fibroids can occupy space in the uterus and prevent the fetus from positioning correctly for birth, increasing the risk of abnormal fetal presentation, such as breech or transverse position.

Increased risk of complications during labor and delivery: Fibroids can affect the contractility of the uterus and cause labor to be longer or more difficult. They can also increase the risk of complications such as uterine rupture or excessive bleeding during childbirth or in some cases of blocking the birth canal (Fibroid Praevia).

Abnormal uterine bleeding: Fibroids may be associated with abnormal uterine bleeding during pregnancy, which may require monitoring and medical treatment.

What role can hysteroscopy play in the case of fibroids?

Hysteroscopy is a medical procedure used to diagnose and treat certain uterine pathologies. In the case of uterine fibroids, hysteroscopy can have several important roles:

1.**Diagnosis**: Hysteroscopy can help diagnose submucosal fibroids, which grow inside the uterine cavity and can cause symptoms such as abnormal uterine bleeding or infertility. During a hysteroscopy, the doctor can directly visualize the uterine cavities and identify fibroids or other uterine abnormalities.

2. **Evaluation of the location and size of fibroids:** Hysteroscopy can provide detailed information about the location and size of submucosal fibroids. This information is important for planning appropriate treatment and determining whether fibroids are likely to cause complications during pregnancy or childbirth.

3. **Biopsy**: In some cases, hysteroscopy can be used to take biopsies of tissue from inside the uterine cavity. This can be helpful to confirm the diagnosis of uterine fibroids or to rule out other conditions such as endometrial cancer or uterine sarcoma.

4**. Treatment:** In addition to its diagnostic role, hysteroscopy can also be used for the treatment of submucous fibroids (all types in the FIGO classification from 0 to 4). Therapeutic procedures such as hysteroscopic myomectomy or endometrial ablation may be performed during hysteroscopy to remove fibroids or treat abnormal uterine bleeding associated with them.

Personally, I have a lot of experience in the treatment of submucosal fibroids by hysteroscopic means, being considered advanced hysteroscopy, and I recommend that a patient who has this type of intervention be performed only by doctors with experience in this type of treatment.

When these coexist with other conditions such as endometriosis and adenomyosis, how can we differentiate between the symptoms?

Differentiating the symptoms associated with uterine fibroids, endometriosis, and adenomyosis can be difficult because these conditions can have significant overlap in the symptoms they cause.

However, there are some specific differences that can help identify each condition:

Uterine fibroids:

- Typical symptoms include pelvic pain or pressure, heavy menstrual bleeding (menorrhagia), pain during intercourse, and feeling of fullness or discomfort in the lower abdomen.
- Fibroids can also cause symptoms related to compression of nearby organs, such as the bladder (causing a frequent need to urinate) or the rectum (causing constipation or rectal pressure).
- Symptoms may be more pronounced during menstruation or pregnancy.

Endometriosis:

- Characteristic symptoms include severe pelvic pain, often located in the lower pelvic area or behind the pelvis, which may be present during menstruation, before or after intercourse, or during bowel or urinary movements.
- Other symptoms may include abnormal menstrual bleeding, infertility, chronic fatigue, and abdominal or intestinal discomfort.

Adenomyosis:

- Common symptoms include intense pelvic pain and severe menstrual cramps, which may be more severe than those normally experienced during menstruation.
- Adenomyosis can also cause heavy menstrual bleeding (menorrhagia), pain during intercourse, and sometimes pelvic pressure or discomfort.
- Symptoms may be more pronounced during menstruation and may be associated with changes in the menstrual cycle, such as longer periods or breakthrough bleeding.

How can uterine fibroids be treated?

Treatment of uterine fibroids can vary depending on the severity of the symptoms, the size of the fibroids, the patient's age and her desire to become pregnant. Some treatment options include:

1. Active monitoring
2. Medication
3. Surgical intervention: myomectomy or hysterectomy.
4. Non-surgical procedures such as:

Embolization of uterine arteries.
Radiofrequency myolysis.
HIFU (ultrasound therapy) High-intensity focused ultrasound (HIFU).

> **Non-surgical procedures are not 100% recommended for infertile or childless patients.**

The treatment of uterine fibroids must be individualized according to the needs and preferences of each patient, and the decision about the most suitable treatment plan must be made together with a specialist doctor.

Is there a risk of malignant transformation?

Yes, there is a very small risk of uterine fibroids turning into a form of cancer called uterine leiomyosarcoma. However, it is important to emphasize that this transformation is extremely rare. Uterine leiomyosarcoma is a rare form of uterine cancer and is much less common than benign uterine fibroids.

Most uterine fibroids are benign and do not have a significant risk of turning into cancer. However, it is important to monitor your symptoms and undergo regular check-ups to detect any suspicious changes in the fibroids or to assess the risk of cancer.

In the case of myomectomy, is it recommended to morcellate them in a special bag, to prevent the spread?
Yes, in the case of laparoscopic myomectomy, it is recommended to morcellate them in a special bag called ENDOBAG to minimize the risk of fibromatous tissue spreading into the abdominal cavity and to reduce the risk of postoperative adhesions.

Morcellation of fibroids in the endobag prevents direct tissue contact with the abdominal wall and adjacent organs, which may reduce the risk of adhesion formation and spread of tumor cells within the abdominal cavity to reduce the risk of dissemination within the abdominal cavity if it contains islets of sarcomatized cells.

This technology helps improve the safety and effectiveness of laparoscopic myomectomy, reducing the risk of postoperative complications and facilitating patient recovery.

> **It is important that this technique is performed by a surgeon experienced and qualified in laparoscopic myomectomy to ensure a correct and effective procedure.**

What happens to uterine fibroids at menopause?

During menopause, a woman's hormone levels change significantly, and this can have an impact on uterine fibroids. Uterine fibroids usually tend to shrink and stop causing symptoms during and after menopause. This is due to the drop in estrogen and progesterone levels in a woman's body during menopause.

As hormone levels drop, uterine fibroids, which are sensitive to estrogen and progesterone, may begin to shrink and shrink in size. Symptoms associated with fibroids, such as pelvic pain or heavy menstrual bleeding, may also decrease or disappear completely during menopause.

However, it is important to point out that menopause will not affect all uterine fibroids in the same way. Some fibroids may continue to grow or remain unchanged even after menopause. Fibroids can also react differently to hormonal changes and the effects of menopause depending on the size, location and individual characteristics of each fibroid.

It is important that women continue to monitor themselves and talk to their doctor about any changes in symptoms or the size of fibroids during and after menopause. Even though fibroids may stop causing obvious symptoms, it is important to monitor them for any complications or significant changes that may require medical evaluation and management.

RYEQO FOR THE TREATMENT OF ENDOMETRIOSIS-ASSOCIATED PAIN

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> **Ryeqo is a newly-introduced combination therapy for endometriosis-related menstrual pain, or so-called “Dysmenorrhea”. The term dysmenorrhea refers to lower abdominal – and to some extent back - pain that occurs during menstruation.**

To perfectly understand the mechanism of action of Ryeqo, a good understanding of the female endocrine physiology and the pathogenic processes of endometriosis is fundamental. In normal healthy conditions, the hormonal function of the ovaries is regulated by the pituitary gland and the hypothalamus. The hypothalamus is the lower part of the brain. It regulates the secretory function of the pituitary gland through a hormone called: “Gonadotropin-Releasing Hormone” abbreviated as “GnRH”.

Once the GnRH reaches the pituitary gland, it binds to specific receptors in it and activates them. This process stimulates the pituitary gland to release two hormones into the bloodstream: The Follicular-stimulating Hormone (FSH) and the Luteinizing Hormone (LH). FSH is mainly released during the first phase of the menstrual cycle “the follicular phase” and LH is released during the last 14 days of the menstrual cycle “the luteal phase”.
Once the FSH reaches the ovaries, it provokes in turn the secretion of the gonadal estrogen. Estrogen induces the proliferation and growth of the endometrium (the innermost layer of the uterus) and endometriosis.

Once the menstrual cycle comes to an end, the circulatory levels of the estrogen and progesterone decrease, which induces menstruation.

On the endometriosis level, this induces bleeding of the lesions in a way similar to the normal endometrium. The aforementioned process occurs monthly and is thought to provoke the intense cyclic symptoms of endometriosis. During the premenopausal years, the ovarian production of estrogen is decreased gradually to reach its lowest blood concentration in menopause. This hypoestrogenic environment in menopause is believed to be the main reason for the sharp decline in endometriosis and its related symptoms in postmenopausal patients.

On this basis, achieving medically menopause-like concentrations of estrogen is believed to suppress endometriosis and its related symptoms. This therapeutic approach is called “medically-induced menopause” and could be achieved through two drug groups: The GnRH agonists (mimickers) and the GnRH antagonists (inhibitors).

Although the mechanism of action of both drug groups is different, both medications when administered in the correct dosages reduce the circulatory estrogen levels to menopause-like concentrations. It should be noted that medically-induced menopause is not permanent and could be reversed by stopping the administered medication.

Now back to our main topic, Ryeqo is a relatively new medication administered orally once daily (one pill per day). Each tablet of Ryeqo consists of three pharmacological substances: Relugolix 40mg, Estradiol 1 mg, and Norethindrone acetate 0.5 mg. The administration period of Ryeqo is not specified and it could be taken without interruption.

> **Relugolix is the main acting substance of Ryeqo and it is classified as a GnRH antagonist**

Relugolix binds reversibly to the GnRH receptors on the pituitary gland and impedes the pituitary secretion of FSH and LH. This leads to a menopausal-like status due to the suppression of ovarian estrogen production. However, to prevent the menopausal symptoms from happening, synthetic estrogen (estradiol 1 mg) and progesterone (Norethindrone acetate 0.5 mg) were incorporated into the tablets. These doses of estradiol and norethindrone acetate are thought to keep the circulatory estrogen levels higher than the threshold that induces the menopausal symptoms and lower than the threshold that activates endometriosis.
The efficiency and safety of the Relugolix combination therapy (or Ryeqo as commercialised in Europe) were investigated in two large replicated studies called SPIRIT 1 and The studies included more than a thousand patients with endometriosis and compared the administration of Ryeqo to the administration of empty pills (placebo) for 24 weeks.

At the end of the study, 75% of patients treated with Ryeqo had a significant decrease in dysmenorrhea in comparison to 27-30% of patients treated with the placebo. The dysmenorrhea intensity was reduced by 73-75% and the intermenstrual pelvic pain intensity was reduced by 49-50% in patients treated with Ryeqo. In the abovementioned studies, Ryeqo stopped menstruation in most of the treated patients. However, almost one month after the suspension of Ryeqo, the menstrual cycle resumed normally. It should be noted that the effectiveness of Ryeqo as a contraceptive medication is currently under investigation.

The drug was well-tolerated by the patients and the most common side effects were headache (27-39% of patients), nasopharyngitis (6-14% of patients), and hot flashes (10-14% of patients). The effect of Ryeqo on bone mineral density was minimal and could be described as “clinically irrelevant”.

It should be noted that all hormonal treatments for endometriosis are suppressive rather than “cytoreductive”. This means that hormonal treatments “switch off” endometriosis and its associated symptoms, but they do not remove the endometriotic lesions from inside the body. The same goes for Ryeqo since it suppresses endometriosis by decreasing the blood levels of estrogen, rather than acting on the endometriotic lesions themselves. Therefore, the recurrence of endometriosis-related pain is very likely to happen once the intake of Ryeqo is suspended, as it is for all the available hormonal therapies.

Although endometriosis has been known for more than 150 years, only recently, the disease has attracted attention and more studies are being published in the field. On the other hand, the lack of accurate and non-invasive diagnostic tests makes recruiting patients in clinical trials and observational studies hard. In addition, research on endometriosis-related pain and infertility takes a long time and sometimes it is hard to follow up with the patients. The ethical aspects are always controversial whenever research on pain and infertility is conducted. For these reasons, most of the available studies on endometriosis are of limited value due to the difficulty –and sometimes the impossibility- of performing robust studies.

Menstruation is normal. Debilitating pain is

NOT

One in ten women is affected by **endometriosis**.
Many of them are also **infertile**.

If you experience serious menstrual pain, your gynecologist should check whether you suffer from ENDOMETRIOSIS.

An awareness campaign of the SOS INFERTILITATEA ASSOCIATION
www.sosinfertilitatea.ro

“From a histopathological perspective, there are several differences between endometriosis and the normal endometrium”

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What is histopathology and why is it important in endometriosis diagnosis?
Histopathology plays a crucial role in the diagnosis of endometriosis. It involves the microscopic examination of tissue samples to identify the presence of characteristic features associated with the disease. Endometriosis is a gynecological condition where endometrial-like tissue, similar to the lining of the uterus, is found outside the uterine cavity. Histopathology allows for the accurate identification and confirmation of endometriosis lesions, enabling appropriate diagnosis and subsequent management.

How is the histopathological diagnosis of endometriosis made?
To make a histopathological diagnosis of endometriosis, tissue samples are obtained during surgery, typically through laparoscopy. The samples are then processed, embedded in paraffin, thinly sliced into sections, and stained for microscopic examination. The histopathologist examines these sections under a microscope to identify the presence of endometrial glands and stroma outside the uterus, which are the defining features of endometriosis. The diagnosis is confirmed when these characteristic structures are observed in the tissue samples.

If the diagnosis is unclear, what other tests can be done?
In cases where the histopathological diagnosis of endometriosis is unclear or if the lesions lack one of the components (glands or stroma), additional tests can be performed to aid in the diagnosis. These tests may include immunohistochemistry, which involves using specific antibodies to detect markers associated with endometriosis.
Immunohistochemistry can help differentiate endometriosis from other conditions that may have similar microscopic features.

> “
> The main distinction between endometriosis and endometrium lies in the location of these tissues.

Under a microscope endometriosis is made of glands and stroma. In what conditions these two components can be altered or missing?
Under certain conditions, the glands and stroma in endometriosis lesions can be altered or even missing, making the diagnosis challenging.
For example, in cases of long-standing endometriosis, the glands may become cystically dilated or filled with hemosiderin pigment, leading to changes in their appearance. In some instances, endometriosis lesions may undergo fibrosis or scarring, where the stroma becomes dense and collagenous.

> Despite these alterations, experienced histopathologists can often recognize the characteristic features of endometriosis based on the presence of atypical glandular structures or the identification of other associated features.

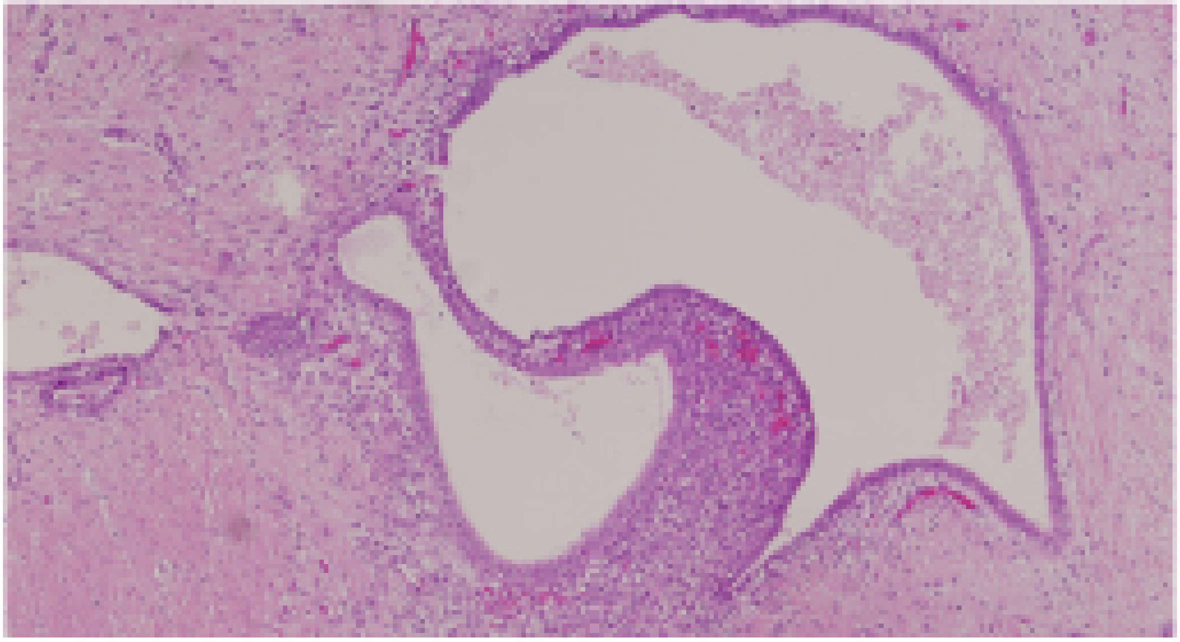
Endometriosis is considered to be endometrial tissue outside the uterine cavity, although various tests have shown differences between them two. From a histopathological point of view, what are the main differences between endometriosis and endometrium?
From a histopathological perspective, there are several differences between endometriosis and the normal endometrium. The main distinction lies in the location of these tissues. The endometrium is the lining of the uterine cavity and exhibits cyclical changes in response to hormonal fluctuations. In contrast, endometriosis is characterized by the presence of endometrial-like tissue outside the uterus, which does not respond to hormonal changes in the same way as the endometrium. Additionally, endometriosis lesions can display a variety of structural and cellular alterations compared to the normal endometrium

Can we have false positives or false negatives in endometriosis?
In the histopathological evaluation of endometriosis, false positives and false negatives are possible but relatively rare. False positives may occur when benign conditions mimic endometriosis histologically, emphasizing the importance of correlating clinical and histopathological findings. False negatives can occur if the samples obtained during surgery do not include areas of endometriosis, especially in cases where the lesions are small or located in challenging anatomical sites.

Is immunochemistry a test that can be used in endometriosis diagnosis?
Immunohistochemistry is a valuable adjunctive test in the diagnosis of endometriosis.

It involves the use of specific antibodies to detect markers associated with endometriosis, such as estrogen and progesterone receptors, CD10, and others. Immunohistochemistry can help differentiate endometriosis from other conditions and provide additional supportive evidence for the diagnosis. However, it should be noted that immunohistochemistry is not used as a standalone diagnostic tool but rather as a supplement to the histopathological examination.

Ovarian endometriomas are diagnosed in the same way as other types of endometriosis?
The diagnosis of ovarian endometriomas, which are cystic lesions filled with endometriotic tissue, follows a similar histopathological approach as other types of endometriosis. The cyst wall and its contents are examined microscopically to identify the characteristic features of endometriosis, such as glands and stroma. In some cases, the cyst wall may show additional changes, such as fibrosis or inflammation, which can be seen in long-standing or complicated endometriomas.



Biopsy Specimen shows benign looking endometrial glands, stroma and adipose tissue within a background of connective tissue. Low power view (H&E staining x 10 magnification)
Source: EC Gynecology.

What is the difference between intra-operative histological examination and post-operative? Which one of them is more accurate?
Intra-operative histological examination, also known as frozen section analysis, involves the rapid processing and microscopic evaluation of tissue samples during surgery. It provides immediate feedback to the surgeon regarding the presence of endometriosis or other pathologies, allowing for real-time decision-making. However, frozen section analysis has limitations, including potential artifacts and sampling errors, which may affect its accuracy.

Post-operative histological examination, on the other hand, involves the routine processing and thorough examination of tissue samples after formalin fixation. It allows for a more comprehensive evaluation of the entire specimen, providing a detailed diagnosis. Overall, post-operative histological examination is considered more accurate than intra-operative analysis due to its meticulous processing and evaluation.

Do endometriosis lesions alter/change in time? For example in a patient that was diagnosed with endometriosis in their 20's but undergoes surgery 10 years later, are there any notable differences in the examined tissues?
Endometriosis lesions can exhibit changes over time, especially in response to hormonal fluctuations and therapeutic interventions. In some cases, the lesions may regress or become less active, while in others, they may grow or develop new areas.

Additionally, surgical interventions, such as excision or ablation of endometriosis lesions, can alter the appearance of the tissue. Therefore, when a patient undergoes surgery for endometriosis after a significant time interval, there may be notable differences in the examined tissues compared to the initial diagnosis. These differences can include changes in the size, activity, or architectural features of the lesions. Histopathological evaluation of the surgical specimens provides valuable information about the current status of the disease and helps guide further management decisions.

Careful sampling and consideration of clinical information are crucial to minimize the risk of false negatives.

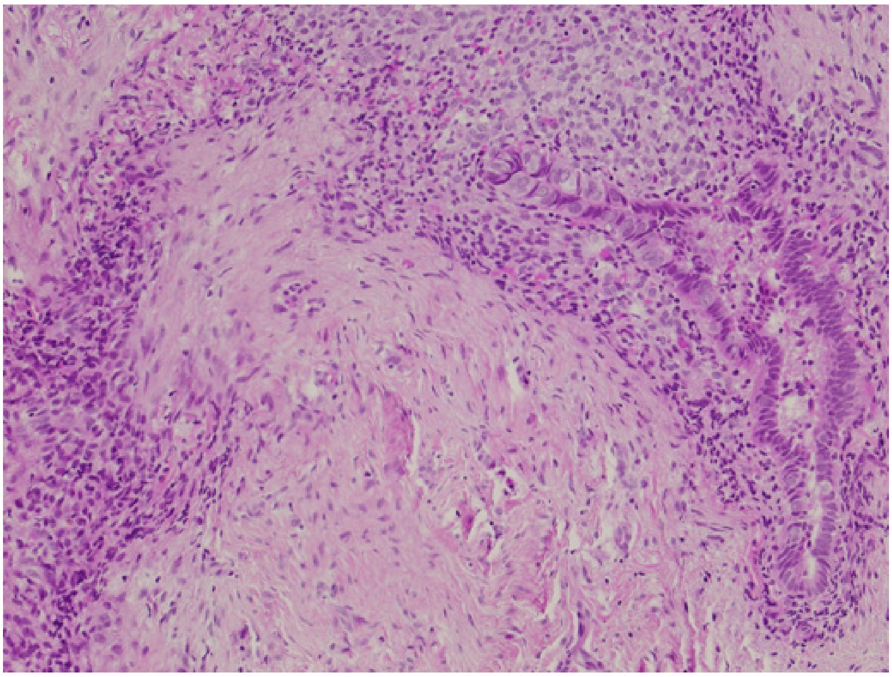
Many patients have endometriosis in multiple locations. Do all need to be sent to the lab, or it's up to the surgeon to decide what to send?

In cases where multiple locations of endometriosis are suspected or identified during surgery, it is generally recommended to send representative samples of each lesion to the laboratory for histopathological examination. This approach ensures a comprehensive evaluation of the disease extent and helps confirm the diagnosis in different anatomical sites. By examining multiple lesions, the histopathologist can assess the variability in morphological features and provide important information regarding disease severity, activity, and associated findings.

Can surgery make samples hard to diagnose? For example the use of an electrocauter.

Surgery techniques, such as the use of electrocautery, can potentially affect the histopathological diagnosis of endometriosis. Electrocautery involves the application of electrical current to tissue for cutting or coagulation purposes. While it can be an effective tool during surgery, it can cause thermal artifacts and tissue alterations that may affect the interpretation of histopathological findings.

For example, electrocautery can cause tissue necrosis, charring, or alteration of cellular morphology, making it challenging to distinguish between normal and pathologic structures. Therefore, it is important for the surgeon to use cautery judiciously and for the histopathologist to be aware of the potential artifacts associated with electrocautery when interpreting the tissue samples.



Biopsy Specimen shows unremarkable endometrial glands and stroma, adipose and fibrous tissue.
High power view (H&E staining x 20 magnification).
Source: EC Gynecology

Ovarian Endometrioma Unpacked: Causes, Diagnosis and Treatment

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> **Among the many manifestations of endometriosis, ovarian endometriomas, often referred to as "chocolate cysts" due to their contents of dark old accumulated and degraded blood products, are particularly troublesome. They are quite common, occurring in 20-45% of women with endometriosis and can result in increasing pain and an additional impact on fertility. In contradistinction, extra-ovarian endometriomas are very rare. The genesis of endometriomas is tightly related to the broader condition of endometriosis.**

Endometriosis Formation Theories Relation to Ovarian Endometriomas

The exact cause of endometriosis is poorly understood. Commonly quoted theories include retrograde menstruation, coelomic metaplasia, embryologic Müllerianosis and lymphatic or hematogenous spread.

More recently we are beginning to understand multi-gene influences on these processes and multiple environmental factors that turn relevant genes on and off via epigenetic controls. Keep in mind that environmental factors are not just diet, exercise habits and toxin exposure, but also stress and mind-body interactions.

The development of ovarian endometriomas probably involves additional unique mechanisms such as invagination of the ovarian cortex after endometriotic cell surface implantation, compounded by repeated bleeding into these invaginated areas and resulting blood-filled cyst formation.

Deeper endometriomas may be due to other mechanisms such as lymphatic translocation of endometriosis cells into the ovarian stroma.

Growth and Location of Endometriomas

Ovarian endometriomas are lined by active endometriosis and possibly related stem cells, which may increase the number of active cells within the cysts. They are filled with degraded blood because the endometriosis cells keep bleeding into the cyst cavity and there is no escape for this blood. Thus, unless they leak, they continue to grow in size. Although endometriomas are primarily associated with the ovaries, endometriosis can occur anywhere in the body.

This includes locations like the abdominal wall, thoracic cavity, and even the umbilical region. Endometriomas may rarely form in any of these areas, usually associated with deep infiltrating endometriosis that also continually bleeds into nearby tissues.

Symptoms Specific to Endometriomas

Endometriomas can cause increased pain beyond endometriosis, especially during menstrual cycles. This is because their presence is often associated with a greater amount of disease and more adhesions, which can lead to increasing peritoneal irritation, inflammation, reactive fibrosis and more pain.

At some point endometriomas can leak and this fluid can compound the inflammation. Endometriomas can also contribute to non-cyclic chronic pelvic pain, dyspareunia, and are commonly associated with worsening subfertility.

Diagnosis of Ovarian Endometriomas

An ultrasound is often the first imaging test used to look for endometriomas. It's a non-invasive procedure that uses sound waves to create a picture of your ovaries. On an ultrasound, endometriomas may appear as fluid-filled cysts with a distinctive, "ground glass" appearance.

The more there are solid structures present and the more there is significant blood flow to these structures, all assessable by ultrasound, the more it may not be an endometrioma but rather a tumor, benign or malignant.

If the diagnosis is still unclear after an ultrasound, or if more detailed images are required, a Magnet Resonance Imaging (MRI) scan may be recommended. An MRI provides a much more detailed image than an ultrasound and can be particularly helpful if surgery is being considered.

The reason is that it can also look for associated findings like deep infiltrating lesions, adenomyosis and related anatomic details for surgical planning. If an MRI is ordered it should ideally be a 3-Telsa (3-T) which uses as a stronger magnet and results in more precise images.

Classification of Ovarian Endometriomas
Endometriosis is generally classified by the depth, extent, and location of endometriosis cell implants.

Ovarian endometriomas are additionally categorized based on their size, degree of endometriosis cell implants and the severity of the fibrotic encapsulation.

This classification aids in determining the surgical approach and potential complications during surgery. The larger the cyst, the more invasive the endometriosis implants are, and the more fibrosis is present, the harder it is to completely excise these without destruction of normal ovarian tissue.

> **A special category is that of "kissing ovaries", a finding on imaging where the ovaries are touching each other (often with multiple endometriomas) deep in the pelvis (cul-de-sac). This is not an official classification but portends probable extensive deep pelvic endometriosis. Practically, this should serve as a warning that the surgery will likely be challenging and that a higher level of expertise would be prudent to seek out.**

Surgical Intervention Criteria

The gold standard for diagnosis is minimally invasive laparoscopic or robotically assisted laparoscopic surgery. This is because surgery allows for a definitive pathologic diagnosis and allows for concurrent treatment intervention, which focuses on excision of all endometriosis lesions, including the endometrioma(s).

The more complex the surgery is anticipated to be (it can be quite unpredictable) the more robotic surgery allows for better precision than laparoscopy due to superior magnified 3-D optics and wristed instruments (like tiny human hands) that are more delicate.

Surgical intervention for ovarian endometriomas is typically considered when they cause significant pain, are suspected to be malignant based on imaging, interfere with fertility, or when their size and growth dynamics suggest increasing potential complications. The decision to operate also depends on patient-specific factors including age, symptoms, other medical conditions, and desire for fertility.

Some guidelines suggest surgery for endometriomas which are 6cm or larger. However, this is controversial because only about two to three percent of patients with an endometrioma have disease limited to the ovary. Put another way, upwards of 40% have extraovarian endometriosis, including deep infiltrating disease. All of these diseases require attention and generally continue to grow, creates fibrosis and causes symptoms. So, care must be individualized.

Managing Surgical Risks

First of all, the presence of an endometrioma signals greater overall disease which may be causing other organs and structures like bowel, bladder and ureters to be bound together in dense inflammatory adhesions and fibrosis or scarring. This means the surgery is highly likely to be complicated and risk of complications increases significantly, mandating expert surgeons who can handle anything that is found, including bowel resection and repair.

During surgical removal, it is prudent to prevent or at least reduce the spillage of cyst contents, which can exacerbate inflammatory responses or seed new implants. It bears repeating that the fluid inside the cysts is not just old blood but active endometriosis cells which can grow elsewhere if they escape.

> **Techniques involve careful cyst excision and the use of preemptive controlled drainage, barriers, such as containment bags, and, if leakage occurs, washes to minimize the risk of dissemination.**

Surgical Outcomes

While general statements can be made, exact outcomes in an individual will vary widely. It depends on what is actually found during surgery, the skill of the surgeon, the equipment available, and the goal. Fertility outcomes are generally improved after endometrioma resection and pain can be significantly reduced.

However, what is removed (e.g. how much ovarian tissue, whether not the closely apposed Fallopian tubes are damaged, if all visible endo can be excised or not) will affect desired outcomes. Generally, one measure of ovarian reserve is the Anti-Mullerian hormone (AMH) level. It is not a perfect test but can suggest how much reserve is available before surgery.

AMH will almost always decrease after surgery but in most situations will normalize to preoperative levels after three to nine months. Recurrence of endometrioma will differ depending upon what is done but over the ensuing two years it can be as low as 6% and climbs to over 30% after seven to eight years.

Nonsurgical Options

An individualized assessment is certainly very important, and a lot of factors come into play that might lead to at least a temporary non-surgical approach. Of note, there are no non-surgical mainstream medical or alternative holistic methods that can eliminate endometriomas.

Watchful waiting involves regular monitoring without immediate medical or surgical intervention. It's often chosen when symptoms are mild or when surgery is not an option for whatever reason, including medical conditions that may place a patient at high risk for surgery. Hormonal therapies can help control the growth of endometriosis tissue and alleviate symptoms, but they are not suitable for those trying to conceive and they will not eliminate endometriosis or endometriomas.

Pain management, including the use of nonsteroidal anti-inflammatory drugs (NSAIDs), can help manage symptoms. Of course, there are other pain management techniques including pelvic floor physical therapy (with precautions to not rupture a larger endometrioma), acupuncture, heating and electrical stimulation units. However, these are all just short-term temporizing measures that mainly just limit symptoms.

Follow-up

The frequency of screenings for endometriomas varies depending on individual factors such as your treatment history, symptoms, and overall health. Generally, ultrasound every six to twelve months is prudent but can be highly variable.

If fertility is the main concern it's important to work closely with a fertility specialist. They can help you understand the potential challenges and explore options such as in vitro fertilization (IVF) if needed.

Conclusion

The management of ovarian endometriomas requires a comprehensive and very personalized approach that considers not just the endometrioma but also the extensive systemic nature of endometriosis and all of its potential manifestations. For all of the reasons listed in this article, obtaining expert consultation is very prudent. Surgical training varies between countries but in most cases expert endometriosis consultants have obtained additional training beyond general gynecology residency.

Egg freezing before endometriosis surgery

Elias Tsakos MD, FRCOG
Medical Director of Embryoclinic - Assisted Reproduction Clinic in Thessaloniki, Greece.

Endometriosis is yet not fully understood as a condition, nor its implications for fertility. As a result, the optimal management of the endometriosis patient in the context of fertility is still being studied.

Endometriosis is a disease that can impact all aspects of one’s life. Can you explain to us how fertility is affected?

Endometriosis negatively affects fertility in a multitude of ways. Firstly, it exerts a direct effect on ovarian function; causing slower follicular development, smaller dominant follicle size and inflammation-induced increase in oxidative stress in the ovary, leading to cellular degeneration and oocyte impairment.

Secondly, it affects fallopian tube function via effects on tubal epithelium function and peri-tubal adhesion formation. Thirdly, it affects embryo implantation in the endometrium, impairing the expression of necessary cellular proteins. Finally, it has even been shown to affect sperm function and integrity within the uterus, thus impairing conception.

One of the myths is that pregnancy cures endometriosis. What happens with endometriosis during pregnancy?

Indeed, this is a myth that arose due to some initial positive observations, combined with a lack of effective treatment options at the time, leading to its propagation. The available evidence unfortunately comes from few, small, heterogeneously designed studies and has shown a variable response of endometriosis to pregnancy, from exacerbation to regression, with likely relapse of symptoms after pregnancy, not to mention several endometriosis-related obstetrical complications risk.

Both endometriosis and surgery can impact fertility. In terms of surgery, what is the impact on fertility?

Unfortunately, due to the wide spectrum of potential endometriosis loci, severity and progression speed, a single answer cannot cover all cases. Practice guidelines do not recommend routine application of surgery, as research has not revealed a consistent positive effect on fertility, with a potential negative effect on ovarian reserve in the case of ovarian endometrioma, pointing out, however, its beneficial effect in selected cases.

In your experience when is egg freezing recommended in women with endometriosis?

Egg freezing may be performed in the presence of endometriosis, ovarian endometrioma in particular, given the severe impact on oocyte reserve.

> **Pregnancy therefore should not be the answer in modern endometriosis care.**

Egg freezing is an option that many women are going for, either due to age or due to illness. In your experience when is egg freezing recommended in women with endometriosis?
Egg freezing may be performed in the presence of endometriosis, ovarian endometrioma in particular, given the severe impact on oocyte reserve. Whether this is the best option for a woman depends on the severity of the underlying condition and her family plan. For cases of severe endometriosis and particularly for bilateral endometriomas, due to the increased risk for premature ovarian insufficiency, oocyte freezing should be considered if the woman wishes to delay childbearing for the foreseeable future.

One of the key factors in having a successful pregnancy is the quality of eggs. If we do egg freezing in an endometriosis patient that has endometriomas before surgery, will the quality of the eggs be affected?
Endometriomas greatly affect oocyte reserve and quality on their own, even without the potentially damaging effect of surgery. Therefore, oocyte number and quality may be lower compared to women without endometriomas. However, data from the single large retrospective study on the topic to date have indicated that it is a viable option with acceptable reproductive outcomes.

How soon after surgery, the embryo transfer can take place?
Typically, with modern minimally invasive surgical techniques, complete recovery may be achieved within 2 to 4 weeks and thus preparations for embryo transfer may begin as early as that. However, one should keep in mind the variability of endometriosis severity, which in turn affects the extent of the surgery, not to mention the impact of additional comorbidities that the patient may have, ultimately resulting in the extension of the required recovery time in some cases.

When eggs are collected before surgery, is it better to have them fertilised and freeze the embryos, or freeze them and then fertilise them?
In general, embryos are considered more resilient to the stress of freezing and thawing, compared to oocytes. The advent of modern vitrification technology has mitigated these effects to a degree, but they still persist, not to mention the likelihood of refreezing the embryo resulting from fertilization of the frozen oocyte for various reasons, dramatically increasing its exposure to freeze stress. Therefore, when a partner is available, embryo freezing should be preferred over oocytes.

If eggs are not collected before surgery, how soon after can they be collected?
Ovarian stimulation and oocyte retrieval may commence as soon as the woman has completely recovered from the surgery and when a menstrual cycle with promising baseline parameters occurs. This time interval largely depends on the stage of endometriosis and the type of surgery performed, in addition to the presence of other comorbidities and menstrual disorders and could vary from 4 weeks to a few months. The input of both your surgeon and reproductive specialist is strongly advised.

They say that hormonal stimulation can exacerbate endometriosis. How true is it based on your experience?
Unfortunately, as is the case with most endometriosis-related issues this too remains unclear, as endometriosis has a tendency to progress insidiously, cause disproportionate clinical symptoms to its severity and recur even in the absence of ovarian stimulation. However the limited available evidence so far suggests that stimulation does not exacerbate symptoms, or increase the risk of recurrence.

What is the consensus of managing fertility in endometriosis patients?
So far, practice guidelines emphasize the need for individualization in the approach of each patient, and careful weighing of the advantages and disadvantages of the available treatment options (ART, surgery, medication), always in accordance with clinical symptoms and family planning.

“Like many others advocating for change, I have walked the path of endometriosis”

Advocacy

Millions of women around the world suffer from endometriosis. Some of them use their experience to educate and raise awareness. Abeesha Toussaint-Maximay, the founder of Trinidad and Tobago Endometriosis Association, is one of many endometriosis advocates that is using her voice to make changes.

You are one of the steering committee members of the World Endometriosis Organization. What is the steering committee responsible for?

I had the privilege of serving on the steering committee for nearly three years. We worked towards advancing the organisation's mission. Our focus included fostering collaboration, nurturing stakeholder relationships and sharing expertise , and contributing to endometriosis research. Initiatives such as Meet and Greet events and newsletters were used to showcase the impactful work of the global community. Notably, our involvement in projects like the Endometriosis Phenome and Biobanking Harmonization Project highlighted the collaborative efforts among patients, clinicians, and researchers during my tenure. I am confident that the WEO will make a lasting positive impact on a global scale.

> “The strong desire to fill the gap in support in Trinidad and Tobago and to improve health outcomes for patients compelled me to take action”

Most endometriosis advocates have endometriosis themselves. What’s your story and what made you use your voice to change the narrative?

My journey to the quality of life I now enjoy was long and challenging, but later on, I was blessed to receive effective endometriosis care from an experienced gynaecologist. Through this painful experience, I found purpose! The strong desire to fill the gap in support in Trinidad and Tobago and to genuinely improve health outcomes for patients compelled me to take action. Advocacy was not easy, especially given my introverted nature. However, with the unwavering support and clear goals, I remained steadfast in my commitment to effecting positive change for those afflicted by this condition, even beyond my tenure with the Trinidad and Tobago Endometriosis Association [TTEA].

As a person of responsibility in various organisations that you were part of over the years, how hard is it to get funds, or get governments to make endometriosis a priority?

This remains a challenge! Unlike the US, France and Australia, there has been no allocation for endometriosis care in the national budget of Trinidad and Tobago. This is crucial, especially for national strategic goals like systemic changes, advancing endometriosis research and addressing challenges associated with clinical management.

However, in the past the government through a number of ministries partnered with and supported the work of the TTEA, and in some cases, was a sponsor at events. Despite these challenges, I am hopeful that the government will prioritise endometriosis.

From your experience, what are some of the particular issues faced by non-white endometriosis sufferers?

Honestly, I initially overlooked this until I encountered the studies and narratives from the US on how race and ethnicity impact endometriosis patient care. Common issues ranging from delayed diagnosis to dismissal of symptoms, and misconceptions about treatment are prevalent in Trinidad and Tobago. The current TTEA's president speaks candidly about the prevalence of wrong treatments patients often receive. Also, there are cases of endometriosis patients with other gynaecological conditions such as uterine fibroids. However, I'm unaware of any studies in Trinidad and Tobago, attributing these experiences to race and ethnicity.

Why is endometriosis awareness important?

Endometriosis awareness is essential for confirming the condition's existence, fostering understanding of the condition's complexities and the requirements for effective care among all stakeholders. There are patients who do not know the cause of their pain and think it is normal whilst others cannot access or afford effective patient care. Increased awareness is crucial for early diagnosis, validating patient experiences, allocating resources as well as building supportive communities. Ultimately, the aim is a better quality of life for those afflicted by endometriosis.

> **"Endometriosis should have its own national healthcare plan"**

If there was an endometriosis action plan, what would be the first issues tackled?

This is challenging given the wide-ranging issues to be addressed. Instead of reinventing the wheel, we can learn from countries like Australia, the US, and France, which have prioritised awareness, education, clinical management, and research. Though distinct, they are interconnected and require attention simultaneously. However, if I must select, I would prioritise updating clinical practices to meet international best practices because of the urgent needs of endometriosis patients. I would also prioritise establishing a national endometriosis research unit and repository, which will enhance our understanding of the disease, providing the evidence needed to drive impactful change.

> **"It is crucial to address health disparities and advocate for improved care for all endometriosis patients, regardless of their racial or ethnic background"**

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

Classifying endometriosis as a disability requires a comprehensive, multi-stakeholder driven assessment supported by relevant studies for that jurisdiction. Its impact varies, and effective action on endometriosis priorities may reduce the need for such classification. I think providing easily accessible support, including financial assistance during times of employment disruption, is crucial for patients. I certainly welcome engagement on this topic in Trinidad and Tobago and the wider Caribbean region.

How can one advocate for themselves?

Advocacy begins with education.Understanding endometriosis and its issues are crucial. Familiarise yourself with relevant studies and research. If there are limited studies in your country or cultural context, use existing studies that are closely aligned with your experience to strengthen your discussion. This knowledge forms the foundation for effective advocacy. Remember, as a patient, you have rights. Tailor your advocacy efforts to your goals and stage of advocacy, ensuring that your voice is heard and your needs are met.

Induced menopause in patients with endometriosis

Dr Cristina Odukoya
Specialist
Obstetrics-gynecology

Endometriosis is a gynecological condition frequently found in women of reproductive age, but it is also found in approximately 2-4% of postmenopausal women.

It is an estrogen-dependent disease which means that physiologically, the period of transition to menopause when the level of estrogen drops significantly alleviates specific symptoms, mainly pain.

Therefore, the target of drug treatments administered to a selected category of patients with endometriosis should be precisely this suppression of ovarian activity and menstrual cycles that occurs physiologically in the menopausal patient. Thus a temporary menopause is induced.

> **Estrogen is a crucial hormone for maintaining the proper functioning of most organs and tissues, especially bone**

This therapeutic strategy is used in patients who have already undergone a surgical procedure for endometriosis but with the aim of preserving fertility and reproductive function in order to inhibit the remaining endometrial tissue that has metabolic activity and could increase the risk of symptomatology recurrence.

This is possible even after correct and rigorous surgery performed by an endometriosis specialist.

The medication in this case complements the surgical procedure. But the medication can also be used per primam in a patient with endometriosis who has not followed or has no surgical indication but has intense symptoms and a significant impact on the quality of life.

There are several drugs used for this purpose such as the gonadotropin-releasing hormone agonist (GNRH-a) which is the most popular and is administered for a period of 3-6 months, a single monthly intramuscular injection.

Other drugs used are progestogens under different administration formulas that can be used in the longer term. The longer the duration of administration, of course, the more serious the side effects of the drop in estradiol levels.

The main disadvantages of these drugs are symptoms such as hot flashes, night sweats, decreased libido, vaginal dryness, mood disorders, anxiety, brain fog, muscle pain, joint pain. All of these occur by decreasing estrogen levels and secondarily predispose to decreased bone density and cardiovascular disease when administered over a longer period. Estrogen is a crucial hormone for maintaining the proper functioning of most organs and tissues, especially bone. For example, after a 6-month course of GNRH agonist treatment, bone density decreases by 4-6% and approximately 20% of patients complain of joint and bone pain.

In order to protect the patient from these side effects but at the same time to maintain the beneficial therapeutic effect, very small doses of estrogen and progesterone hormones are added from the beginning or after 3 months of treatment with GNRH, called add-back therapy.

In patients using GNRH for less than 3 months, only herbal supplements, vitamins, minerals can be administered as adjuvants in combating menopause-like symptoms.

Eating behavior and lifestyle are essential, anti-inflammatory diet, exercise, but also alternative programs such as acupuncture, reflexology, traditional Chinese medicine and cognitive-behavioral therapy.

However, newer drugs have appeared that combine both types of preparations, those with the role of reducing menstrual flow and the pain associated with endometriosis, but also the hormonal restorer based on estrogen and progestin. Thus, in this combination, the therapeutic effect is maintained and adverse reactions are combated through a single preparation, easy to use, in the form of a capsule that is taken only once a day.

In patients who experience vaginal dryness or pain during intercourse, additional estrogenic preparations in the form of vaginal creams or ova can be added, and in patients with reduced libido, tibolone or testosterone gels can be an option.

Patients do not have to worry about the reactivation of remaining endometriosis foci after surgery or the recurrence of symptoms if add-back therapy is added to the basic treatment because the estradiol level is checked by the doctor during the treatment. An estradiol level below 40-50 pg/mL will not lead to reactivation of endometriosis but will be sufficient to prevent peri-menopausal symptoms and loss of bone density. Thus, it is a significant win for the patient.

All patients with endometriosis and medically induced menopause should benefit from add-back hormone replacement therapy, except for those with a specific contraindication. This is important for cardiovascular and bone protection and increases the patient's compliance to treatment.

Both the endometriosis specialist and the gynecology endocrinologist work together to provide the best treatment options for the endometriosis patient.

Endometriosis of the sacral plexus and sciatic nerve

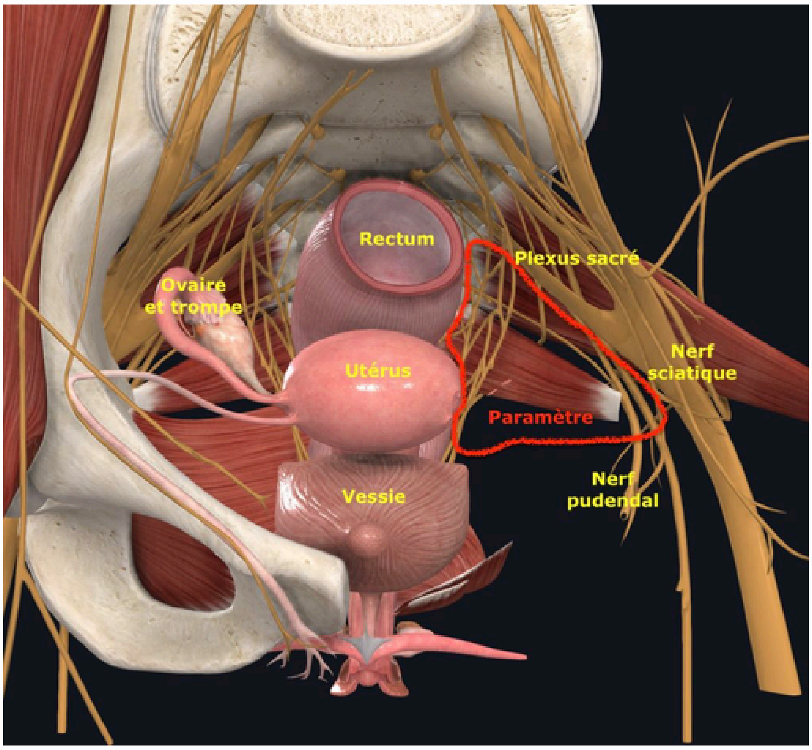
Horace Roman, M.D

- Founder of Institut Franco-Européen Muntidisciplinaire d’Endométriose
- Honorary Professor at Aarhus University Hospital, Denmark
- Master Surgeon in Multidisciplinary Endometriosis

> **Deep endometriosis can affect the sacral plexuses, especially when they occupy the lateral space of the vagina and rectum, also called the parametrium. The sacral plexus is located in the lateral, external and deep part of the parametrium, in contact with the pelvic wall. Endometriosis of the parameter often infiltrates not only the sacral plexus, but also the vagina, rectum, ureters or even the bladder.**

Deep parametrial endometriosis nodules may compress, wrap or infiltrate large-diameter nerve structures such as the sacral roots, sciatic nerve, obturator nerve, or pudendal nerve, as well as fine nerve structures such as the splanchnic nerves, hypogastric nerves, and plexuses lower and upper hypogastric. (Fig 1)

An endometriosis nodule on the sacral plexus or sciatic nerve is a relatively rare location!



There are 2 types of parametrial nodules:

Type 1. Large nodules occupy the medial part of the parameter, compressing or infiltrating the sacral roots, but also the rectum and vagina. These are the most common conditions of the sacral plexuses (85-90%). They cause pain in the buttocks or in the perineum associated with urinary or digestive disorders. (Fig 2)

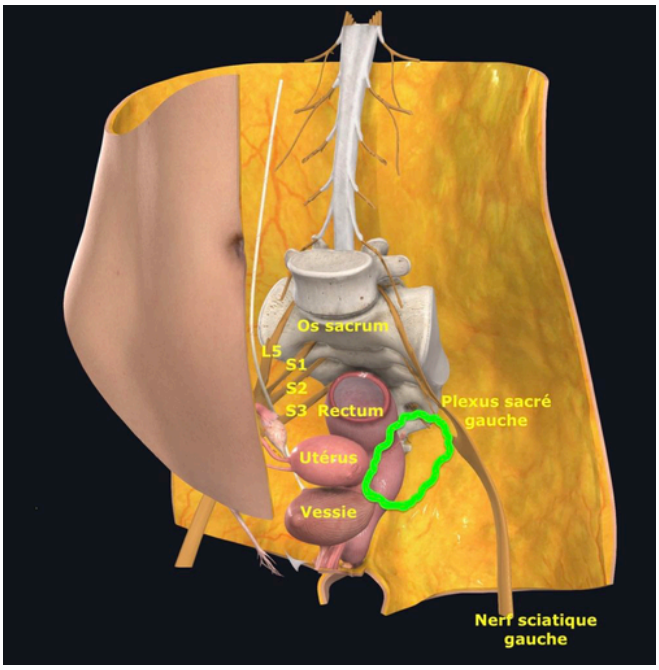


Fig 2

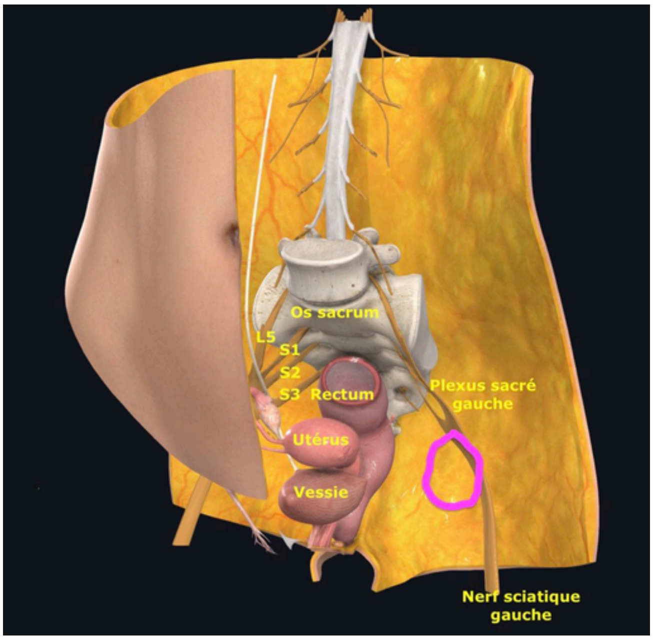


Fig 3

Type 2. Lateral nodules compressing or infiltrating the sciatic, pudendal, and obturator nerves. These are rarer lesions (10-15%), manifested by pain or motor disturbances in the buttock and lower limb. On the other hand, digestive and urinary disorders are less common. (Fig 3)

Deep endometriosis nodules of the sacral plexuses can be responsible for several specific symptoms, especially during menstruation:

- **Sciatica**: pain that starts in the buttock, goes down the back of the thigh, to the bottom of the leg.
- **Pudendal neuralgia (pudendalgia):** pain due to damage to the pudendal nerve, which involves the perineum, from the labia majora to the clitoris and the side of the anus.
- **Pain in the region of the obturator nerve**: pain on the medial surface of the thigh, to above the knee.
- **Bladder or rectal dysfunction:** difficulty emptying the bladder, especially during menstruation (patients are forced to push by contracting abdominal muscles, or bend forward, to compress the bladder and help empty it) or a slow transit and difficulty when evacuating the bowel.
- **Sensation of vaginal dryness.**

This type of clinical presentation of endometriosis is rare and often unknown to doctors. Therefore, these symptoms are initially rarely attributed to endometriosis, but rather to rheumatological, osteo-articular or muscular causes.

Anatomy of the parameter and the sacral plexus

The sacral plexus is made up of sensory and motor nerves. Some motor nerves are called "somatic" because they manage the voluntary motor response of the skeletal muscle fibres, lower limbs, buttocks, or pelvis. Others are called "vegetative" because they are involved in the autonomic (involuntary) contraction of pelvic and abdominal organs (rectum, colon, bladder), erectile organs, genital and skin glands, or vessels.

The somatic innervation (fig 4) of the pelvis originates from nerves or roots in the spinal cord, either from the lumbar area (denoted L, from 1 to 5) or from the sacral area (S, from 1 to 4 or 5). The roots exit the spine through the vertebral foramina and interconnect into branched structures, also called "plexes": lumbar and sacral.

The sacral plexus (fig. 5) consists of the last lumbar root (L5) and the S1, S2, S3 and S4 or S5 roots. These nerve roots include afferent (information collected in the periphery and directed to the spinal cord and brain) and efferent (information is sent to the muscles), involved in sensory perception and voluntary movements of the lower limbs.

Fig 4

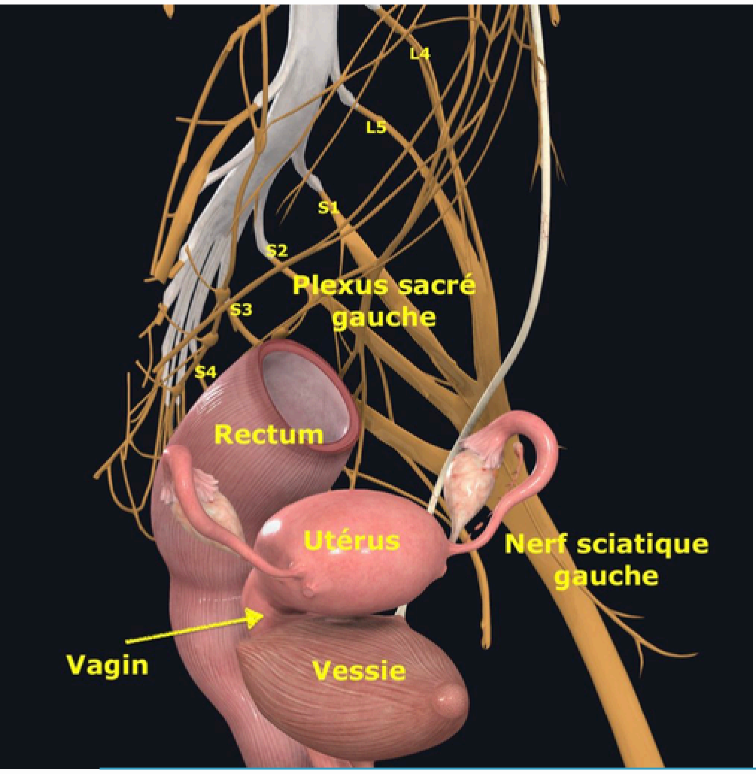
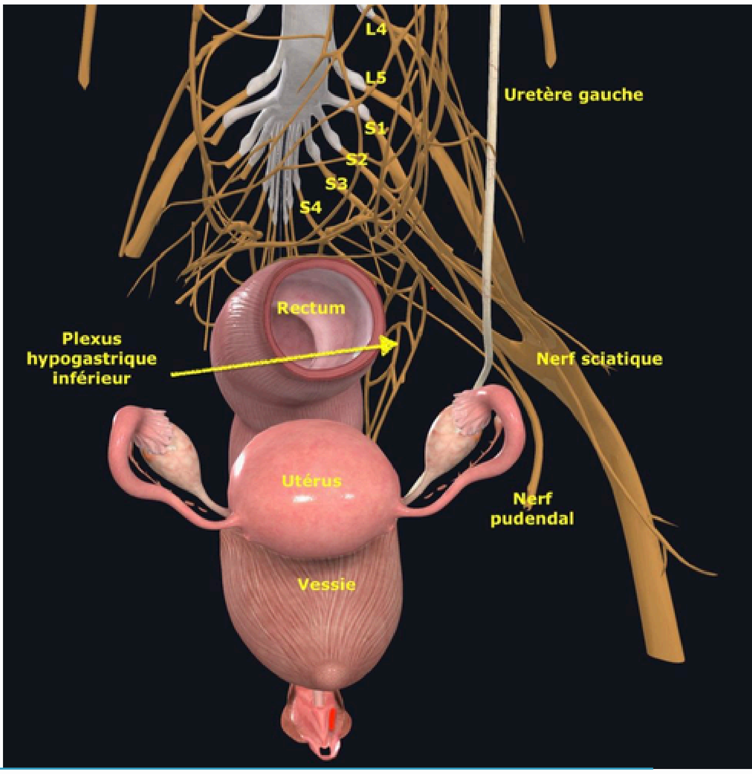


Fig 5



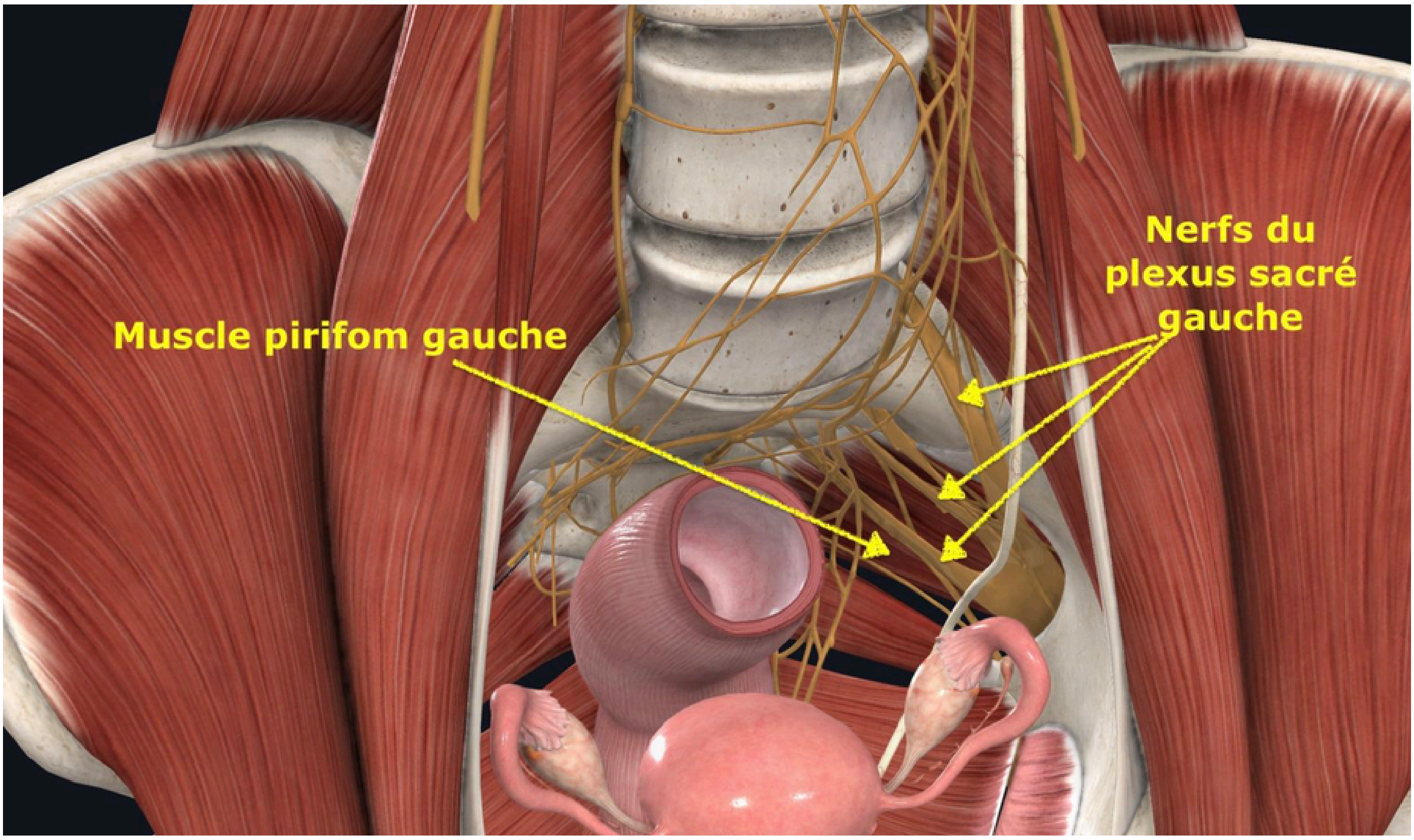


Fig 6

The sacral roots are located in the posterior part of the pelvis, between the sacrum and the lateral wall of the pelvis, in front of the piriformis muscle (Fig 6). They converge and give rise to larger calibre nerves (from 4 mm to 1 cm):

The sciatic nerve (mainly with somatic fibres of L5, S1 and S2), which leaves the pelvis to the posterior surface of the thigh, where it takes a descending course to the calf and leg. It is involved in the motility of the calf and foot and the sensation of the posterior surface of the lower limb down to the foot.
The pudendal nerve (mainly S2, S3 and S4) running to the perineum (the area between the two thighs, containing the clitoris, vulva and anus) and to the external sphincter of the anus.

Finally, small-caliber (on the order of 1-2 mm) predominantly vegetative fibers originating from S2, S3, and S4 interconnect to form a cobweb network located in the depth of the parameter, laterally rectum and below the ureter: inferior hypogastric plexus. Very fine nerves are born from this spider's web, which reach the bladder, the bottom of the vagina and the rectum: the splanchnic nerves.

The splanchnic nerves control the voluntary emptying of the bladder, the function of the internal sphincter of the urethra, but also influence rectal mobility and sexual functions.

The inferior hypogastric plexus also receives the hypogastric nerves, whose diameter is around 1-2 mm, which are involved, among other things, in the sensation of bladder fullness.

Near the sciatic nerve passes the obturator nerve, which originates from the lumbar plexus (L2, L3 and L4), which allows movement of the thigh adductor muscles that move the thigh towards the midline of the body (thigh approximation), and provides sensitivity to the medial surface of the thigh.

Pelvic Nerve Anatomy explains the location of pain, motility disorders, and pelvic organ function when the sacral plexus or the sciatic, obturator, and pudendal nerves are affected.

Surgery for sacral plexus endometriosis nodules cannot be considered without a careful preoperative evaluation.

MRI is the essential, mandatory examination that allows the surgeon to visualise in 3 dimensions the location, dimensions, boundaries and volume of the endometriosis nodule. The examination evaluates the damage to the neighbouring organs (rectum, ureter, urinary bladder, vagina, piriformis muscle) and makes it possible to plan an intervention, with the participation of a multidisciplinary team. (Fig 7,8).

Excision of deep endometriosis lesions of the sacral plexuses and sciatic nerves is performed laparoscopically, with or without robotic assistance. It occurs in a different way for type 1 and 2 nodules. Despite its complexity, for us this intervention is well standardized, following very standardized steps, which allow both a complete excision of the lesions and a reduction in the risk of intraoperative hemorrhage and reducing the risk of postoperative functional sequelae.

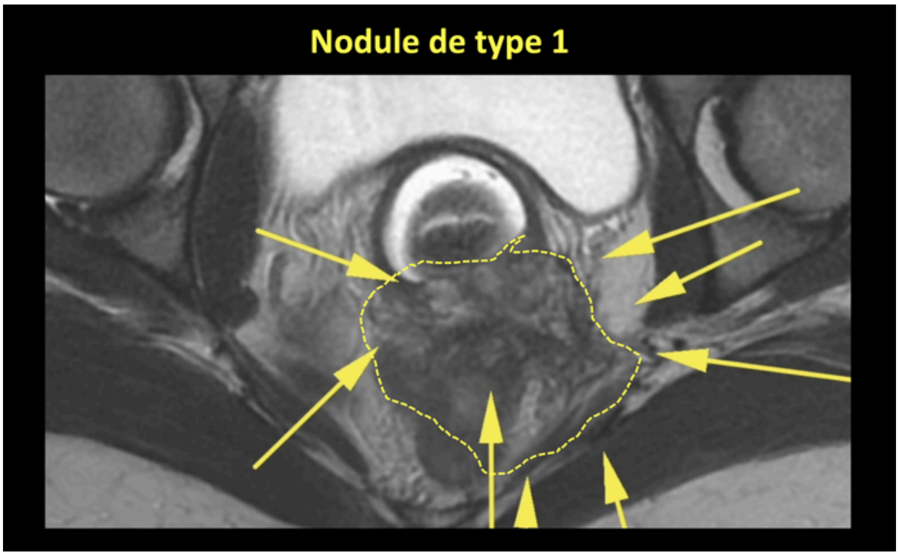


Fig 7

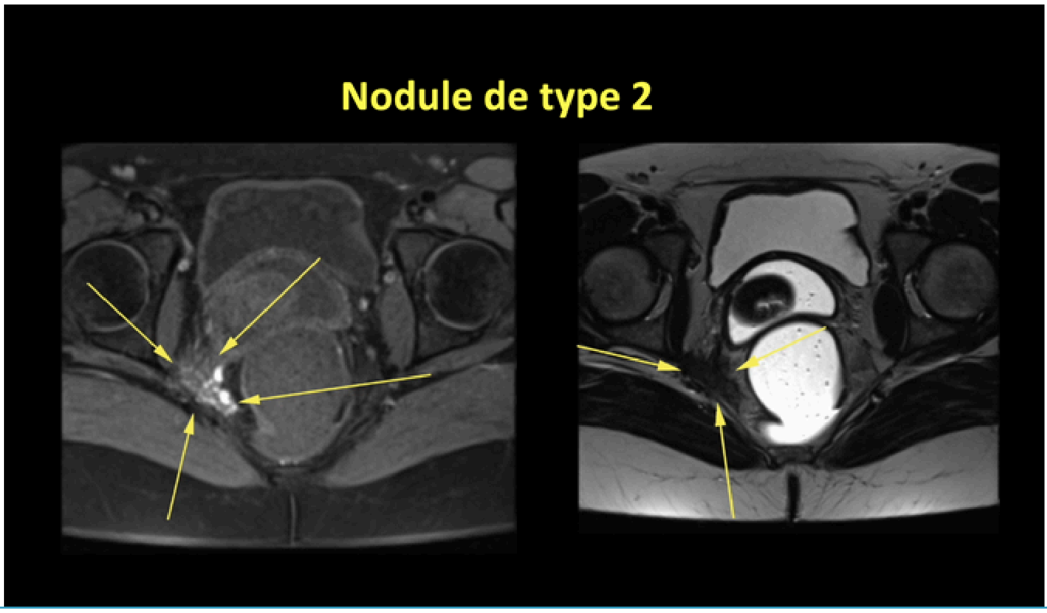


Fig 8

The duration of the surgery depends on the complexity of the deep lesions, especially if several additional procedures are performed on the rectum, ureter, vagina or bladder. An intervention for endometriosis of the sacral plexuses includes, during a single operation, several interventions, each of which is of great complexity.

> **The duration of such a surgical intervention can vary from 2 to 8 hours.**

It is important to understand that sometimes it is impossible to preserve certain nerves during the excision of large endometriosis nodules of the parameters, especially the finer ones. Sacrificing these small nerves can lead to at least temporary impairment of bladder and rectal function.

However, in certain cases, when endometriosis concerns both parameters, we are obliged to perform a complete resection on the side where the disease seems most aggressive and to perform a minimal act on the less affected side, to avoid complete denervation of the bladder urination, rectum or vagina. While sacrifice of small-caliber pelvic nerves can be considered unilateral, surgery for large-caliber nerves such as the sciatic or obturator nerves should be as conservative as possible to avoid major motor or sensory disturbances.

The duration of hospitalization varies from 3 to 7 days, depending on the type of surgery performed and the postoperative results. Recovery is faster if the surgery does not involve suturing the rectum or ureters.

The postoperative consequences can be marked by several immediate complications, which must be clearly presented before the operation:

Atony of the bladder

Voluntary emptying of the bladder is achieved by a command transmitted to the bladder by the splanchnic nerves. The splanchnic nerves are bilateral, but their participation (dominance) can be unbalanced. They can be affected both by the endometriosis nodule (infiltration, compression, irritation, in this case the symptoms are present before surgery) and by the surgical procedure. During surgery, the splanchnic nerves, which are very fragile, can be removed en bloc with the nodule or can be sectioned.

Even when preserved, the splanchnic nerves can be damaged as a result of the release of heat from the energies used to coagulate the blood vessels, or even stretched during dissection, which can lead to neuropraxia. The term neuropraxia is used to describe moderate nerve injury that results in temporary impairment of nerve function and is a temporary loss of the myelin sheath of the nerve without any associated axonal injury. This demyelination slows down the speed of electrical impulse conduction within the nerve and therefore alters the transmission of information through the nerve.

The prognosis of these conditions is favorable, with full recovery most often within a few weeks or months, with the reformation of the myelin sheath. The clinical result is difficulty in emptying the bladder, which constantly retains a variable amount of urine. If the volume of urine remaining in the bladder at the end of urination (post voiding residual or RPM) exceeds 100 ml, patients must use small bladder catheters to empty the bladder several times a day (usually 5 or 6 times) , at the set times and after the attempt to urinate voluntarily.

Bladder function gradually improves within 4–6 weeks postoperatively, and self-catheterization can be stopped when RPM consistently falls below 100 mL.

When self-catheterization is indicated, it is learned before leaving the clinic. Patients are asked to regularly note the volumes voided by catheterization (voiding calendar) and communicate them to the surgeon.

The frequency of bladder atony requiring systematic self-catheterization is approximately 25% at clinic discharge and decreases to approximately 5% one year after surgery. Recovery of bladder function is explained by regression of neuropraxia, edema and local inflammation due to surgery.

Neuropathic pain, paresthesia or hyperesthesia in the regions of the sciatic, obturator and pudendal nerves

These pains are the clinical expression of irritation, nerve edema or neuropraxia of somatic nerves and are manifested by electrical mini-discharges, tingling or painful sensations triggered by minimal stimulation (contact with clothing).

These symptoms require specific treatment with drugs that interfere with nerve transmission, such as pregabalin, amitriptyline, gabapentin, given for several weeks or months.

These symptoms are present in about 17% of cases one year after surgery.

Long-term data are encouraging, both in terms of clinical improvement and fertility. It is important to note that women with deep endometriosis involving the sacral plexus or sciatic nerve rarely have associated ovarian or tubal disease. This could explain the very high rates of pregnancy (77%) and post-operative births, with spontaneous conception in half of the cases.

This information should encourage patients for a surgical approach, even in a situation where they want a pregnancy. In fact, the scientific data do not allow the first intention recommendation of in vitro fertilization in this situation, which could postpone the surgical intervention that thus becomes technically more complex, due to the continuous growth of the lesions.

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SOS Infertility PROJECTS

> We change mentalities.
> We change destinies.

- **The Subprogram for in Vitro Fertilization and Embryotransfer**, a financial support program for hypofertile couples created by the Ministry of Health of Romania in 2011, at the direct initiative and with the participation of the SOS Infertility Association.

- **Active advocacy for the IVF Project** supported by the Ministry of the Family (since 2022) and for the "IVF – A Chance for Infertile Couples" Project (2018-2021) supported by the Bucharest City Hall/ASSMB, as well as advocacy in order to initiate similar local programs in other localities in the country (Constanța, Craiova, Medgidia, Ștefănești).

- **The project "A chance for life" (since 2016)** – a completely free in vitro fertilization procedure offered by each of the partner clinics registered in the project. In the first seven editions, 104 free IVF procedures were offered by lot, with a market value of over 460,000 euros, as a result of which over 50 children have already been born and other pregnancies are underway.

- **The Magazine (since 2019) and the podcast "What do you know about YOUR FERTILITY?"** (since 2023), media that offer fertility education to the general public.

- **The Eva and Clara Brunel Memorial Grant** (since 2021), an up to 6,000-euro grant offered annually by the SOS Infertility Association to perform an in vitro fertilization procedure on a couple who lost an advanced pregnancy or a child at birth.

- **The Jean-Pierre Brunel Memorial Grant** (since 2022), an up to 6,000-euro grant, universally accessible, offered annually by the SOS Infertility Association to perform an in vitro fertilization procedure.

- **The National Awareness Week** of the social and medical phenomenon of infertility in Romania – annual awareness & advocacy event (since 2012); since 2016, the national event is part of the pan-European European Fertility Week campaign.

- **Traveling exhibitions, exhibited in spaces with high visibility in Bucharest and in the country:** "Infertility exists. And it hurts", "Foray into the history of in vitro fertilization", "Infertility can be defeated".

- **SOS Infertility Support Groups** – meetings of infertile people, a psychological support group, a nutrition and weight loss support group, coordinated by qualified psychologists and nutritionists, film nights on infertility or adoption, followed by debates.

- Active presence and initiatives in **Fertility Europe projects**, the pan-European federation of hypofertile patient associations.

Urinary incontinence and genital prolapse

Dr Răzvan Betea
consultant
gynecologist
www.drbetea.ro

> **Uterine prolapse and urinary incontinence are two health problems women face that can significantly affect their quality of life. Dr. Răzvan Betea, gynecologist, provides more information about these conditions.**

Urinary incontinence is characterized by the involuntary loss of urine. There are 2 situations encountered through which it manifests:
stress urinary incontinence, coughing, sneezing and urinary incontinence due to urgency

The causes are distinct and I will explain them.
In the case of stress urinary incontinence, they are represented by changes in the suburethral tissue and the change in the angle between the bladder and the urethra determined by:

- birth of a heavy fetus,
- obesity,
- menopause,
- prolonged physical exertion,
- local cellular deficit.

In the situation of overactive bladder, there is a premature reaction of the bladder muscles that contract to empty the bladder faster than necessary, resulting in frequent urination and characterized by the patient's inability to reach the toilet quickly, at which point urine loss occurs.

Prevention recommendations would be the following:

- proper diet to avoid obesity and diabetes
- avoiding foods that irritate the bladder: spicy, carbonated drinks, coffee, alcohol;
- avoiding smoking which can cause coughing and therefore the increase of intra-abdominal pressure with the appearance of incontinence;
- avoiding strong physical exertion.

The vaginal mucosa can be dry, thickened, chronically inflamed, infected and can present with ulcers, sometimes painful or that can bleed, being confused with genital cancer.

The symptoms of vaginal prolapse are similar. The presence of cystocele and rectocele is usually associated.

The diagnosis is made during examination by a specialist doctor. If the patient has severe incontinence, the doctor may recommend tests to measure how well the bladder is working (urodynamic test).

How is it treated?
Asymptomatic or grade I or II prolapse does not require treatment. Symptomatic or grade III prolapse can be treated non-surgically if the perineum can structurally support the pessary.

If symptoms are severe or persistent, surgery is indicated, usually a hysterectomy accompanied by surgical repair of the pelvic supporting structures (colporrhaphy) and vaginal suspension (suture of the upper portion of the vagina to nearby stable structure). Surgery is delayed until all ulcerations have healed.

The gynecologist specialist can also recommend self-care measures. If uterine prolapse causes mild symptoms or if it is asymptomatic, simple self-care measures can prevent the prolapse from getting worse. Kegel exercises to strengthen the pelvic muscles, lose weight and treat constipation are effective treatment methods for strengthening the uterus and the organs in the area.

Complications of uterine prolapse
Uterine prolapse is often associated with prolapse of other pelvic organs:

- anterior prolapse (cystocele): weakening of the connective tissue that separates the bladder and vagina can cause the bladder to move into the vagina.

- posterior vaginal prolapse (rectocele): weakening of the connective tissue that separates the rectum and vagina can cause the rectum to bulge into the vagina, leading to difficulty in bowel movement;
- severe uterine prolapse can displace part of the vaginal lining, causing it to protrude outside the body. Vaginal tissue rubbing against clothing can lead to vaginal injuries.

How can we prevent its occurrence?
- reduce the risk of uterine prolapse, there are some effective methods of prevention, especially if they are applied in a timely manner:
- preventing constipation by consuming fiber-rich foods and adequate fluid intake;
- avoiding lifting too much weight;
- cough control (avoiding smoking and taking treatment for chronic cough or bronchitis);
- avoid weight gain.

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Management of deep infiltrating endometriosis

Dr Attila Bokor
Associate Professor, Semmelweis University
Head of Minimally Invasive Surgical Unit
Coordinator of the Endometriosis Centre,
Semmelweis University (Budapest, Hungary)
EEL Executive Board

Considered a severe form of endometriosis, deep infiltrating endometriosis can affect many areas and organs from the body.

What are the main types of endometriosis?

The three main phenotypes of endometriosis are peritoneal (superficial), ovarian (endometrioma) and deep infiltrating endometriosis (DIE or DE).

What is deeply infiltrative endometriosis?

In case of deep infiltrating endometriosis the lesions penetrate more than 5 mm below the peritoneal surface.

Superficial versus deep infiltrating endometriosis: where do we typically encounter them? As in what areas/organs are mostly affected by?

Superficial endometriosis is predominantly found on the pelvic peritoneum. Deep infiltrating endometriosis can reach deep into the extraperitoneal space and occupy various pelvic organs such as the bladder, ureters, gastrointestinal tract, sacro-uterine ligaments or the vagina.

What are the complications of deep infiltrating endometriosis?

Endometriosis can cause scar tissue formation inside the pelvis or abdomen and on nearby organs. This can lead to adhesions and bind one organ to another. In some cases patients do not experience noticeable symptoms, but rarely, life-threatening complications such as ectopic pregnancy or bowel blockage can happen.

> **“In women with endometriosis, intestinal involvement is estimated to occur in 3.8–37% of the patients. Intestinal endometriosis usually affects the rectosigmoid colon.”**

Lesions obstructing the urine flow, like ureteral or parametrial endometriosis can cause hydronephrosis and consecutive renal dysfunction or hypertension. Endometriosis affecting the pelvic nerves can cause sensory or motoric dysfunction and pain.

What is deep rectovaginal endometriosis and can it impact the bowel?
Rectovaginal endometriosis occurs when tissue similar to endometrial tissue grows outside of the uterus and into the rectum, vagina, or the structures between them. It can interfere with bowel functioning. Symptoms of rectovaginal endometriosis can include bleeding from the rectum, painful bowel movements, constipation etc.

One of the most frequent questions of patients is the stage of endometriosis. Is deep infiltrating endometriosis a stage 4? Or staging is not impacted by the type of endometriosis?
Taking into account the size and number of the adhesions and endometriotic lesions, endometriosis can be classified into four stages using the revised American Society of Reproductive Medicine (rASRM) scoring system. Stage I-II means minimal or mild disease with superficial or few deep implants. Stage III is moderate disease with many deep implants, ovarian cysts and filmy adhesions. Stage IV means severe disease with many deep implants, ovarian cysts and dense adhesions or extragenital implants.

It is important to note that the stage of the disease does not necessarily reflect the level of pain or presence of symptoms.

Based on the area/organ affected, what symptoms can cause it?
The most common symptoms in endometriosis are painful menstruation, infertility, chronic pelvic pain and pain during sexual intercourse. Lesions affecting the urinary tract can cause complaints like painful urination, haematuria (blood in urine), while patients with endometriosis of the gastrointestinal system can experience symptoms like painful defecation or haematochezia (blood in stool), constipation, diarrhoea or feeling of incomplete emptying.

> **“ Endometriosis is a disease in which tissue that is similar to the endometrium grows outside of the uterine cavity. These fibrotic patches of tissue are called "nodules," "lesions," or "implants."**

How can we diagnose deep infiltrating endometriosis?
Suspicion of endometriosis can arise based on the patient’s complaints or during a physical examination or imaging tests (e.g. transvaginal ultrasound, MRI), Ultimately laparoscopic or robotic surgery with or without histologic examination can confirm the presence of the disease

What is the impact of deeply infiltrative endometriosis on a person’s fertility?
In women with deep endometriosis the most affected factors are gamete migration and tubal function, which can be impaired by the irregular anatomy, extensive intra-abdominal adhesions, and the chronic inflammatory environment which is characteristic for the disease. There is no clear evidence on the impact of DIE on infertility.

In terms of surgery, when is it recommended?
The first line therapy of endometriosis is the medical treatment (hormonal or analgesic)
In case of bowel or urinary tract obstruction or if the pain is severe and not responding to medical treatment, surgery is recommended. The most appropriate management of infertile patients with deep infiltrating endometriosis, particularly the asymptomatic ones with pregnancy intention, remains an open debate between the application of artificial reproductive technology methods and surgical treatment of endometriosis. Although there is no convincing evidence that operative laparoscopy for deep endometriosis improves fertility, surgery may be a treatment choice for symptomatic patients who want to become pregnant.

"I proved that I am stronger than endometriosis, and now I am a mother"

At 36, Geanina, from Bucharest, has been through a lot. A debilitating disease that steals the chance to become a mother from many women, plus 25 cm of Geanina's intestine.

Before becoming a mother, Geanina went through a complex operation, performed by Prof. Elvira Bratila and Dr. Rubin Munteanu. Now it's sunny on her street too, and next to her dear baby, Geanina, will smile. Her tears were replaced by hope.

During 2019-2021 I entered a clinical trial with pills for endometriosis. The treatment worked, momentarily, the cysts dissapaeard but then less than 3 months later they reappeared in full force. In 2022, together with my husband, we started to think that we want a child and started the necessary investigations to get pregnant, being told that I will need in vitro fertilization.

> **I am Geanina, the girl with scars and now the mother with scars. I hope my story will inspires and gives hope.**

My fight with endometriosis began in 2014 when a 7 cm cyst was discovered during a routine checkup. I was told that I had to have an operation as soon as possible. That's what I did 2 months later at a state hospital with a gynecologist without specialization in endometriosis. As I had no information about this disease at that time, in addition I had no pain, the only change was that my period came every 40 days. After the operation I was treated for 6 months with injections to stop menstruation, everything was fine for a while but then the cysts reappeared.

She thought it was just a cyst, but the endometriosis MRI showed a devastating situation. Endometriosis grade 4 with intestinal involvement.

We were lucky to find out at the end of the year that we are the winners of the Christmas project for a free IVF from a charity project. On this occasion, I went to see a specialist who, after checking the analyzes and an ultrasound, recommended that I do an MRI with an endometriosis protocol. Receiving the result was heartbreaking:

I found out that I have endometriosis grade 4 and adenomyosis, I was referred to Professor Elvira Brătilă where the operation was indicated.

Now we were closer to our dream, we knew exactly the steps, we had all the information, we had the best team of doctors for us. And in April 2023 I was already stimulating and collecting oocytes, 7 oocytes were collected and 4 embryos were fertilized. The date of the operation came, May 29, it took place at the Memorial hospital, with the multidisciplinary team consisting of Professor Elvira Brătilă and Doctor Rubin Munteanu.

The operation was successful, all foci were removed and 25 cm of bowel resection. I recovered very quickly after the surgery, the mobilization was fast, in 5 days I was home, and after a few days I was already 80% recovered.

> THEY RESECTED 25 CM OF MY INTESTINE

3 months after the operation, the embryo transfer took place. On 21.09 at 2 in the morning I took the pregnancy test and I was very happy, I had 2 dashes, my first 2 dashes, my husband was sleeping, I woke him up and we were all happy.

At 6 weeks and 3 days I went to the first ultrasound where I also heard the first heartbeats, an emotional moments for us. Few days later, at 7 weeks I had my first bleeding, I thought I was miscarrying, but it was just a hematoma and after 2-3 days it disappeared.

At the first morphology I found out that I have placenta previa, although I hoped that it would rise, unfortunately this did not happen, the reason being more than likely adenomyosis. At 24 weeks I also did the glucose tolerance test, and the results showed that I also have gestational diabetes, which I was able to control only with diet.

At 33 weeks, however, I was admitted to the hospital, due to bleeding caused by placenta previa, and 2 weeks after admission, the heavy bleeding started. I was rushed into the caesarean section and within 40 minutes of the onset of bleeding I already heard the cry of my baby, Ares-Andreas, my warrior.

Unfortunately immediately after birth he had to be moved to intensive care, his lungs were not developed enough, although we had given injections for their maturation since the beginning of the hospitalization, in addition he also developed bronchopneumonia and it was necessary to intubate him. But now it is good. From a strong mother, only a warrior could be born.

Dr CĂTĂLIN-BOGDAN COROLEUCĂ: The crucial role of surgery in the diagnosis, treatment and management of disease, in improving quality of life and fertility

Interview conducted by Flori Stan

Endometriosis is a complex condition with a significant impact on the lives of patients and society

There are several treatment methods, each with its own effectiveness. Of these, excisional surgery has proven to be the most beneficial. Regarding the surgical treatment of endometriosis, Dr. Catalin-Bogdan Coroleuca, specialist in obstetrics and gynecology and doctor of medical sciences, surgeon in endometriosis, says that it is important that all endometriosis lesions to be correctly identified pre-operatively, to allow the creation of a multidisciplinary team , if the patient has intestinal implications.

> “The most important aspect in the decision of surgical treatment is the location of the lesions”

What are the most common symptoms of endometriosis?

One of the cardinal symptoms reported by endometriosis patients is dysmenorrhea, or pain during menstruation.The anamnesis must be thorough and look to find out if dysmenorrhea pain is influenced by medication. Other commonly reported symptoms are pain during intercourse, pain outside of menstruation, and constipation or fast bowel movements.

> "Conservative surgery focuses on removing endometriosis lesions while preserving the reproductive organs, to reduce symptoms and preserve fertility."

What diagnostic methods are available for endometriosis?

Imaging investigations for the diagnosis of endometriosis should be guided by anamnesis (patient history) and clinical examination. In many cases, transvaginal ultrasound is sufficient to establish the therapeutic indication, even in advanced forms with intestinal damage. MRI examination with endometriosis protocol is reserved for cases where there is a discrepancy between the clinical examination, the symptoms reported by the patient and the lesions identified on the transvaginal ultrasound.

How does the grade and location of endometriosis influence the decision regarding surgical treatment?

I believe that the most important aspect in the decision of surgical treatment is the location of the lesions. The correct preoperative identification of all lesions allows the creation of a multidisciplinary team (including a general surgeon) in complex cases where the patient presents nodules with intestinal damage.

What risks and complications surgery has and how is it managed?

Surgery for endometriosis can be effective, but it can be accompanied by certain risks and complications. Here are some of them and how to manage them:

- **Excessive bleeding during or after the procedure**. To manage this, the doctor can use precise surgical techniques and closely monitor the patient during the operation and in the postoperative period.

- **Infection:** There is a risk of infection in the surgical area. To minimize this risk, use aseptic techniques and administer antibiotics before and/or after the procedure.

- **Damage to adjacent organs**: During the operation, damage to other nearby organs, such as the bowel or bladder, may occur. To prevent these situations, the doctor must be careful and aware of the patient's anatomy and use precise surgical techniques.

- **Anesthetic risks:** Anesthesia used during surgery may have some risks, such as allergic reactions or respiratory complications. Managing these risks involves careful assessment of the patient's health before the procedure and careful monitoring during anesthesia.

It is important for the patient to discuss with the doctor all the risks and complications associated with surgery for endometriosis and to be aware of them before making a decision. Also, adequate preparation before the intervention and careful follow-up in the postoperative period can help minimize these risks.

> **“The data obtained at 6 months, 1 year, 2 years and 3 years postoperatively demonstrate an improvement in the quality of life both on the scale of mental health and physical health"**

How does the operation improve the quality of life of the patient with endometriosis?

Quality of life in patients with endometriosis is one of my favorite topics. We studied this aspect longitudinally, in the long term, both in patients who benefited from interventions in the digestive sphere and in those who only benefited from the excision of deep endometriosis lesions. Each score is calculated based on 7 items described in detail.

> **"The purpose of surgery is to excise endometriosis lesions to restore tubal anatomy or to perform excision or clipping of the tubes (if they are completely non-functional)."**

What are the benefits of the surgery on fertility and what are the factors that can influence the success in achieving a pregnancy after the intervention?
Before discussing the impact of surgery on fertility in endometriosis, we must take into account the fact that the reproductive prognosis of these patients is intrinsically modified by the presence of the disease. First of all, in practice we observe that these patients have a lower ovarian reserve (compared to patients without endometriosis at the same age). This aspect is probably the result of chronic inflammation that also indirectly affects the ovarian reserve (even in the absence of an ovarian cyst). Second, tubal anatomy may be affected. In this case we are talking about the presence of endometriosis lesions at the level of the tubes or by affecting the tubal motility and permeability following the formed adhesions. The purpose of surgery is to excise endometriosis lesions to restore tubal anatomy or to perform excision or clipping of the tubes (if they are completely non-functional).

In making this decision together with the patient, we must take into account several aspects: the location of the lesions, the degree of endometriosis and the patient's desire to get pregnant.

What are the future prospects for surgery in endometriosis and how might surgical treatments evolve to improve patient outcomes and experience?
The long-term outlook for surgical treatment in endometriosis is promising. Surgical treatment both for endometriosis and for other pathologies is represented by the development of effective solutions through a minimally invasive way. Technology and tools allow interventions to be carried out with increased precision and efficiency. A good example in this case is robotic surgery.

> **"RECOVERY IS A PROCESS, AND PAYING ATTENTION TO YOUR NEEDS AND FOLLOWING YOUR DOCTOR'S ADVICE CAN CONTRIBUTE TO AN EASIER AND MORE EFFECTIVE RECOVERY"**

What are the postoperative recommendations for a quick recovery and how can the durability of the beneficial effects of surgery be maintained in the long term?
After endometriosis surgery, follow these tips:

- Rest and take your pain medication as prescribed.
- Watch for signs of complications and contact your doctor if anything unusual occurs.
- Eat healthy and drink plenty of water.
- Return to normal activities gradually and follow your doctor's instructions for wound care.
- Don't hesitate to seek emotional support if you feel the need.

Postoperative and long-term treatment in patients who have undergone surgery with complete excision of deep endometriosis lesions must be individually tailored.

These advantages may make robotic surgery an attractive option for endometriosis patients, giving them a better chance of recovery and symptom management.

Indocyanine green (ICG) staining: This technique involves the use of a fluorescent dye, indocyanine green, which is injected into the patient's blood. Under the light of a near-infrared light camera, your blood-laden endometriosis tissue fluoresces, making it easier to identify during surgery. This technique may be particularly useful in locating small lesions or in areas with increased vascularity but is currently in the clinical trial.

The Psychological Relief of an Endometriosis Diagnosis: Validating Pain and Overcoming Dismissal

Faith Gichanga
Psychologist

Endometriosis is a condition that affects millions of women globally and yet remains widely misunderstood and often misdiagnosed.

For many endo patients, the journey to receiving a formal diagnosis can be difficult and one filled with years of debilitating pain, dismissive medical professionals, and a constant struggle to be heard and validated. As a person living with endo myself, I understand this struggle first hand after receiving a diagnosis 20 years later since onset of the symptoms. However, when that diagnosis finally comes, it brings with it not just medical clarity but also profound psychological relief.

The experience of living with undiagnosed endometriosis is often marked by feelings of frustration, confusion, and isolation. Imagine enduring excruciating pain every month during your menstrual cycle - pain that feels far beyond the realm of normal but is repeatedly brushed aside by doctors as "just part of being a woman" or "all in your head." This dismissal not only undermines the physical suffering but also erodes one's sense of agency and self-trust. Many women begin to question their own experiences, wondering if they are exaggerating or imagining the severity of their symptoms.

This gas lighting effect can have significant psychological repercussions. It can lead to feelings of self-doubt, anxiety, and even depression as women struggle with the disconnect between their lived reality and the health system's refusal to acknowledge their suffering. The constant invalidation of these experiences can also strain relationships as partners, family members, and friends may also assume that the woman is exaggerating her symptoms – further isolating the endo patient.

The lack of a clear diagnosis also hinders access to appropriate treatment and support. Without a formal acknowledgment of their condition, women may find themselves going through ineffective treatments or medications that only provide temporary relief, further exacerbating their sense of hopelessness and despair.

> “They shuttle from one doctor to another hoping for a more effective solution”

However, when a patient finally receives a diagnosis of endometriosis, it becomes a turning point in her journey. It is not just about having a name for her condition; it is about validation of her pain, experiences, and perseverance in seeking answers despite being dismissed time and again. The psychological impact of this validation cannot be overstated.

First of all, a diagnosis brings a sense of vindication. It confirms that the pain was real, that the symptoms were not imagined, and that her suffering was not in vain. This validation is crucial for rebuilding trust in oneself and in the medical system. It allows women to reclaim their narrative and advocate more effectively for their needs, whether it be access to specialized care, pain management strategies, or support groups where they can connect with others who understand their journey.

Additionally, a diagnosis opens the door to tailored treatment plans that target the root cause of the pain. This personalized approach can lead to better symptom management and improved quality of life.

Knowing that there are medical options available and a team of healthcare professionals who are knowledgeable about her condition can instill a sense of hope and empowerment that may have been lacking during years of uncertainty.

Furthermore, the psychological impact of a diagnosis extends beyond the individual to their support system. Loved ones who may have been skeptical or dismissive in the past often experience a shift in understanding and empathy.

As a mental health practitioner who works with endo patients, I acknowledge that receiving a diagnosis is not a cure-all for the emotional toll of living with endometriosis. The journey toward healing, both physically and psychologically, is ongoing and multifaceted. It may involve therapy to address trauma and emotional distress, lifestyle adjustments to manage symptoms, and ongoing advocacy to raise awareness and improve healthcare outcomes for all women with endometriosis.

A Spousal Journey Through Endometriosis

Our WHOLE life has yet to be LIVED, but the suffering this disease has inflicted on my family began 8 years ago. Before that it was a burden only my wife carried alongside her mother. Through the years I have witnessed the many ups and downs that come with this disease, I have watched my wife suffer and spent many of the 8 years in and out of hospitals attempting to get her help or at least figure out where to start. The saddest part about this journey was watching the medical industry tear my wife apart, both mentally, physically and you could say spiritually even. This was partly due to a basic lack of understanding and knowledge of this disease within the medical industry, but also a lack of belief in the everyday struggles, pains, and ailments my wife was experiencing.

Our trips to the doctors or emergency room often lead to nothing but a gas lighting doctor saying, “everything appears fine”. After years and years of these words being uttered, one may begin to think they are going crazy, while also continuing to be misdiagnosed. Before my wife crossed my path that’s exactly where she was. Questioning herself, her worth, her lived experience.

I don’t think people really understand the level of emotional trauma this particular journey can take on the person suffering from the disease and also the family whom is taking this journey with them.

Partners Voices

> **Through the years of explaining to my children why mommy is always crying, why mommy is always tired and hurting, why we can't always go do this or that because our finances are so tied up in all the medical bills piling up. Yet with no true answers to be had, no cures and no relief, you begin to become numb alongside your partner. You begin to lose hope. You begin to lose faith.**

Cameron Hardesty
Board Member
Getting the Better of Endometriosis

But thankfully with a will to find a way and a refusal to give up, we finally found the answer she was looking for. Finding a doctor who believed her and had the proper training on this disease was the key. Days and nights of research she did led her to her diagnosis. Even now, 5 years after receiving a diagnosis she still suffers, but no more silence. With 2 removals of disease and a handful of reconstructive or organ removal surgeries, she is continuously managing her pain, sickness, and mental health.

I spend a lot of time thinking about our journey, and the journeys other people may have with this disease. It pains me to know that so many people are suffering in silence, with little hope for the answers they seek, and a high probability of never finding them.

It pains me knowing there are partners out there, like myself, who struggle alongside our Endo warriors in this battle. Keep communication open with each other, don't close each other out. Go to appointments. Ask questions. Learn new ways of intimacy together, that may not be as painful but still bring connection. Pay attention to their triggers, help them track them and work on adjusting things together. These are just a few tips to give to spouses or partners as ways to support and manage this disease as a unit. Honestly, it's a lot of trial and error. It is NOT EASY. But for the one you love it is worth it to the very end. I know she'd do the same for me.

I hope that one day, the disease itself and all that applies to it, becomes a more prominent, updated subject amongst the medical industry and in social settings. Until then we will keep persevering and fighting the good fight together.

Fertility in women after the age of 40

Dr Radu Maftei
specialist in obstetrics-gynecology,
specializing in the treatment of infertility
and endometriosis

The reason these types of articles are becoming more frequent is because advanced maternal age has become a critical public health problem globally. The reasons for reaching this point are multiple and they all "hide" behind the pretext of being successful in your career and taking advantage of the career opportunities that arise. In reality, however, we are all subject to the same unit of measure: **TIME.**

Career and success depend on the importance that each of us gives to them at a given moment in life, what matters in the end are other things. There are some studies done on patients hospitalized in palliative care units, all of them mainly regret things related to family and the time spent with their loved ones. Now let's also understand why pregnancy should not be postponed for ages over 35-40 years.

A misconception that many women have is that they see the presence of menstrual cycles as being fertile.

With advancing age, two important, irreversible processes take place: the decrease in the ovarian reserve and changes in the integrity of the DNA in the oocytes. Each woman is born with a finite number of follicles and their number decreases until puberty when women are left with approximately 500,000 follicles (ovarian reserve).

Then, with each menstrual cycle, a variable number of follicles are lost until the entire reserve is used up and menopause sets in. In reality, a woman's fertility declines dramatically 10 years before menopause. And the average age of onset of menopause is around 50 years.

I personally think that awareness campaigns about fertility should be introduced like we have about the consumption of tobacco, salt, sugar, fats, etc. In this way, we might reduce the percentage of patients over 40 who end up needing assisted human reproduction procedures.
Also, patients must understand that at the age of 40 they must see the infertility specialist from the start, not after a year of trying. Important success rates can be saved.

An important first step is to check the ovarian reserve and this is done very simply through a blood test called Anti-mullerian hormone (AMH). It shows the ovarian reserve but not the quality of the oocytes. The best predictor of oocyte quality remains patient age. There are some studies that show that in elderly patients, the presence of a low AMH value is associated with a higher rate of embryonic aneuploidy and low pregnancy rate.

> **Another preconception that I often encounter in my patients is that a good AMH value when they are over 40 means that they have a very high chance of success.**

I always tell them that I prefer a young patient with low ovarian reserve from whom I manage to collect 5-6 oocytes than a 41-year-old patient from whom I collect 12 oocytes. The reason oocyte quality declines with age is the cumulative negative effect of environmental and behavioral factors on the ovaries and the resulting suboptimal follicular environment. This causes genetic abnormalities in the oocytes, which is confirmed by studies that have shown that over 75% of the genetic abnormalities present in aborted pregnancies are of oocyte origin.

"DNA damage theory" best explains the decrease in oocyte quality: at the level of the DNA structure, small breaks accumulate over time that cannot be repaired. With advancing age, the repair processes of the DNA structure become more and more deficient and accumulation of DNA damage lead to poor oocyte quality.

An important negative effect on the integrity of oocyte DNA is also the increased concentration of free oxygen radicals. So a diet rich in antioxidants (but not short-term but as a lifestyle) and supplements rich in antioxidants can have a beneficial effect in some cases.

Fertility is not only about the chance of getting pregnant, but also about the chance of giving birth to a healthy baby, at term and with a low degree of maternal-fetal risks. With advancing age, the frequency of benign uterine pathologies (fibroma, adenomyosis) and implicitly also malignant ones increases. These pathologies can affect the chance of getting a pregnancy as well as its evolution.

I tell my patients that pregnancy is a physiological condition for the body, but it involves significant changes at the hormonal, cardiovascular, metabolic and immunological level, therefore the older the body is, the less adaptability it has and the risks of abortions, premature birth, gestational hypertension, diabetes gestational and genetic abnormalities we grow.

The European population is aging rapidly and the population renewal rate is falling through two mechanisms: the decrease in the number of children per family and the increasingly advanced age for the first child. Although there is sufficient clinical data attesting to a direct link between advanced age and decreased fertility and an increased risk of genetic abnormalities, awareness of these risks among older women is still quite low, which is why I find these extremely important attempts to raise awareness among the population.

Ulrik Bak KIRK: Endometriosis is surrounded by major gender issues and social norms which have led to the creation of myths and misconceptions, affecting health care services and policy support needed.

FEMaLe Project

What is FEMaLe and why is the need for such a project?
The EU-funded Finding Endometriosis using Machine Learning (FEMaLe) project is working on a machine-learning multi-omics platform that can analyse various data and translate the information into a personalised predictive model. The main focus of the project is to improve intervention for individuals with endometriosis by devising digital tools that can improve disease management and support the delivery of precision medicine.

Representing a high burden for patients, health care systems, and society, endometriosis still remains an insufficiently understood and under-researched condition, mainly due to severe lack of research funding, in line with women's health in general.

What are some of the biggest projects that you have worked on, or are working on?
FEMaLe will design and validate a comprehensive model for the detection and management of people with endometriosis to facilitate shared decision making between the patient and the healthcare provider, enable the delivery of precision medicine, and drive new discoveries in endometriosis treatment to deliver novel therapies and improve quality of life for patients.

Moreover, FEMaLe builds bridges across disciplines and sectors to translate genetic and epidemiological knowledge into clinical tools that support decision-making in terms of diagnosis and care aimed at both general practice and highly specialised endometriosis clinics – all via machine learning and artificial intelligence.

How beneficial technology is in improving care for endometriosis sufferers?
FEMaLe relies on participatory processes, advanced computer sciences, genetics, state-of-the-art technologies, and patient-shared data to deliver a mobile health app for people with endometriosis (Lucy App) as well as a computer vision-based software tool for real-time augmented reality guided surgery of endometriosis (SurgAR).

By collecting patient-reported data on symptoms in a large random sample of people in the reproductive age using the Lucy App, FEMaLe will get updated estimates on the extent and geographical distribution of debilitating pelvic pain in this group. By linking this information with existing data on diagnoses of endometriosis, it will be possible both to get an estimate of the health-related and social consequences of diagnostic delay, but also to develop a description of people with endometriosis to be used to achieve early diagnosis and treatment of endometriosis with pelvic pain.

What are your future plans?
The societal issues surrounding endometriosis transcend borders. The announcement of a National Endometriosis Action Plan in France in 2022 is progress. However, no other nation in Europe has decided to tackle the societal problems with endometriosis on a political level with strategies and dedicated funding. Considering the far-reaching implications of the disease, this is unacceptable.

> **It is of utmost importance that each and every member country of the European Union recognizes the severity of endometriosis, acknowledges the societal problems resulting from this illness and increases the quality of life for patients strategically through national and international policies.**

From your experience what is the biggest challenge that patients face?
Those with endometriosis are at greater risk of infertility, multisite pain, and other co-morbidities. Persistence and recurrence of symptoms are common regardless of available treatments. FEMaLe seeks to combat the negative effects of the disease on patients, particularly the heavy impact on work, relationships, and the sex-lives of people with endometriosis, and challenges to healthcare providers in primary and secondary care.

We will enable patients and healthcare providers to performing shared decision making to improve informed decisions, patient safety, and personalised treatment regimes.

> **Imagine if endometriosis could be diagnosed and treated sooner to bring this burden down – not only for those affected by endometriosis, but also for society in general.**

What is the scope of FEMaLe?
FEMaLe brings forward a deeper understanding of complex diseases, not just endometriosis. We will co-create digital tools with patients and healthcare providers to help stratify patients for much more accurate diagnosis and to personalise the selection of the best drugs.

The estimated annual cost of endometriosis per person affected is an astonishing 9,500 EUR, due to loss of productivity and direct health care costs, similar to diabetes, Crohn's disease, and rheumatoid arthritis. Preventive responsive actions to people suffering from diseases, including endometriosis, will greatly optimize the quality of life and also reduce healthcare costs, e.g., through reduced number of surgeries, hospitalisations and rehabilitation programmes. Based on estimations from health maintenance organizations, FEMaLe may be able to reduce overall cost of endometriosis treatment by at least 20% in the long term.

Are healthcare institutions and doctors willing to look at how they can integrate AI in patient care?
FEMaLe stresses equity, ethics, and empowerment through education in health literacy, and we will ensure that all patients, whether vulnerable or resourceful, and healthcare providers can use the clinical decision tools and achieve maximum benefits.

Ulrik Bak Kirk
Chief Consultant and FEMaLe Coordinator (ID: 101017562).
PhD Fellow studying video consultations in general practice.

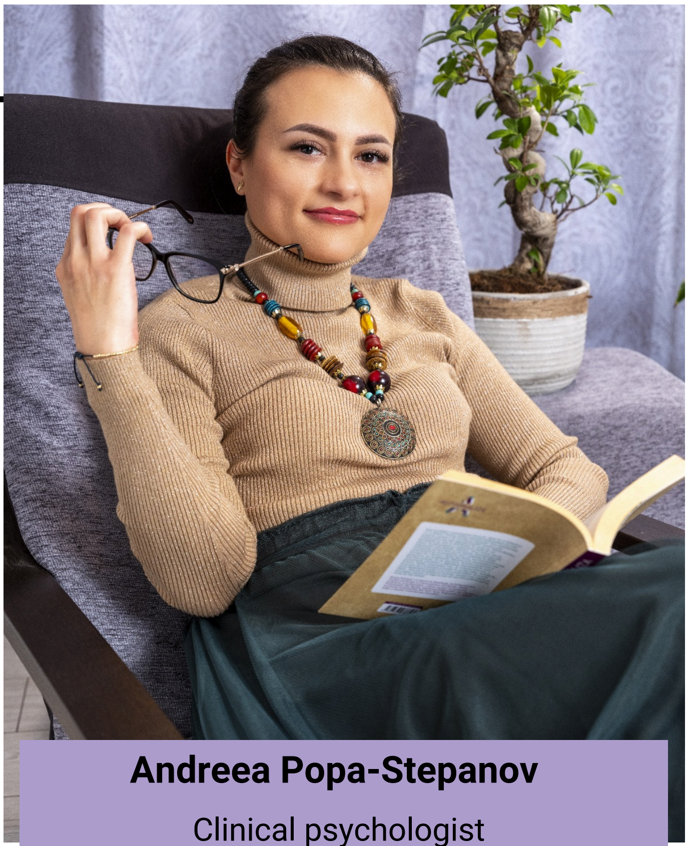
The importance of psychological counseling in patients with endometriosis

Eendometriosis is a chronic condition that has a negative impact on the life of a sufferer, including on the career. Women with endometriosis generally experience medical and social abuse, which also affects their emotional state. In addition to excruciating pain, women with endometriosis also have to deal with doctors who do not believe them and who tell them that the pain is in their head. Ms. Andreea Popa Stepanov, clinical psychologist, explains more about the importance of psychological counseling for women with endometriosis.

Endometriosis is a condition that requires the attention of a multidisciplinary medical team, including a psychologist.

Its role is essential, especially in psycho-emotional preparation before surgery, to reduce anxiety and stress associated with surgery.

> Psychological counseling before endometriosis surgery is an essential resource in managing negative thoughts and emotions.



Andreea Popa-Stepanov

Clinical psychologist
Psychotherapist of psychodynamic orientation
Specialization in work and organizational psychology
Business & Life Coach
NLP Practitioner, Time Line Therapy™, Hypnosis

The first objective I have in mind in meetings with patients is to help them see the surgical intervention as a solution, to trust the medical team and this whole healing process.

Another stage of psychological counseling is the understanding that the psyche constantly interacts with the body. Thus, the success of the intervention and the postoperative recovery largely depend on the psychoemotional balance of the patient.

Another goal I pursue with patients is to assess their level of anxiety and identify automatic thoughts specific to the context in which they are.

The most common fears of patients who are going to undergo endometriosis surgery are: the success of the operation, the pain felt after the operation, how long the recovery will take and when they will be able to return to their normal daily activities. The most common fear is related to the recurrence of the disease. Therefore, it is essential that patients receive all the necessary information about the surgical procedure.

Knowing the details of what will happen during surgery and what the post-operative period entails helps reduce uncertainty and lessen fear.

It is necessary for patients to understand that it is not the surgical intervention itself that causes their emotions and behavior, but their own thoughts, or, more precisely, the way in which they interpret the event. In order to be aware of the connection between the activating event, thoughts and emotional, behavioral and physiological consequences, I use the cognitive-behavioral ABC model. Cognitive restructuring is the technique by which maladaptive and dysfunctional thoughts are replaced with functional and adaptive thoughts, which will give rise to functional emotions, essential in the healing process.

From the category of relaxation exercises, the breathing technique is very useful for patients, being easy to learn and put into practice both in the pre- and post-operative phase.

Along with medical support, psychological intervention is a basic component of endometriosis treatment. The two ways of approaching the suffering patient are complementary, without replacing each other. Psychological counseling or psychotherapy addresses the emotional, cognitive, behavioral, and social aspects that arise from the illness and contribute to pain-related dysfunction.

Psychotherapy allows a better psychological adaptation to the surgical intervention and to the entire healing process, and the psychologist can support the patient during these trials, offering her the necessary tools to manage her thoughts, emotions, and behaviors.

The Endometriois CARE Act was reintroduced in the USA

Great news from the USA. A common effort of patients, doctors and patients organisations led to the Endometriosis CARE Act to be reintroduced at the Capitol. Part of the wonderful team who managed this were Shannon Cohn and Dr Dan Martin.

Dr Dan Martin, the newly appointed Executive and Medical Director of The Endometriosis Foundation of America, has shared with us a few facts about the Act.

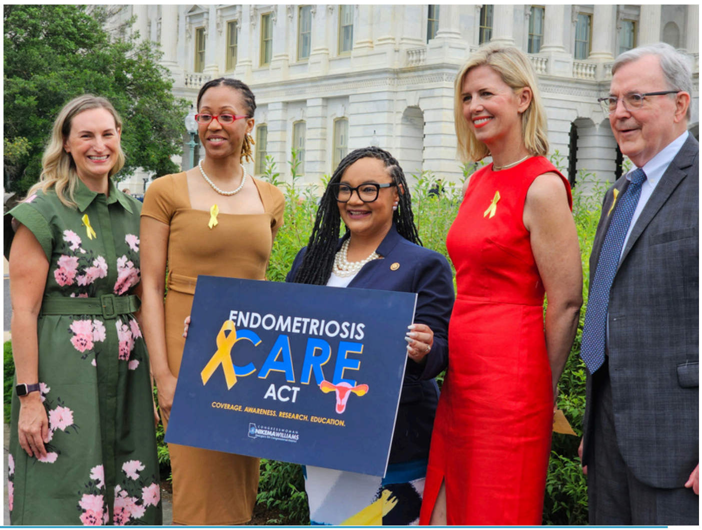
The bipartisan Endometriosis CARE (Coverage, Awareness, Research, and Education) Act, reintroduced on May 23, 2024, proposes annual investments over five years, including $50 million for research to improve treatment options and develop a cure for endometriosis. Additionally, the act allocates $2 million for public education about endometriosis, $2 million for disseminating information to healthcare providers, and $500,000 for a study on endometriosis disparities.

This initiative aims to raise awareness and improve care for over 10 million individuals diagnosed with endometriosis in the United States. An even larger group remains undiagnosed due to inequalities in care, lack of education, lack of access, normalisation of pain, and other barriers to proper treatment. Globally, it is estimated that more than 230 million people suffer from pain, infertility, swelling, bleeding, or other issues related to endometriosis.

t's time to address menstrual cramps that interfere with daily activities in adolescents and young adults as a significant problem. The initial treatment for menstrual pelvic pain is the same as for endometriosis. The difference arises when conservative management fails or when progression is suggested by changes on exam or imaging. With adequate awareness and access to care the extent of endometriosis has been limited.

A study by Knox et al. [PMID: 31292729] showed that no adolescents developed more than mild endometriosis over 10.2 years. While some advocate for early surgery, data indicates that early surgery leads to increased repeat surgeries, with up to 47% of those under 20 needing repeat surgery within two years (Yeung et al. PMID: 21420081). For ages 19 to 29, 36% required repeat surgery within two years, and 72% by seven years, decreasing to 14% and 24% for those aged 40 or older (Shakiba et al. PMID: 18515510).

Increased research is essential for the five general groups diagnosed with or concerned about endometriosis. Therapeutically, better answers are needed for the two most challenging groups: those with no response or only moderate response to medical or surgical treatment of pain or infertility. Research is also necessary for the next two groups: those with a good response to medical or surgical treatment and those found to have endometriosis incidentally during exams or surgery for other reasons. Understanding why these groups fare better may help improve outcomes for more sufferers. The fifth group includes those suspected of having endometriosis due to symptoms or family history. Proactive care, as used in Knox et al., may help limit their problems. Future non-invasive diagnostic tests, useful in general ObGyn, family practice, or emergency rooms, could enhance research and clinical care.



THE 7TH EUROPEAN ENDOMETRIOSIS CONGRESS

Held in a newly developed centre of Bucharest, Nord Event Centre by Globalworth, the 7th Endometriosis European Congress was held in Romania for the first time. With the aim of sharing the latest information on endometriosis the said congress had it all: live surgeries, various talks, symposiums, live scans presentations and of course, a party.

The congress was organised by Prof Dr Elvira Bratila, from Romania, and Dr Harald Krentel, the president of the Endometriosis European League and it started with 3 interesting pre-congress courses: ultrasound diagnosis of endometriosis and adenomyosis, ASEA session on Endometriosis-associated infertility and the EEL endometriosis school. The day ended with an information session on how centres are certified as specialist centres in endometriosis.

The second day of the congress started in a big way. Addressing hundreds of participants in the Summit hall was the president of the EEL himself, Dr Harald Krentel and Prof Elvira Bratila.

At dawn, as some might say, a group of endometriosis patients were on their way to, hopefully, a life with no pain. Transmitted live from Memorial Hospital, a Turkish network of hospitals, 3 complex surgeries in patients with deep infiltrating endometriosis. Two of them were performed via keyhole by Prof Elvira Bratila and Mr Shaheen Khazali, and the 3rd one was done robotically and was performed by Prof Horace Roman. The 4th surgery transmitted live took place in Portugal and was performed by Helder Ferreira.

These live surgeries were transmitted in two parts, with each surgeon taking their time to explain what they are doing. As in many such occasions, there was a panel of renowned endometriosis surgeons sharing their thoughts and experiences on performing complex surgery that requires bowel resection.

Of course everyone's attention was on the screen and the members of the panel did a great job by asking questions and extracting useful information for the participants.

In the other room, on the 1st floor, two different sessions took place, both equally important: ovarian endometrioma and optimising fertility outcomes. Speakers from France, Spain, Morocco, Turkiye, UK and Romania to name a few kept the participants captivated with presentations on ethanol sclerotherapy in ovarian endometrioma, ovarian stripping, and avoiding ovarian adhesions after endometriosis surgery.

For the fertility discussion, the new president of the EEL, Mr Mohamed Mabrouk touched on an important subject: Only one surgery in a patients lifespan, when is the optimal moment? As endometriosis impacts fertility, knowing when to operate in patients that wish to conceive, can be in some cases, crucial for the person in cause.

Following it was a networking and lunch break, with two sponsored symposiums: relugolix in endometriosis treatment, and specialist endometriosis centres. The former was moderated by Prof Hand Tinneberg, while the latest was a joint talk from experience from the only two specialists centres in Romania: EndoInstitute founded by Dr Voicu Simedrea and Endomedicare Academy founded by Prof Elvira Bratila, and presented by Dr Catalin Coroleuca, a member of her team.

The rest of the day continued with presentations of best videos and abstracts and imagining diagnosis as well as classification of endometriosis. Amongst spears for the day were Dr Vimee Bindra, Mr Shaheen Khazli, and Dr Jörg Keckstein.

Overall the information shared over the 2nd day was plenty and tailored for whatever area one might be interested in. Although the whole day felt fast-paced, it was one with many familiar faces and renowned specialists. There was lunch provided, coffees, water and pastries. Lots of photos were taken and I am sure that many contact details were changed.

Live surgery panel discussion, 7th June

“Horace, a fool with a tool is still a fool”

Dr Hudelist

Prof Horace Roman performed a robotic surgery and members of the panel were discussing the difference and benefits between laparoscopy and robotic surgery

The last day of the congress was as before with two consecutives sessions: one on adenomyosis where speakers talked about some of the most frequent questions of patients: types of adenomyosis, surgical and non-surgical options. Although non-surgical options are quite a few, Dr Rudy De Wilde, mentioned that in patients wishing to retain fertility higher consideration should be given. Dr De Wilde also stressed the fact that adenomyosis is a COMMON disease.

In the other room, the area of interest was represented by the use of new technology. From using AI to diagnose endometriosis, apps such as Lucy and the use of large data to diagnose endometriosis to the benefits and limitations of robotic surgery, and Enzian. The morning session was concluded with the impact of social media with participants such as Emma Cox, the CEO of Endometriosis UK and, I believe, Pille Pargmae sharing their thoughts on social media.

Soon after the network break the second part of the morning session started with talks on bowel endometriosis in the Summit Hall and information on managing treatment failure in endometriosis. That room was packed, showing how many doctors want to better understand endometriosis treatments.

During the launch break two simultaneous symposiums took place: a Davinci robot moderated by Dr Moawad with Mr Tsepov and Mr Khazali taking turns to share their experience in robotic surgery. The other symposium was a salivary test used for diagnosis of endometriosis, that seems to have a reliability of 95%.

After the lunch break, we were back to scientific sessions with the wonderful Prof Liselotte Mettler talking about the evident secrets of endometriosis, and awards announcements as well. Prof Horace Roman picked the award for the best video whilst Mr Ertan Saridogan took back to the UK the award for best abstract.

The day was yet to finish and we were very soon enlightened by a round table discussion with no less than 11 endometriosis specialists from all over the world. Each one of them had something unique to say about how far we have come in endometriosis, based on their experience, and what the future holds for us. The day was finished with sessions on topics such as diaphragmatic endometriosis, the risk of malignant transformation, mesh use in abdominal wall endometriosis and the use of robot in ureterolysis.

If a day before we saw 4 live surgeries, this time we saw live ultrasounds. The final talks of the congress brought to the table information on pelvic nerves and medical treatment in endometriosis.The congress ended up with a group photo of doctors sharing the same passion.

It wasn't only work, it was fun as well. Participants and speakers attended a gala dinner on Friday evening at one of the most poshest restaurants/clubs in Bucharest, Fratelli. It started with dinner followed by a round of dancing with all time popular songs. Dancing the night away as they say, many talents were seen on the dancing floors and a lot of enjoyment, with the lovely Liselotte Mettler being without any doubt the star of the night.

New executive board of EEL was announced and we also got to sing Happy Birthday to Dr Gaby Moawad. After all turning 20 is a big step. I had a chance to talk to him and I can say he is a very lovely person, funny and down to earth.

As with every congress, there were plenty of exhibitors at this congress as well covering medical equipment, medications and technology. Stands were spread over ground and 1st floor, with plenty of participants visiting them. The ground floor was dedicated to medical equipment and medication.

DuxM pharma solutions

An impressive stand of the DuxM had information on a supplement used for improving fertility in men and women. It was visited frequently by attendees and their leaflets and booklet were seen in many hands. Endometriosis and infertility sometimes can go hand in hand, so it is no surprise that the DuxM stand represented an interest for participants.

Meditrina

A pharmaceutical company from Romania, Meditrina had an interesting stand with 3 lovely staff: 2 ladies and a gentleman, who surprisingly was keen in learning about endometriosis. With a variety of informational leaflets for supplements used for the management of urinary infection as well as dietary supplements especially for women suffering from PCOS.

Medfusion

Managed by two lovely ladies, Medfusion brought to attendees attention one of their new supplements for endometriosis management and other gynaecology health issues.

Merck

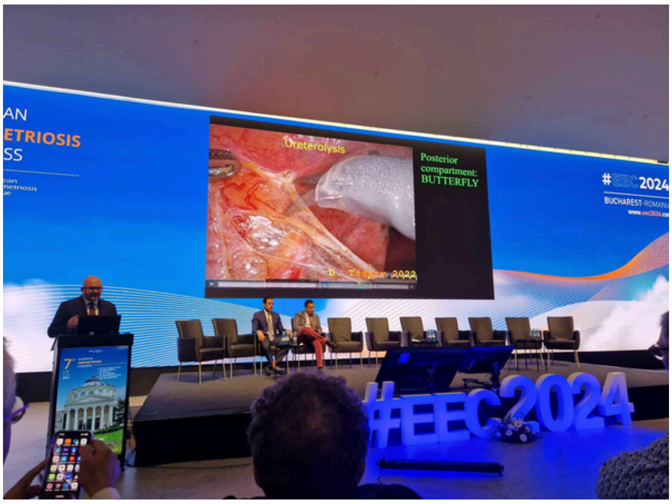
A global medical company, Merck had their own stand with information on hormonal medication use in IVF. A great news for Romanian patients is the restart of the national programme for IVF, a project that will provide vouchers for couples undergoing fertility assisted procedures.

Samsung

At the entry there was a Samsung stand, a provider of ultrasounds. Managed by a lovely young lady, the stand had on display a few ultrasounds such as: Hera W9 and Hera W10.

DaVinci

A revolutionary technology in minimally invasive surgery, the well-known company had their own stand on the ground floor with attendees being able to try the robot and find out its benefits. Davinci was also one of the sponsors of the robotic surgery symposium moderated by Dr Gaby Moawad, with Mr Khazli and Mr Tsepov sharing their experience.


Ureterolysis
Posterior compartment: BUTTERFLY
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EEL PRESIDENT
Dr. Harald K


7th EUROPEAN ENDOMETRIOSIS CONGRESS
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What is the rate of repeat su
patients?


7th EUROPEAN ENDOMETRIOSIS CONGRESS
6-8th June
EEL European Endometriosis League
Reoperation li
N=155 (14.2%)
Reoperation likelihood:
3% at 1 year
11% at 3 years
18% at 5 years
23% at 7 years
28% at 10 years
Horace Roman (France)


7th EUROPEAN ENDOMETRIOSIS CONGRESS
6-8th June 2024
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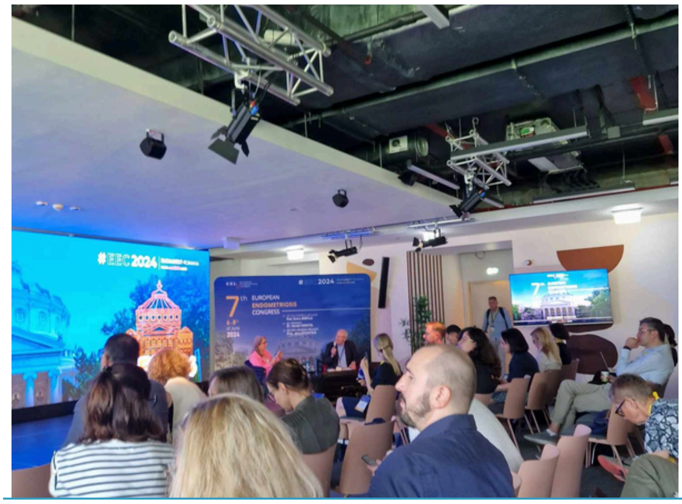
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Shaheen Khazali
Centre for Endometriosis and Minimally Invasive Gynaecology (CEMIG London)
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Asociația
persoanelor cu
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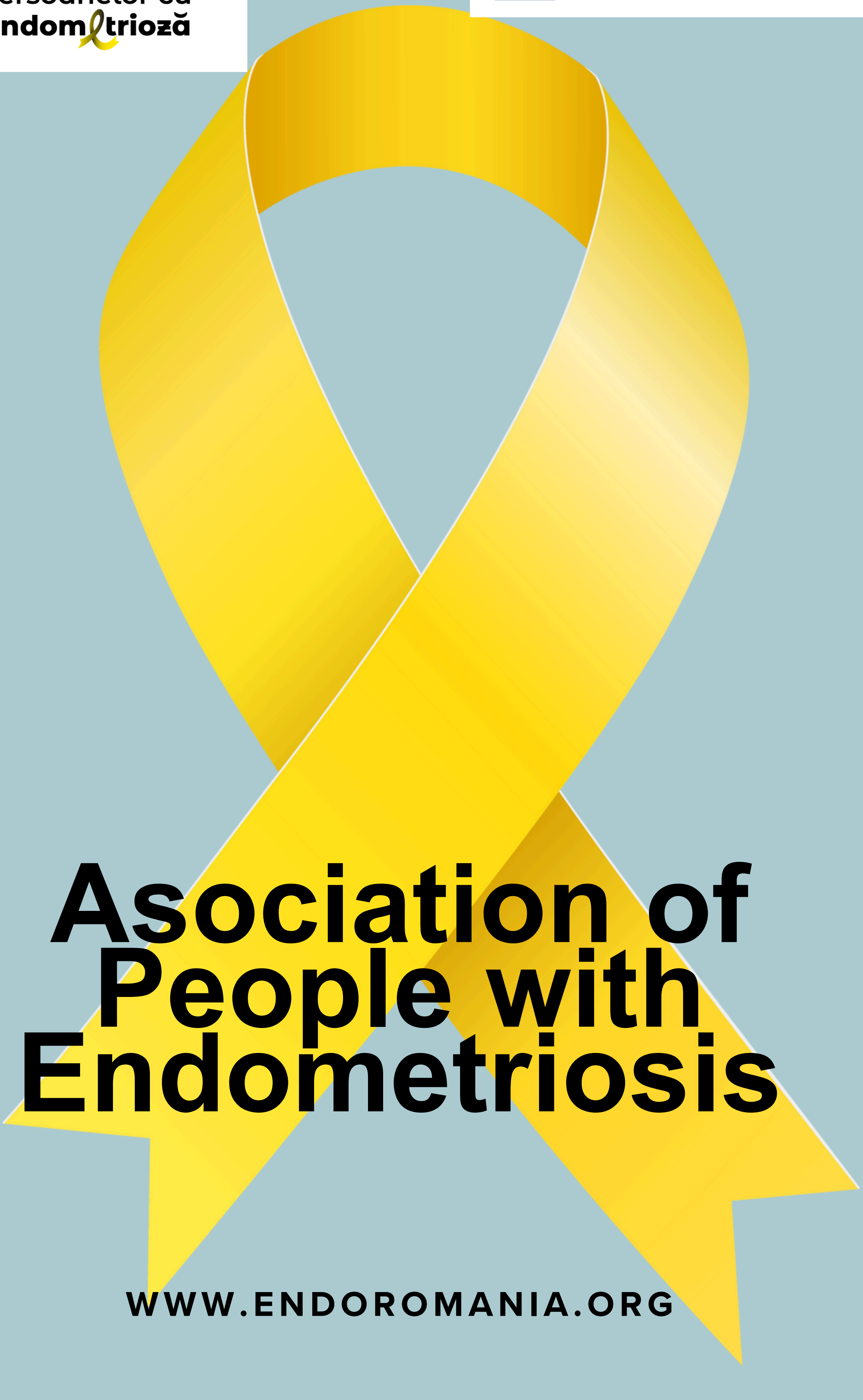

Asociation of People with Endometriosis

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