

ENDO LIFE

DIGITAL MAGAZINE



**Prof Dr Horace
ROMAN**
20 years of service
for patients with
ENDOMETRIOSIS

DR CHARLES NAGY

Complications of deep
infiltrating endometriosis of
the bowel

DR THIERS SOARES

The impact of uterine
diseases on fertility

MR ANDREA BILLE

Catamenial
pneumothorax

KRYSTAL COOK

FROM CANADA TO GREECE FOR
ENDOMETRIOSIS SURGERY, AND
A NEW LIFE



Athens Centre for Endometriosis

Multidisciplinary Endometriosis
Specialist Centre



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First, do no harm

Dr Konstantinos Kyriakopoulos
endometriosis excision specialist

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Greece**

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12,483 online readings of our 6 published EndoLife issues

Here's what has happened in the last year!

Welcome to our 4th issue of EndoLife magazine. We are thrilled to share with you many specialist articles as part of our mission to make a positive impact in our community, by bringing in one place information from worldwide specialists.

Firstly, I would like to express my gratitude to all doctors, patients and healthcare staff who contributed to our magazine. Your generosity and dedication to educate people on endometriosis is highly appreciated.

Second, looking back, it has been an incredible effort to produce 4 numbers in two languages, but well worth it. In terms of numbers, our 6 issues that were published so far, have been read on Flipbook 12,483 times. These numbers do not include Facebook, LinkedIn or Instagram statistics.

All our issues are available on Google books, Academia, Research Gate and our websites. And here we are, presenting our 4th issue, one that I can say is close to my heart. One because it's an honour to have Prof Horace Roman on the cover, and second, we have the most patient stories published so far, Krystal, Wendy, Lisa, Robyn and Karen.

December is a special month for me: In 2009, on the 2nd of December I landed at Heathrow from Greece, to live with my partner. It is also my birthday month. I have not celebrated my birthday in years now, but when I will turn 50 for sure it will be a big english-greek-romanian party.

This year I started a master with Faculty of Medicine of University College of London, called **Health Professions Education**. At the end of it, I will be able to teach/organise courses for healthcare staff.

I went to **The Endometriosis European Congress** in Bucharest, met some of these lovely endometriosis specialists from around the world. I played a small part in the screening of **Below the Belt** in Athens organised by Dr Konstantinos Kyriakopoulos. 2024 was a full year and I am looking forward to 2025. Happy holidays!

Camelia Serban

President and founder
People with Endometriosis Association
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With **Prof Dr Liselotte Mettler** and **Dr Gaby Moawad**
at the European Endometriosis Congress in Bucharest



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

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

Concept: Camelia Serban

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

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ADVANCES IN IMAGING DIAGNOSIS OF ENDOMETRIOSIS:

Impacts on Treatment and Patient Outcomes

Endometriosis, a chronic and often debilitating condition affecting millions of women worldwide, has long posed challenges in both diagnosis and management due to its varied presentation and complex progression. Over the past decade, significant advancements in imaging technologies have revolutionized the approach to diagnosing and treating this condition. These innovations have dramatically improved the precision of preoperative diagnoses, enabling the accurate identification of lesion location and severity. Consequently, these developments have contributed to better surgical outcomes, reduced recurrence rates, and fewer complications, representing a paradigm shift in the management of endometriosis.



Several of these pioneering studies were conducted by our research team here in São Paulo, highlighting the importance of collaborative and evidence-based work for the advancement of knowledge and treatment of endometriosis.

The Evolution of Imaging in Endometriosis Diagnosis

Historically, endometriosis diagnosis relied heavily on clinical examination and invasive laparoscopic procedures. While laparoscopic surgery provided direct visualization and biopsy of endometriotic lesions, it was limited by its invasiveness, cost, and accessibility—particularly for identifying deep infiltrating endometriosis (DIE).

The emergence of non-invasive imaging modalities such as transvaginal ultrasound (TVUS) and magnetic resonance imaging (MRI) has significantly improved diagnostic accuracy.

These tools offer high sensitivity and specificity, particularly for detecting complex presentations of the disease. TVUS has become a cornerstone in diagnosing and mapping endometriotic lesions, especially with advancements in three-dimensional (3D) and four-dimensional (4D) imaging technologies. MRI, with its superior soft tissue contrast and multiplanar capabilities, complements TVUS by providing enhanced visualization of lesion depth and extent.

A multicenter study analyzing the concordance between the AAGL 2021 Endometriosis Classification and preoperative imaging findings highlighted the reliability of TVUS in identifying severe cases (Stages III and IV). This underscores the critical role of imaging in modern endometriosis management, not only as a diagnostic tool but also as a guide for surgical planning.





SPECIALIST ARTICLE BY

MAURICIO ABRAO, MD

Former president of the AAGL, and a faculty member of the University of Sao Paulo, Obstetrics and Gynecology, Dr Mauricio Abrao is a renowned endometriosis specialist from Brazil, having contributed significant improvements in endometriosis care and research.

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Transformative Impact on Surgical Outcomes

Preoperative imaging has revolutionized surgical strategies by enabling precise lesion mapping and comprehensive pre-surgical assessments. Advanced imaging allows for more targeted surgical interventions, such as tailored approaches for bowel endometriosis, including shaving, discoid resection, or segmental bowel resection. These tailored procedures minimize complications and preserve healthy tissue, ultimately improving the patient's quality of life.

By identifying the exact location and extent of lesions, imaging-based planning reduces the need for exploratory surgeries. This is particularly important for managing deep infiltrating lesions that involve critical structures such as the bowel, bladder, and ureters. Minimizing intraoperative surprises through detailed preoperative imaging enhances both surgical precision and patient safety.

Reducing Recurrence and Enhancing Patient Safety

Recurrence remains a major challenge in endometriosis management, with residual disease often contributing to persistent symptoms and diminished outcomes. Advances in imaging have addressed this issue by facilitating complete lesion excision. The ability to map and remove all visible lesions significantly reduces disease persistence and recurrence.

Moreover, imaging technologies like TVUS with bowel preparation and advanced MRI protocols have improved lesion visualization, aiding in precise surgical planning and minimizing risks. For example, better visualization of deep lesions reduces the likelihood of complications such as fistulas or vascular injuries during surgery. This focus on safety not only shortens recovery times but also enhances overall patient satisfaction.

Emerging Technologies and Future Directions

The future of endometriosis diagnosis and management is promising, with emerging technologies set to further transform the field:

- **Confocal Laser Endomicroscopy (CLE):** This technology provides real-time, cellular-level imaging during laparoscopic surgery, enabling the identification of subtle lesions that might otherwise be missed. Early studies have shown its potential to enhance diagnostic accuracy and reduce the time between diagnosis and treatment.
- **Artificial Intelligence (AI):** AI-powered algorithms are increasingly being developed to analyze imaging data. By identifying patterns across vast datasets, these tools can improve diagnostic precision, standardize interpretations, and even predict disease progression.
- **Image Fusion:** Integrating data from multiple imaging modalities, such as TVUS and MRI, allows for more comprehensive diagnostic views. This fusion enhances the characterization of lesions and improves surgical planning and outcomes.
- **Noninvasive Biomarkers:** Research into protein and genetic biomarkers offers a potential complement to imaging technologies for early detection and monitoring. While not yet widely implemented in clinical practice, these advancements could transform endometriosis management by enabling more personalized treatment strategies.

Addressing Quality of Life

Beyond the clinical aspects, addressing the impact of endometriosis on quality of life is paramount. Tools such as the Visual Analog Scale (VAS) for pain assessment have become essential for evaluating symptom severity and guiding targeted interventions. Studies consistently highlight the correlation between severe pain (VAS ≥ 7) and reduced quality of life, emphasizing the need for early diagnosis and comprehensive care



Robotic Surgery in Endometriosis:

Advancements, Benefits, and the Team Behind It



Tanushree Rao

MBBS, MS, MICOG, MROCG,
FRANZCOG, AGES trained

Robotic technology allows for greater dexterity and stability, reducing the risk of unintended tissue damage. This precision is particularly beneficial in managing deep endometriosis lesions near critical structures like the bowel, bladder, and ureters.

Endometriosis is a complex condition that often requires surgical intervention, especially in cases where medical management is insufficient or when the disease is deep-seated. In recent years, robotic surgery has emerged as a cutting-edge approach, offering precision and improved outcomes for patients. But what exactly is robotic surgery, and why is it becoming a preferred choice?

What is Robotic Surgery?

Robotic surgery is a minimally invasive technique that uses advanced robotic systems to assist surgeons in performing complex procedures with enhanced precision, flexibility, and control. While the term 'robotic' may evoke images of robots performing surgery independently, it's important to clarify that the surgeon is always in control. The most common system in use is the da Vinci robotic platform, which translates the surgeon's hand movements into precise micro-movements of instruments. These instruments are inserted through small incisions and guided using high-definition 3D visuals, allowing surgeons to operate on intricate areas, such as deep pelvic endometriosis, with unmatched accuracy.

How Does it Function?

In a robotic surgery setup, the system comprises three key components:

- **The Robotic Console:** This is the control station where the surgeon sits. The console includes 3D visualization, magnified up to 10 times, providing a clear and detailed view of the operative field. The surgeon manipulates the controls, and these movements are translated into precise actions by the robotic arms.
- **The Patient Cart:** This component houses the robotic arms that hold the surgical instruments and the camera. The instruments have a greater range of motion than a human wrist, allowing for precise dissections and suturing in difficult-to-reach areas affected by endometriosis.
- **The Vision System:** This system provides real-time high-definition visuals, enhancing depth perception and offering a highly detailed view of the tissues and structures being operated on.



The Benefits of Robotic Surgery for Endometriosis

Robotic surgery offers several key benefits, including:

- **Precision and Control:** The enhanced visualization and the ability to perform fine movements allow for meticulous dissection of endometriotic lesions without damaging surrounding tissues.
- **Minimally Invasive Approach:** With small incisions, patients experience reduced post-operative pain, shorter hospital stays, and quicker recovery times.
- **Enhanced Surgeon Ergonomics:** The surgeon sits comfortably at the console, reducing fatigue during lengthy and complex procedures.

How many people are involved in robotic surgery and what roles they have?

A successful robotic surgery requires a well-coordinated team of specialists working together. Here's a breakdown of the key roles:

- **Lead Surgeon:** The primary surgeon operates the robotic console, directing the robotic arms with precision. In endometriosis surgeries, the lead surgeon must have a deep understanding of pelvic anatomy and robotic skills to meticulously excise lesions.
- **Assistant Surgeon:** Positioned at the patient's side, the assistant surgeon is responsible for changing instruments on the robotic arms, suctioning fluids, and helping with tasks that require manual intervention, such as repositioning tissues.
- **Robotic Technician (or Nurse):** The technician or nurse is responsible for ensuring the robotic system is functioning smoothly. They prepare the robotic instruments, dock and position the robotic arms, and troubleshoot any technical issues.
- **Anesthetist:** An anesthetist monitors the patient's vitals and ensures optimal anesthesia throughout the procedure. Robotic surgeries can be longer, so careful monitoring is critical.
- **Surgical Nurses:** The circulating nurse and scrub nurse work in tandem to provide necessary supplies, maintain sterility, and assist with patient positioning and preparation.



When is Robotic Surgery Recommended for Endometriosis?

Robotic surgery is particularly advantageous for cases involving deep infiltrating endometriosis, where lesions are situated near delicate structures like the bowel, bladder, and major blood vessels. It is also recommended for patients with large or multiple endometriotic cysts or when previous surgeries have resulted in extensive adhesions. In conclusion, robotic surgery has transformed the management of complex cases of endometriosis, offering precision, better visualization, and improved outcomes for patients. It requires a well-trained and coordinated team, each playing a crucial role to ensure patient safety and success.

Final Thought

If you or someone you know is considering surgical options for endometriosis, it's essential to discuss the benefits and risks with a specialist. Robotic surgery may not be suitable for every patient, but it has opened new avenues for treating complex cases effectively and with fewer complications.



Pneumothorax in endometriosis



Andrea Bille MD, PhD

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Catamenial pneumothorax is usually associated with endometriosis and happens within 72 hours since the period starts. From 3% to 6% of spontaneous pneumothorax (lung collapse) cases meet the definition of catamenial pneumothorax. The mean age of onset is 32-35.

Endometriosis can cause small holes or openings (fenestrations) in the diaphragm, which would allow air and fluid to pass through into the pleural space. Many women with catamenial pneumothorax also have endometrial tissue in the lungs, a condition called thoracic endometriosis. Another theory that has been proposed as a cause of catamenial pneumothorax is the spontaneous ruptures of blebs. Blebs are small blisters or pustules that may be filled with fluid or air and can develop on the lungs.

Some researchers speculate that hormonal changes during the menstrual cycle may cause blebs to rupture, which in turn can result in pneumothorax.

An episode of small pneumothorax may be treated with oxygen followed by observation and rest. Large pneumothorax may require the insertion of a chest tube to release trapped air and/or blood, thereby allowing the lungs to re-expand.



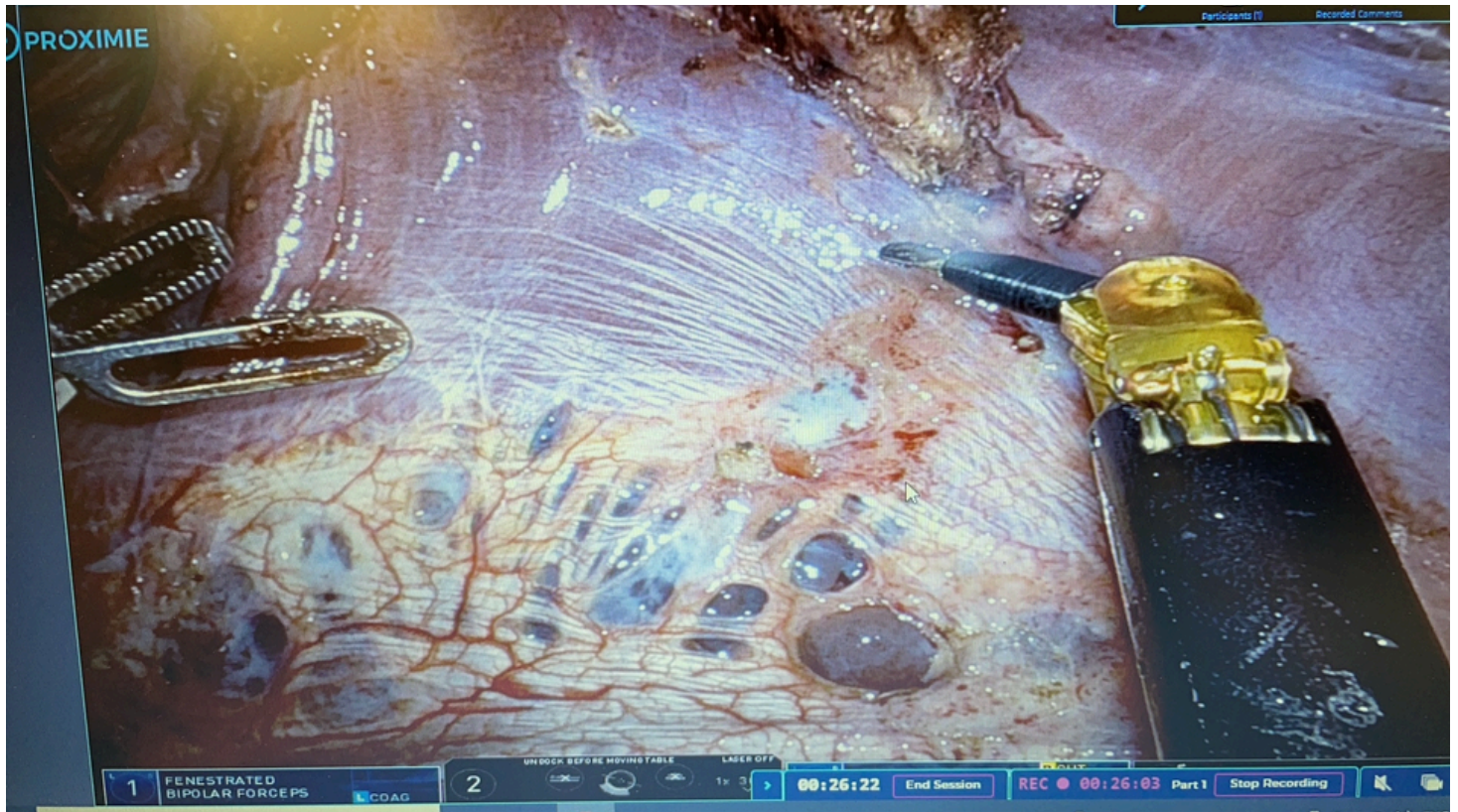


Photo: diaphragmatic fenestrations

Patients with catamenial pneumothorax may experience monthly episodes of chest pain that can radiate to the shoulder blades, shortness of breath or difficulty breathing (dyspnea), dizziness, fatigue, and a dry cough. Some women have reported a “crackling” sound upon inhaling during an episode.

Both surgery and hormonal therapy, either separately or in combination, have been used to treat women with catamenial pneumothorax to prevent recurrence.

Surgery may be performed to remove (excise) all suspected areas of endometrial tissue in the lungs and pleural space and to repair any damage or holes within the diaphragm. Surgery may also be used to remove small blisters located on the top of the lungs (apical blebs).

Surgery is performed minimally invasive, nowadays robotic surgery helps to achieve a more radical resection of all endometriosis and allows to repair the fenestrations in the diaphragm and mesh placement to repair the defect if big.

In addition, chemical pleurodesis may also be used to treat women with catamenial pneumothorax. Chemicals or drugs may be used to cause inflammation of the two layers of the pleura creating adhesions. Hormonal therapy may also be used to treat women with catamenial pneumothorax, usually as an adjunct to surgical therapy.

Surgery for catamenial pneumothorax is well tolerated, chemical pleurodesis may cause pleural thickening and chronic pain and should be used in case of recurrent pneumothoraces.



Dr Eduard Cernat Orthopaedic and Spinal Surgeon

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Qualifications and experience

- Fellow of the European Board of Orthopedy and Traumatology
- Fellowship in spinal surgery
- Worked in England, Ireland, and Belgium

Surgeries

- Hip and knee replacement
- Meniscus repair
- ACL repair
- Frozen shoulder
- Arthroscopy
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20 YEARS OF SERVICE FOR WOMEN WITH ENDOMETRIOSIS

For Romanians, Horațiu, for foreigners, Horace, and for all, Dr Roman, the surgeon known around the world as an expert in endometriosis. At the age of 10 he got so invested in medicine, that he never envisaged doing anything else. He graduated with a medical degree, top of his class, but life took him outside Romania in France, where he currently leads one of the largest endometriosis centers in Europe. He is an academic, does research and broadcasts live from his operating room at various medical conferences and congresses. Despite the impressive career he has, and the achievements, some are in national premiere, the surgeon Horace Roman is modest. Endometriosis is the condition that won him over, that fulfills him, a passion that he shares with all surgeons who trains with him. Mentor, colleague, friend, the surgeon who brings color back into the lives of women suffering from endometriosis, Horațiu Roman is admired and respected by doctors all over the world. 20 years dedicated to women with endometriosis, 20 years since the scalpel is his weapon for endometriosis, 20 years of fighting endometriosis.

Prof Dr Horace Roman

Specialist in endometriosis surgery
Franco-European Institute of Endometriosis

"I discovered endometriosis following a specialisation internship in an endometriosis center in France, in Clermont Ferrand, in the last year of my residency"



Why is endometriosis such a neglected disease?

At the moment, endometriosis is much less ignored than it was 20-30 years ago. In my 5th year of residency I would not have been able to diagnose endometriosis.

In residency training in France in the early 2000s, endometriosis was almost completely ignored. However, this is no longer the case in 2024, because at the moment there is a specific subject for the boarding school exam in France that I wrote myself. There are 10 pages that medical students have to learn almost by heart so that they can be able to diagnose, and solve a clinical case of endometriosis as part of their board exam. From this point of view, the revolution is extraordinary.

“Endometriosis has been rediscovered in the last, let's say 40 years, thanks to two phenomena, two revolutions that have taken place in medicine

First one is the introduction of laparoscopy, which allows us to see in the most hidden corners of the abdomen, the image is greatly enlarged, as such we can recognize endometriosis lesions much better than 30 years ago, when we looked with the eyes in open operations.

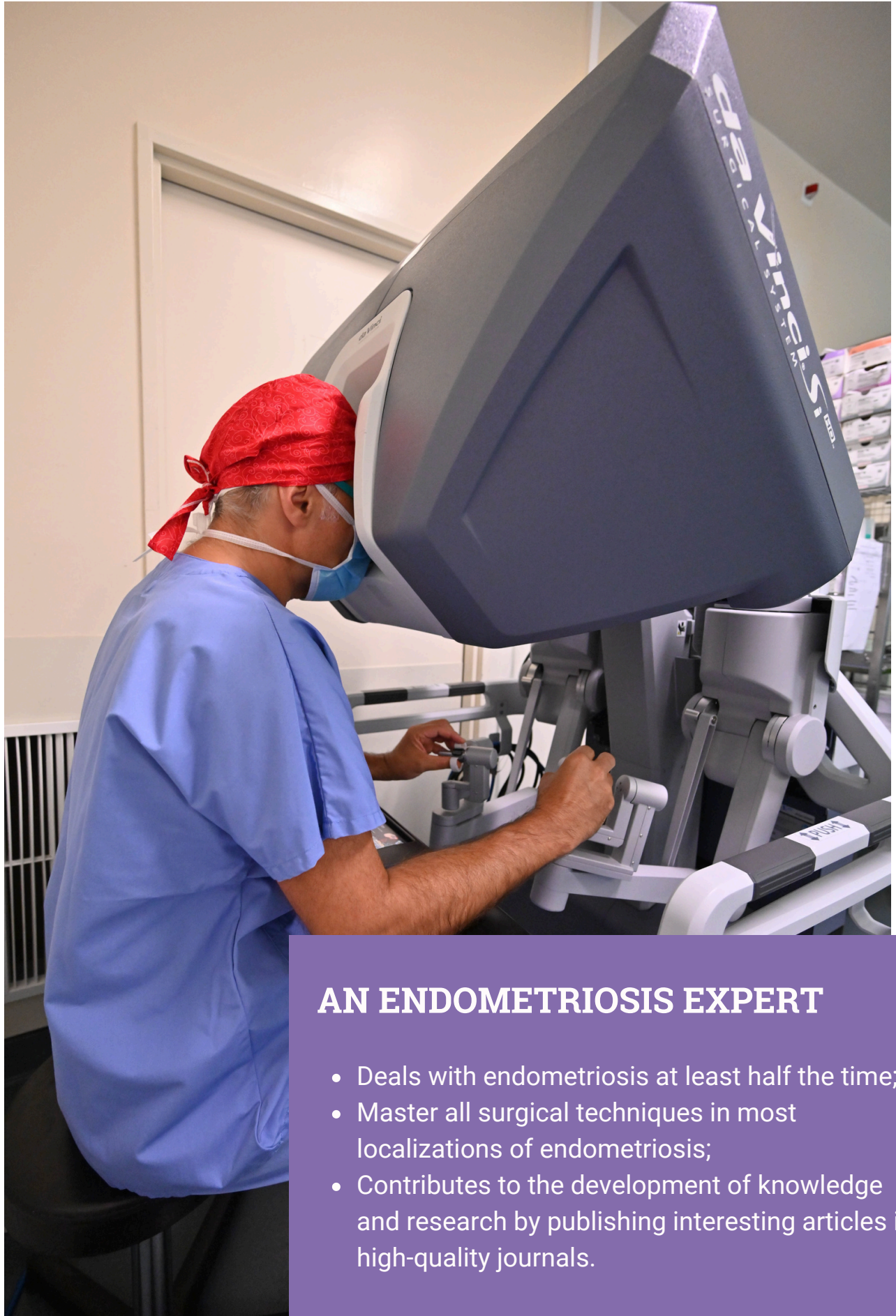
The second one is the MRI, which has allowed us to understand what deep endometriosis nodules look like. Like an iceberg, we don't see deep endometriosis nodules very well because they are under the peritoneum, outside the abdominal cavity, and I imagine that 50 years ago surgeons did not really understand either the appearance or the boundaries of deep endometriosis lesions.

In my opinion, we are seeing an increase in the prevalence of endometriosis in the general population because, at least in developed countries, women are menstruating much more compared to all previous generations, from the very early until the end of the 20th century. Pregnancies are much more rare, first pregnancy is late, after the age of 30. Plus, they breastfeed much less. Practically, all periods of physiological amenorrhea that previously somehow protected women from the development of endometriosis lesions, have been considerably reduced. The ubiquitous presence of endocrine disruptors around us can also influence the appearance and development of endometriosis lesions. The increase in the frequency of using infertility treatments may also contribute to the growth of existing lesions, in parallel with an increasingly frequent reluctance to use hormonal contraceptives.

When it comes to hormone treatment in a patient with endometriosis, the balance is clearly tipped in favor of benefit. The benefits of treatment far outweigh the risks and severity of side effects. This also applies to surgery. But the reluctance of certain patients is obvious, and if the doctor does not insist, does not take the time or does not have the patience to explain everything to the patient, to tell them what the risks are if they take the medication, but also what the risks are if they do not take it, then the abandonment of the treatment it's almost automatic.

“In medicine, whatever gesture we do, whether it's surgical, whether it's medical, we always do it juggling the balance between benefit and risk”





AN ENDOMETRIOSIS EXPERT

- Deals with endometriosis at least half the time;
- Master all surgical techniques in most localizations of endometriosis;
- Contributes to the development of knowledge and research by publishing interesting articles in high-quality journals.



What it means to be an endometriosis specialist?

I think being an endometriosis specialist can be measured very simply in the percentage of time or the percentage of patients you see. In my opinion, an expert in endometriosis is someone who deals, at least half the time, with endometriosis, who masters surgical techniques in 90% of endometriosis locations, who tries to make some contribution to the development of endometriosis knowledge and research by publishing articles in high quality magazines.



A surgeon who operates on endometriosis, uterine fibroids, uterine prolapse, ovarian cancer, uterine cancer, cervical cancer can say that he/she is a good surgeon, but s/he cannot say that they are an expert in endometriosis.

That to me is the definition of an endometriosis expert. Now, apart from endometriosis experts, there are many surgeons who are excellent and versatile and can operate on most forms of endometriosis with very good results.

When I started dealing with endometriosis 20 years ago, endometriosis initially represented 50% of my surgical work. In 2011, I completely stopped the treatment of prolapse and other uro-gynecological pathologies, and in 2013 I also stopped the oncology activity by performing a last pelvicectomy for advanced cervical cancer.

"The opposite of the expert is the polyvalent surgeon, which is very good in itself and very respectable"



It is not possible to be an expert in endometriosis, ultrasound, cancer, fibroid surgery, fetal medicine and uro-gynecology at the same time



I decided to focus not 50%, but 100% on endometriosis. I did it because I believe that you are better if you do only that. Now I work in an endometriosis center where we are 5 surgeons and the condition to enter our center is to only do endometriosis. We are 5 surgeons who only operate on endometriosis, of all types, all locations and all stages.

How is the patient with endometriosis?

I cannot describe a typical patient with endometriosis because patients are very different. Endometriosis is a very heterogeneous disease, in which we include many patients who have very little in common.

The first category is the patient who has endometriosis and chronic pelvic pain. Social isolation, professional failure, couple problems, possibly infertility. These are disastrous cases and often in these cases some patients have had multiple operations and basically the endometriosis that has been found is very moderate.

These patients are diagnosed with endometriosis, but their main problem is chronic pain that evolves on its own even in the absence of endometriosis. This category of patients is also the most difficult to treat, in my opinion, because in this case the surgeon cannot do much. The second category of endometriosis is patients who have very severe endometriosis, who have very significant symptoms during menstruation, but who feel relatively well outside of menstruation.



They have at least one week in the month where they live almost normally, they come back to life. These patients may have very important digestive, urinary, diaphragmatic or pelvic nerve injuries; in these cases, the bigger the lesions, the more effective the surgery.

“For patients with severe endometriosis, a complete surgery performed by an expert brings them enormous benefits”.

We have another category of patients who come to the consultation after their endometriosis is discovered. They have a path of infertility, a path of pain, where they were told that they have nothing, that everything is psychological, and at some point endometriosis is finally discovered. Some of them are relieved that something has finally been found. Another part is outraged because it took them so long to be diagnosed with what could actually have been discovered years before.

There are also patients who are focused on infertility so that if endometriosis appears only as a factor in infertility they want to solve it, but only to the extent that it would help them become mothers. There are many typologies of endometriosis, which is why I am convinced that when you spend most of your time on endometriosis, you come to understand each typology and have a different discourse in front of each one. Because you have every chance to understand what they want and what they expect from you, and then effectively the conversation goes in the direction of their desires, meaning that we accompany them towards what they want to achieve, pregnancy, pain or other symptoms relief.



I recognize the patient with endometriosis and chronic pelvic pain from the waiting room. She is sad, when she gets up her position is slouching, you get the impression that she is carrying all the pain of the world on her shoulders.

What do you consider to be your biggest achievement so far?

It is difficult to choose one, because the career of a doctor is a long road that develops in steps. The first step was graduating from the University of Medicine in Cluj in 1993; there were several colleagues with identical results, but as a result of voting, I was chosen chief of that year class graduation, which left me with an unforgettable memory. Another decisive step was the specialty exam that I obtained at the French Embassy in Bucharest in 1994 and which allowed me to start a career as an intern in neurosurgery in Paris. Another was the medical intern exam that allowed me to become a surgical intern in 1998. Another step is the position of assistant professor or head of clinic in gynecological surgery in the service I wanted in 2004. For me it was an additional step to be naturalized in France in 2001, so that I could make a career in French hospitals because at the time I started, Romania was not part of the European community. I was therefore forced to become French to be able to pursue a career in France, which is no longer the case. Another very important step was the doctorate in medical sciences in 2008. Then the moment I was appointed professor in 2011.

“Among the moments I will never forget is the first broadcast live surgery at an international congress”

There are also moments that I will never forget, such as, for example, the first surgery that I broadcasted live. I was in my operating room broadcasting live at an international congress, I had to explain in English everything I was doing, answer questions, do a proper job because I was watched by hundreds of colleagues. That moment happened two weeks after the birth of my last little girl, so I was also in a state of extraordinary fatigue, because I didn't sleep at night. I know that in the moment I came in contact with the amphitheater where the conference hall was, I woke up instantly.



Another important moment is when I decided to leave the public system and the University Center of Rouen and create the Franco-European Multidisciplinary Institute of Endometriosis (IFEMEndo) in Bordeaux, which was actually followed by an explosion in the volume of surgical activity. Now, I am in a private system, I no longer have the limits of public administration. I set the limits, we can increase the activity practically unlimited, we can open a center in another city or in another country, we opened a center in Abu Dhabi, we can consider it possible to open a center in Romania, we can open a center in Morocco, so everything is possible as long as we have health and energy.

How much does ego affect medicine?

I believe that immeasurable or exaggerated ego in medicine or any other profession, can only affect. Medicine is a field that is very dynamic, changes are important, surgical techniques are renewed all the time and the moment you are not aware of this, you can be overtaken quite quickly. Usually in science, where research is done, you always start from the idea that you're probably wrong and try to prove otherwise.

At the moment, I have written more than 230 articles in different peer-reviewed journals, and most of the articles start from a question that patients or colleagues asked me, or from the criticism of some colleagues, to which I tried to answer with a study in which we checked whether what I am doing is correct or not. Sometimes I demonstrated that my technique was better, other times I found that I was doing no better than the reference technique.

"The more you advance in your career, the more there are those around you who, for various reasons, tell you that you are terribly good, that you are formidable, that you are the most wonderful."

My opinion is that I managed to control by this age, the ego. I can't say how it will be in the future, because the more you advance in your career, more people around you, for various reasons, will tell you that you are the best, that you are formidable, that you are wonderful. It's very easy to lose track of reality. But, in my opinion, there are many doctors who, even on the verge of retirement, have kept this self-critical spirit, and above all, they are always trying to self-evaluate and prove that what they are doing is correct.

"It is very important to be very receptive to everything you do, and ego blocks you from being receptive"

I personally have changed my surgical strategy several times. For example, in colorectal endometriosis, I started by doing colorectal resections around 2004-2008, then I tried to show that shaving is better between 2009-2014.

I conducted the only randomized trial in the literature where I failed to demonstrate the superiority of shaving, In the end I developed the discoid excision so that I have several techniques from which I can choose the most suitable one according to patient needs.

So I didn't hesitate to change what I was doing several times during my career. For endometriosis cysts, I started like everyone else with a cystectomy, after which I did vaporization with plasma energy, now I also frequently perform alcoholization. I think it is very important to be very receptive to everything that is done in other centers. And of course, ego prevents you from being receptive and doubting yourself. Adopting a technique introduced by someone else means that you inevitably accept that they can do better than what you have done so far.

What lessons you received in the 20 years of experience, and what mistakes did you make?

The first lesson I received was when I discovered endometriosis in the Clermont Ferrand center. Fascinated by this disease, I told everyone that I was going to become an endometriosis surgeon and I was going to focus exclusively on endometriosis.



I started writing to all my correspondents that I am ready to deal with all endometriosis patients. At that time, in 2003-2004, there was no surgeon who dealt exclusively with endometriosis. However, I followed the lesson received from a professor from Clermont-Ferrand who told me: *Be careful, this is a disease in which there is a lot to do, there is a lot to discover.*

The second lesson was given by my thesis supervisor who told me: *If you want to dig deep, dig in one place.* He basically advised me to focus on one disease, and I chose endometriosis, which seemed like a pretty crazy idea in the 2000s.

The third lesson he also gave me. He told me: *From the beginning you have to create a database to register the patients that you operate on them. Because when you want to do a study and you go back to the medical files, you have a lot of missing information and you won't be able to do anything really scientific.*

Creating a database from the beginning, turn out to be one of my strengths. At the moment, at IFEMEndo we have a database with over 5,000 operated and registered patients. Afterwards, I received a lot of lessons, from fellow gynecologists, from digestive surgeons or urologists, and I have taken in as much as I could.

I also receive lessons from patients

I receive lessons every day, including from patients. The role of nutrition and its importance in symptom reduction and well-being I learned from the patients. Until 2-3 years ago, nutrition was not much talked about in endometriosis congresses. Every time a patient tells me: *I did this and I feel much better*, I ask them more, I ask for information, so that I can give advice in my turn. Practically every day I learn something.

The disappointments you can have in surgery are many. I have always stated that our profession, surgery, is a dangerous one. Disappointments are operated patients who suffers complications, patients who feel worse after surgery, despite the fact that you have done a surgery that you are very pleased with. There are a few cases like that, I know them by heart. Surgery is a rather thankless job because even if at the end of the operation you feel that you have done the most beautiful intervention in the world, the results are not up to par. And unfortunately, the result can be quite unpredictable.

I always do the same gestures with the same attention and patients do not always have the same result. For example, I remember in 2006 I won a national award with a film of colorectal resection and the film was actually a very beautiful intervention. Surprisingly, the functional outcome was mediocre, one of the most severe surgical failures I had at that time. A young patient whose digestive tube and bladder were as if paralyzed, had a very complicated 2-3 years. And I have never been able to explain to myself at what point the two organs were denervated.

How do you deal with them?

Failures are complicated, I don't live them well at all. I try to be as responsive as possible. If the patient wants a consultation, she has it immediately. I try to help them as much as I can, to refer them to specialists who can bring them the slightest improvement, so that their lives become more bearable. Medicine is not mathematics, and surgery even less so. There is an element of randomness, of unpredictability that is extremely embarrassing, especially when you are embarking on very complex surgeries. This is probably one of the reasons why many surgeons avoid focusing solely on endometriosis. I remember in 2008 an endometriosis specialist in Paris advised me: *Deal with other pathologies as well, because otherwise you will end up crazy.*

How is it that you are so respected by your colleagues, even though in theory you are in competition?

I think I am respected for two reasons. First for what I have done, because I have a high volume of surgeries and publications that are important.



Secondly, by the fact that I have always had very good relations with everyone. The door to my OR was always open to anyone who wants to come.

"I am not in competition with anyone. And I think that the others are not in competition with me either"

I think it's about competition when we would be more surgeons than patients. Then the competition should be fierce, because inevitably some surgeons will run out of patients. But in endometriosis we are in the opposite situation, the number of patients increases every year, in any case at a faster rate than the number of specialists in endometriosis. So I don't think we are in competition with each other.

At IFEMEndo in Bordeaux, I always have four foreign doctors in training or fellowship. When one of them leaves, s/he is automatically replaced by someone else from another country. From 2018 until now, we have received more than 350 surgeons from all continents, who greatly appreciate the time they spend in Bordeaux. They all emphasize that the team is very welcoming, complex surgeries are practically everyday and the discussions are very relaxed.

"I try to have a very relaxed life for the simple reason that I like what I do. When I like what I'm doing, I'm relaxed. And I am glad that I have the opportunity to do this job, to receive colleagues from abroad, and to see that the team members are proud that we are so visited. I only have reasons for satisfaction when I come to work. The moment the job becomes a hobby, you no longer have the impression that you are working".

Are your children following in your steps?

No. I have three daughters aged 15, 13 and 12. None of them want to do medicine. They are all more focused on art, or creation. They all know endometriosis well. The two eldest ones came to the clinic for work experience, they were in operations, they saw me operate. At home I work all the time on surgical films, and on my mobile the intraoperative pictures alternate with those of the family. When the girls look over my shoulder to see what I'm working on, it's always an intraoperative film. They are all very aware of what endometriosis is and what I deal with, and I think they are proud.

A memorable moment is related to my youngest daughter, who was 8 years old and in the third year at school. One day, the teacher said to my wife: **Mrs. Roman, I'll tell you something that happened, Violeta amused me a lot.** The teacher had asked the children to write the name of a famous person. The kids wrote Johnny Depp, President Macron, Kate Perry, only my little girl raised two fingers and asked: **Can I write my daddy's name?**

The teacher said **yes, if you think he's famous.** And Violeta answered: **yes, yes, he is the best endometriosis surgeon.** Even though she is proud of her father and knows what endometriosis is, she doesn't want to do medicine either, because she is passionate about ecology and recycling materials.

If you had to start from scratch, what would you choose?

Same thing. From the age of 10, had no intentions to do any other job than that of a surgeon. At the age of 10, I saw the movie "Red Apples" with Mircea Diaconu and decided to be a surgeon. Everything I did from that moment on was with one goal: to practice medicine and become a surgeon.

All holidays, all weekends I was in the operating room



I entered an operating block for the first time on the first day of the summer vacation after year 1. At that time, under Ceaușescu, there were no residents, because attestations were made on vacant posts. The block of flats of Dej Hospital where I was lived had only a few residents and I had the incredible chance to meet a unique character: Dr. Vaida, an accomplished surgeon with a terrible sense of humor. He liked me from the beginning and I became his student. From that moment on, every holiday, every weekend I was with him in the operating room. My parents used to say to me: **Go and do something else, have fun!** But I answered them that I felt great there. What reason would I have to sit for hours on a terrace, smoking and drinking beer if the operating room was the place that I felt great in?

When I was in Romania, I was very invested in digestive surgery, of course a beginner, I pulled of valves until I could no longer feel my shoulders, but I also did appendicitis or hernia operations. When I came to France, for 4 years I did neurosurgery, and operated on intracranial hematomas, brain tumors, aneurysms. After that I changed the field to gynecology, and finally I discovered endometriosis. Indisputably, endometriosis has brought me so much satisfaction that I have no intention of doing anything else. If I were to start from the beginning, I would follow the same path.



"Endometriosis has brought me so much satisfaction that I have no intention of doing anything else. If I were to take it from the beginning, this is what I would do"

What unfulfilled dreams do you have?

I would have liked us to develop more. A dream would have been to create a chain of clinics worldwide, IFEMEndo clinics, modeled after the IVI-AHR clinics that exist in fertility, to be considered standard, among the best in the world. But this dream is very ambitious today, when advanced surgery is extremely expensive, so I don't have the financial means to fulfill this dream, nor the time. But I don't see the fact that I might do this dream come true as a failure.

You mentioned Abu Dhabi, are you also planning an IFEMEndo center in Romania?

Very recently, the meeting with a former PhD colleague, Dr Ovidiu Gogu Cacuci, opened up an unexpected perspective for me: the establishment of an IFEMEndo center in the very city where I studied medicine, in Cluj Napoca. The model we proposed is similar to that of the IFEMEndo-Middle East Clinic in Abu Dhabi: the creation of a local team of gynecologists dedicated to endometriosis, assisted by expert surgeons in general and urological surgery, and other colleagues from other specialties, to come for training in Bordeaux and to apply the same endometriosis management strategy. My role will be to help them, coordinate through weekly online staffs, but also through my periodic presence in Cluj. This center will be opened at the Medicover Clinic in Cluj Napoca in March 16th, 2025. I am very confident in the success of this project in which I will put not only my energy but also a lot of soul.



The impact of uterine diseases on conception and pregnancy

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What are some of common diseases of the uterus that can impact fertility?

The most common uterine conditions that can affect fertility include fibroids, adenomyosis, polyps, and uterine septum, for example. Each can influence the ability to conceive naturally or impact pregnancy outcomes.

What is the function of the uterus in conception?

The uterus plays a crucial role in conception by providing a good environment for a fertilized egg to implant and develop. It supports the embryo through pregnancy, accommodating growth and enabling nutrient exchange through the placenta.

What is the difference between fibroids and adenomyosis when it comes to conception and pregnancy impact?

Fibroids can directly distort the uterine cavity, affecting implantation, while adenomyosis may impact the muscle function and create a more inflammatory environment.

We know fibroids are of different types. Which one of them affects conception, natural or medically assisted and how?

Fibroids can be of various types, such as submucosal, intramural, or subserosal. Submucosal fibroids, which distort the inner uterine cavity, are more likely to affect conception, especially with natural or assisted reproduction methods. Some intramural fibroids can also affect conception, mainly if they are too close to the uterine cavity.

Do fibroids and adenomyosis occur at the same time and if so, what is the best course of action for someone who wants to get pregnant?

Yes, both conditions can occur simultaneously, around 50% percent of the patients with adenomyosis have fibroids. If a patient wants to get pregnant, it's essential to assess the size, location, and severity. A Gyn surgeon might recommend treatment or monitoring, depending on how these conditions impact the uterine cavity and function.





Given that adenomyosis does not obstruct the cavity, is it risky for conception?

Adenomyosis doesn't obstruct the uterine cavity, but it can create an inflammatory environment that may affect implantation and pregnancy. Therefore, it can present a risk for conception, but the level of risk varies individually.

In a pregnancy with fibroids and adenomyosis, what obstetrical risks exist?

These conditions can increase the risks of preterm labor, miscarriage, and placental abnormalities.

Will the foetus be affected by fibroids?

Large or cavity-distorting fibroids may restrict the space available for the fetus, potentially impacting growth and positioning. In some cases, fibroids can increase the risk of complications, such as premature birth.

What happens with fibroids and adenomyosis during pregnancy?

Fibroids can sometimes grow in response to pregnancy hormones, while adenomyosis might not change significantly. However, both conditions can contribute to increased discomfort and may need monitoring during pregnancy.

In case of multiple fibroids of various sizes that affect the uterus wall and impact cavity as well, after surgery, will the shape of the uterus be distorted, and if so, how will this impact conception and pregnancy?

Myomectomy can impact the shape and integrity of the uterus, which may affect future pregnancies. Scar tissue from surgery could impact implantation or increase the risk of uterine rupture (although rare) during pregnancy, depending on the number and depth of fibroids removed.

Based on what country one might be living in, there are some surgical and non-surgical methods for adenomyosis and fibroids. The opinions regarding their impact on fertility vary. Do we have any studies that show some long-term results for negative and positive outcomes?

The outcomes of treatment can vary. Some studies show that surgical treatments, such as myomectomy for fibroids, can improve fertility in suitable candidates, but it may also introduce risks. Non-surgical treatments are generally less effective for fertility improvement. Outcomes depend on individual factors like age, severity, and other reproductive health conditions. A conservative but promising technique for the treatment of fibroids and adenomyosis is ablation, either by radiofrequency or microwaves. Initial studies show good results, but more studies are needed in the future.



Multidisciplinary team meetings for endometriosis

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Why do we need multidisciplinary care in endometriosis?

Endometriosis is a widespread chronic condition with varying impacts. For some, it significantly impairs quality of life, comparable to other chronic diseases. A patient-centered, individualized approach - considering factors such as age, family planning goals, symptoms, and clinical history - has become a cornerstone of care.

Advancements in diagnostics, classification, and treatment have led to increasingly personalized approaches. Endometriosis is now understood as a systemic disease, not just a localized condition. It can affect multiple organs, alter pain perception, and is associated with other chronic pain conditions. Complex cases, such as patients with chronic pelvic pain, patients with severe deep endometriosis involving the ureter and rectum, or patients with infertility often require multidisciplinary planning to achieve optimal outcomes.

As in many areas of medicine, there is a growing trend toward specialization. Certified centers focusing exclusively on endometriosis aim to provide efficient, high-quality care, particularly for complex cases. Surgical therapy emphasizes well-planned procedures to minimize repeat surgeries. The number of such centers continues to grow, offering comprehensive care tailored to individual needs. Multidisciplinary meetings (MDT) offer a focused and efficient approach for selected cases, allowing evaluations and treatments to be coordinated by a consistent team of health care professionals.



Today's medicine is increasingly complex; one person can no longer do justice to all specialties. MDT meetings may avoid fragmented, serial consultations and provide streamlined, patient-focused care. MDT meetings highlight the importance of collaboration in addressing the multifaceted nature of endometriosis and ensuring the best outcomes for patients.

What is the definition of multidisciplinary team?

An MDT refers to a group of professionals from various fields who collaborate to provide guideline-based, individualized therapy in complex cases, utilizing their concentrated expertise to offer the most efficient care according to the latest standards.



The multidisciplinary approach in endometriosis includes doctors from different field as well as other healthcare professionals, such as physiotherapists or endometriosis nurses.

What are the benefits of multidisciplinary team meetings?

Not every patient requires an MDT meeting, making careful selection is essential to ensure its benefits. MDTs should be reserved for more complex cases where issues are multifaceted, and multiple specialists can collaboratively provide efficient support to deliver the best possible care. The goal is to enhance treatment efficiency and outcomes, minimize frequent changes in health care providers/clinics or lengthy, serial, and potentially unnecessary investigations or therapies, and enable timely interventions and support. Additionally, we hope that an MDT can increase awareness, potentially leading to earlier diagnoses and referrals. MDT meetings for endometriosis, which should also include adenomyosis, appear promising based on experiences from other medical fields and few studies so far. However, scientific studies are needed to validate their effectiveness specifically for endometriosis and adenomyosis.

Apart from surgical members, what other members are needed?

Our recently published consensus paper recommends the regular involvement of the following non-surgical disciplines: General gynecologist, Reproductive Specialist, Radiologist, Pain Specialist, Endometriosis Nurse, and Physiotherapist. Additional specialists can be involved as needed, depending on the specific cases.

What is the preoperative work-up involved in endometriosis multidisciplinary care?

The initial pre-therapeutic work-up in endometriosis multidisciplinary care should not differ from the routine work-up in cases where multidisciplinary care is not required. This involves a detailed medical history with a focus on symptoms and previous treatments, followed by a specialized clinical examination with transvaginal ultrasound (TVUS) and renal ultrasound.

Depending on the findings, such as deep endometriosis that cannot be clearly defined by ultrasound or suspected multiple bowel lesions, an MRI may be necessary. Based on these findings, a pre-therapeutic classification should be performed. There are various classification systems; in our work, the consensus group primarily recommended the #Enzian classification, although others can also be used. An accurate classification of the disease helps all involved parties understand the findings and creates a common language, for example, between gynecologists and radiologists. Based on these findings, it should then be determined whether further treatment should take place at a specialized center and whether a multidisciplinary case discussion is necessary, such as in cases of chronic pain, complex fertility issues, extensive ureteral or bowel involvement. Additionally, further evaluations for the specific case can be considered as needed.

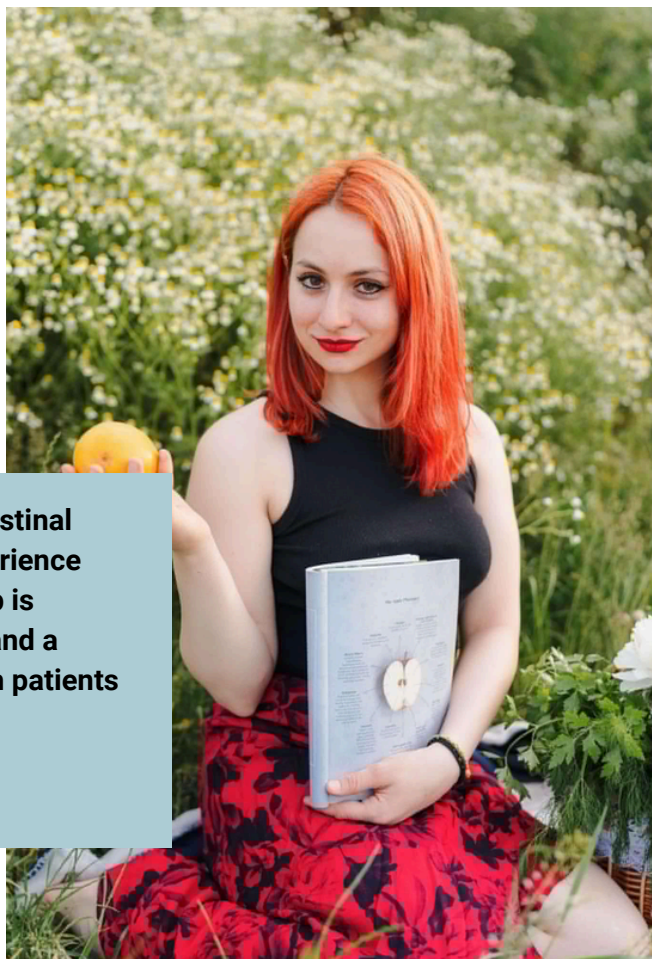
MDT meetings provide an opportunity for professional development and can help strengthen cohesion within the treatment team. All participants become familiar with internal guidelines and procedures. These meetings can also support the direct planning of treatments. Additionally, they could aid in quality assurance by documenting cases in a database, which could, in turn, promote research projects.



What we can eat during Winter Holidays

The importance of nutrition in women with endometriosis and adenomyosis

Passionate about everything that happens in our gastrointestinal tract and how it affects our health, and with 4 years of experience helping people achieve more optimal digestion, Evelin Papp is specialized in the low FODMAP diet by Monash University and a training course from King's College London. She works with patients with endometriosis and other gynecological, endocrine, autoimmune, gastrointestinal and eating disorders.



Diet plays a crucial role in management of endometriosis, as it can influence inflammation, hormonal balance, oxidative stress and the gut microbiome health, factors closely linked to the condition. Associations were found between diets high in fiber, antioxidants, probiotics, prebiotics, curcumin, omega 3, magnesium and decreased symptoms in these women. Adopting a balanced, anti-inflammatory, nutrient-rich diet can relieve symptoms of endometriosis, and working with a registered dietitian can improve the quality of life for affected women.

Specific Holiday Food Obstacles

During winter holidays, the consumption of traditional foods may include many ingredients that can cause digestive or menstrual symptoms, inflammation. This would be food that has a higher concentration of sugar (desserts, pastries, creams), gluten (cake, bread, most pastries), fatty foods (meats, sauces), dairy products (milk and other derivatives more concentrated in lactose), FODMAPs (fermentable carbohydrates such as lactose, fructose, fructooligosaccharides, galactooligosaccharides, polyalcohols, these aggravates bloating, constipation or diarrhoea, abdominal pain).

Evelin Papp

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FODMAPs are found in: wheat, barley, rye (alternatives: bread with mayo or gluten-free based on brown rice, buckwheat, millet), garlic (garlic-infused olive oil from Zaliari), onions, cruciferous vegetables, beets, mushrooms (except pleurotus mushrooms), legumes, apples, pears, grapes, plums, honey, cashews, pistachios, avocados, dairy lactose, mangoes, pineapple.

Identifying food triggers

Keep a food diary for several weeks, note the amount, preparation of the food, time of consumption and symptoms observed after you eat. This will help you manage food triggers much better during winter holidays.





Hydration and exercise

Put more emphasis on drinking water, teas, fruit-infused water, turmeric latte (curcumin is strong anti-inflammatory, add pepper, because piperine helps curcumin assimilation), as this can reduce bloating and constipation. Exercise, such as walking, yoga or pilates can help improve your digestion between holiday meals.

Organized meals

Organized meals can help reduce gastric discomfort, fullness, heartburn and transit problems. Avoid snacking between meals, eat only main meals that include protein, ½ plate of fiber and a quantity you are comfortable with.

Mindful Eating

Mindful eating can help reduce stress and unhealthy eating impulses, improving digestion and reducing endometriosis symptoms. Visualize The Hunger Scale before each meal, even during or after a meal. Imagine a Score from 1 to 10, try to stay at a level of 5-6-7 during the holidays. Determine your current hunger-satiety level and try to befriend it, find its balance. Try to chew food well (25-30x times), for 20-30 minutes, do not rush, because aerophagia can increase bloating.

Dietary fiber

People with intestinal hypersensitivity should reduce whole grains, due to their water-insoluble fiber content, focus on simple potatoes, white rice, white rice noodles. Obviously, if buckwheat, millet, quinoa, whole rice is tolerated, it can be introduced. I recommend focusing on the consumption of water-soluble fibers, introducing them gradually, such as: oatmeal, berries, psyllium to reduce transit problems.

How to prepare a healthy Christmas table

For a healthy Christmas meal, foods rich in anti-inflammatory and antioxidant nutrients are recommended, such as omega-3-rich fish, green vegetables that support liver detoxification, nuts, and seeds.

Foods rich in omega 3

Anti-inflammatory foods, such as those rich in omega-3 fatty acids (eg, fatty fish, flaxseeds, chia seeds, hemp, pumpkin, walnuts), can help reduce inflammation.



Support the estrobolome

Women with endometriosis often experience gastrointestinal problems and microbiome imbalances. Eating foods rich in probiotics and prebiotics can support digestive health and reduce dysbiosis. Probiotics such as Kombucha, sauerkraut, kefir, are rich in lactobacilli and bifidobacteria. Prebiotics such as dandelion tea, pomegranate, nectarines, fennel, chicory, artichokes, almonds, hazelnuts, spelt, and amaranth help regulate digestion. A diet rich in lignans such as flaxseed contributes to the excretion of excess estrogen. Two kiwis a day can help fight constipation.

Liver detoxification

Foods rich in vitamin B complex contribute to liver detoxification, such as: organs, eggs, salads, nuts, seeds, salmon, bananas, meat products. Other contributing nutrients are: magnesium (nuts, seeds, legumes), glutathione (spinach, strawberries, oranges), phospholipids (inositol from eggs, choline, oils, whole grains), flavonoids (antioxidants, include 2-3 colors from vegetables /fruit at every meal).

Reduce alcohol consumption

This habit regulates hormonal health, microbiome and reduces inflammation.

Find nutritious alternatives for the Christmas table
Know your limits, include more healthy fats: nuts, seeds, capers, olives, fish. Prepare the usual Christmas food without added oil to ease digestion, cook the food in the oven or steam. Cook less food, as overloading the fridge and storing food for a longer period of time can trigger food poisoning.

Predominantly plant-based diet

In the "American Gut Project" study – they took stool samples from 10,000 people and found that more diverse gut flora = more flourishing health. Individuals who consumed more than 30 types of plant-based foods had a richer and more diverse microbiota than those who consumed only 10 or fewer.

Antioxidants in plants (polyphenols: colored vegetables and fruits in general) help to balance estrogen and reduce oxidative stress.

Gluten and sugar

Women with endometriosis often have sensitivities to gluten and sugar, and avoiding them can help reduce inflammation. Include gluten-free grains more often, focus on diversifying them, not lists of dos and don'ts. Introduce rice, white or sweet potatoes, soba noodles, chives, buckwheat, millet, quinoa (according to each individual's tolerance). As a sweetener you can use coconut sugar, stevia, dates, fruits, like chocolate.

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RECOVERY AFTER ENDOMETRIOSIS SURGERY

Recovery following endometriosis surgery is a highly individualized process. The surgical procedure, aimed at removing or ablating endometriotic lesions, is a crucial step toward pain relief and improved quality of life. The recovery experience varies widely depending on the location and size of the excised lesions, with surgical complexity ranging from relatively straightforward to highly specialized techniques such as colorectal, urological, thoracic, or neurosurgical interventions. Since the extent of endometriotic lesions does not consistently correlate with symptom severity, predicting recovery duration and time to symptom relief can be challenging, with recovery speed also influenced by factors such as central sensitization and comorbid conditions. Effective recovery after surgery has been shown to depend on preoperative preparation, with improved physical fitness before surgery reducing hospital stays and enhancing postoperative physical performance.

Postoperative Pain and Discomfort

Pain and discomfort are commonly expected in the immediate postoperative period. Patients frequently report mild to moderate abdominal pain, which may be exacerbated by gas retention caused by carbon dioxide used during laparoscopy. This is typically managed with a combination of analgesics, including nonsteroidal anti-inflammatory drugs, paracetamol, and opiate analgesics during the early recovery period. In cases where significant postoperative pain is anticipated, intraoperative lateral transversus abdominis plane block or postoperative epidural analgesia may be utilized to reduce the need for opioids. Non-pharmacological methods, such as transcutaneous electrical nerve stimulation and adequate rest, also play a supportive role in pain management.

Monitoring for Complications

Recognizing warning signs during recovery is critical. Severe or worsening pain, high fever, excessive bleeding, or signs of infection at incision sites should prompt immediate medical attention.



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Fatigue and Physical Activity

Fatigue is a common response to the effects of anaesthesia and the body's healing process. While sufficient rest is essential, prolonged inactivity can delay recovery. Light physical activity, such as short walks, does not exacerbate postoperative pain and reduces the risk of complications like thrombosis. Gradual resumption of physical activities is generally recommended, with heavy lifting and strenuous exercise typically avoided for four to six weeks. Hot baths and saunas should be avoided during the recovery period because of increased risk of bleeding and thrombosis.



Digestive Symptoms and Nutrition

Digestive issues, such as bloating, constipation, and postoperative nausea and vomiting, are frequently reported after surgery. These symptoms are generally short-lived and can be managed with dietary adjustments and appropriate medical treatments. Adequate hydration and proper nutrition are critical to support the body's healing processes and ensure optimal recovery. For patients who have undergone colorectal surgical techniques, strict adherence to pre- and postoperative medical instructions is essential to minimize complications.

Wound Care

Proper wound care is vital, particularly when drains, extended-time bladder catheters, or stomas, are present. Maintaining cleanliness and adhering to care guidelines are necessary to prevent infection and promote healing. For vaginal wounds, sexual intercourse is typically restricted for six to eight weeks to allow for adequate healing. Limited data prevents the establishment of strict guidelines to avoid vaginal wound dehiscence.

Emotional Well-Being

The recovery phase often involves discomfort and emotional stress. Patients are encouraged to seek support from loved ones and support groups, as well as to explore stress-relief strategies such as mindfulness and relaxation techniques. Providing the patient with a full description of the surgery and clear expectations for the recovery period enhances trust between the patient and the medical staff and is essential for reducing anxiety.

Complementary and Long-Term Therapies

To avoid symptom recurrence, hormonal therapies, such as oral contraceptives or hormonal intrauterine device can be prescribed. If both ovaries are removed, hormone replacement therapy may be prescribed to alleviate menopausal symptoms and support overall recovery. Complementary therapies, such as physiotherapy, acupuncture, yoga, and dietary adjustments (e.g., a gluten-free diet), can help address residual pain or discomfort. Lifestyle modifications, such as regular exercise, a healthy diet, and effective stress management, are often recommended as part of long-term recovery.

Recovery Timeline

Recovery typically occurs in phases. During the first one to two weeks, rest is prioritized, with a gradual increase in light activities. By the third or fourth week, many patients report reduced pain and improved energy levels, allowing for the resumption of light duties. Full recovery varies depending on the extent of the surgery, with more extensive procedures requiring longer healing times.

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From Canada to Greece for specialist endometriosis surgery, and a whole new life with no pain

To me, endometriosis is a disease that takes away many different aspects of your life. It's a disease that is so fierce, that it masks itself within your body in a way that is capable of hiding itself from many different doctors and specialists leaving you questioning yourself. This disease is not just a reproductive disease but one that takes on many different faces. This disease requires one with extensive knowledge and training to destroy it, to bring back the aspects of your life that were taken away due to it.

My endometriosis symptoms began around the age of 16. I still remember to this day, sitting in math class as the bell rang and having this horrific rectal pain causing me not to be able to stand up for a few minutes. It took my breath away. For many years I went to my family doctor and was told it was just my period or IBS. At first it began as painful periods with shooting rectal pain in my teens. Once I was in my 20s, I began having bloating, constipation, nausea, fatigue, and sharp knife-like pain in my abdomen during my period.

Pregnancy did not make my endometriosis symptoms better

I also had a hard time getting pregnant. Luckily, I was able to get pregnant and had a healthy baby boy. 6 months postpartum, my endometriosis symptoms came back worse than before. I was in so much pain 5 days after my period would end up until the last day of it. I started vomiting from pain once a month.



KRYSTAL COOK





**Krystal holding her baby
for the first time**

I was offered medication until the age of 40 and then have a hysterectomy

Visiting my family doctor about my symptoms was a huge waste of time. I was always unheard. I eventually had my gynecologist who delivered my son further investigate my symptoms. He did a few ultrasounds which noted adenomyosis and offered to medicate me until I was 40 and to plan for a hysterectomy. To address my endometriosis which was only suspected, he offered ablation. I asked to be referred to an endometriosis excision specialist as this was what I felt was my problem and not my uterus. He agreed to refer. That referral took a year just to be seen.

I travelled to the USA to have an MRI because in Canada I was denied one.

I had a mapping ultrasound completed by one of the apparent best radiologists here for endometriosis and was told I showed “no significant signs” of the disease and that a hysterectomy was the course of treatment. I requested an MRI to have a more thorough look at my uterus prior to agreeing to remove this vital organ which was denied here. I was able to book an MRI in the United States so that was the next test I did, and I am glad I did that. My uterus wasn't showing up as the issue which helped me come to the root of my issues in finding help abroad.

Orilissa made my fingers to lock up

I was put on Orilissa to suppress my symptoms. I trusted my doctor and was trying to live a normal life. This medication did help with pain, but the side effects were horrendous. I am a Dental Hygienist and I noticed after a few months my fingers were starting to lock up. The only thing that changed in my life was the medication. I looked up the side effects of this drug and stopped it right away.

I faced many limitations prior to having surgery abroad. I had no help or support from any medical professional in Canada. I felt alone, sick, and confused as to why there was no solution to my medical issues which were now affecting my daily life. In a Country with so many health care providers that prides itself in healthcare, it was shocking at the level of knowledge that was lacking towards what was happening to me.

In Canada, we do have a free health care system, but with that there are clearly limitations on funding towards this type of disease. Our healthcare is very controlled by funding and unfortunately this is one that suffers. The education and operating room time is not there for surgeons who are needed to treat endometriosis. I went to Greece for this surgery after researching this disease and educating myself on what is necessary to treat it. I needed a multidisciplinary team, with skills and knowledge to combat it. I wanted my life back. I wanted to be there for my son who deserved a mother who was present in every moment, and for my husband who deserved a partner who wasn't constantly tired and sick.

“
Having little chances to have specialist surgery in Canada, I started researching specialists abroad. My research led me to Dr Konstantinos Kyrikopoulos from Athens Centre for Endometriosis in Greece.

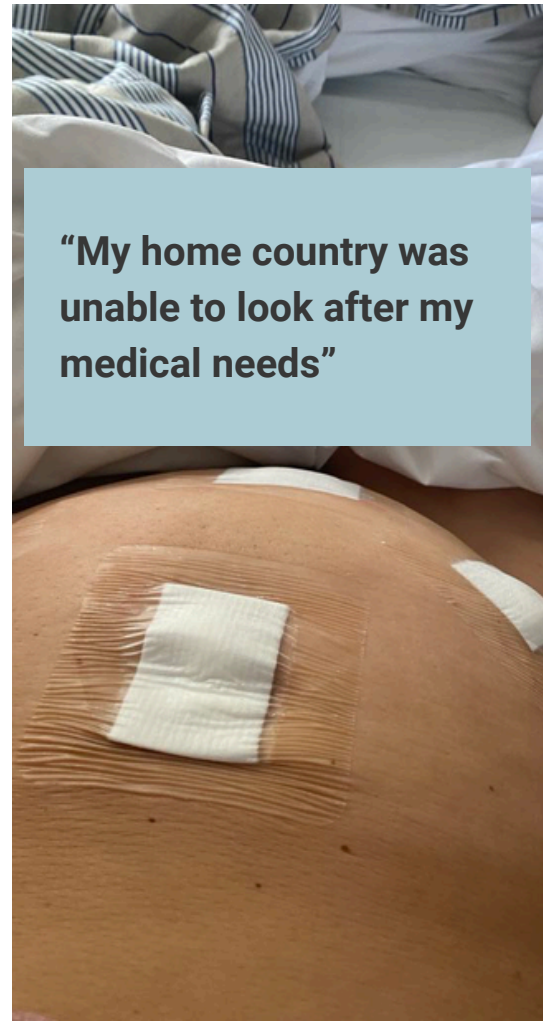


“

I began researching some of the best endometriosis specialists around the world. I had a few consultations. Dr Kyriakopoulos was the first specialist that I felt heard. Being heard was the hardest part of this disease. He felt based on my symptoms that I did most likely have endometriosis. He was pro fertility and wanted to preserve my uterus. These were two important parts of me that I felt were taken or being taken away from me here in Canada and even with a few of the other specialists abroad I spoke with. I had this instant feeling of relief and trusted him. He has an amazing multidisciplinary team present which is such an important part of treating the unknown of this disease. At this point I knew I had to go see him.

”





“My home country was unable to look after my medical needs”

Booking surgery abroad was easier than scheduling an ultrasound here in Canada. I was in direct contact with Dr Kyriakopoulos. He sent me a very detailed outline of what happens all from initial consult, imaging, testing and surgery. I had everything outlined with dates. He was very organized which is something that we lack here in Canada with our healthcare system. He informed me of where surgery would take place versus where his office was for consult and post op appt. I was a part of a Facebook group dedicated to individuals who were planning on or had already had surgery with this surgeon in Greece. This was a very helpful tool. I decided to make a vacation out of it. I went to Santorini a week prior and then stayed in Athens after surgery. It was the best trip of my life, one that got my life back.

Within hours of surgery, I felt relief. I never realized how bad my pain was until it was gone. I was able to walk 5km in Athens five days post op. My life is back. I am no longer fighting bloating, constipation, chronic stabbing pelvic pain, rectal pain, fatigue and nausea. I have a new outlook on life and life has never been better.

My first thought after surgery was “did they find endometriosis or were the Canadian doctors right”. When I woke up, I asked the nurse right away, and she smiled and said yes dear you did have it and he will be in to speak with you shortly. I was so relieved. I was so happy. Yes, you become happy once you KNOW what was wrong with you.



Sciatica in endometriosis

Low lumbar pain radiating to the buttock and leg, often without specific neurological findings, is a common complaint in the general population.

The conventional diagnostic approach focuses on spinal pathologies, as these are the most frequent causes of sciatica. However, when spinal MRI shows no disc bulges or cord compression and no specific cause is identified, treatment is often limited to medications, physiotherapy, injections, or, unfortunately, psychiatric interventions. What is frequently overlooked in these patients are pelvic nerve pathologies involving the sacral plexus, lumbosacral trunk, or sciatic nerve. Conditions like Alcock's canal syndrome (pudendal nerve compression) are well recognised, but supralelevator pelvic nerve pathologies remain underdiagnosed. These conditions require advanced expertise in neuroanatomy and surgical skill. If left untreated, they can lead to debilitating pain and, in some cases, irreversible nerve damage.

Understanding Somatic and Visceral Pain

To understand how endometriosis contributes to sciatica, it is essential to distinguish between somatic and visceral pain. Somatic pain is typically caused by pathologies of the sacral plexus or its branches. It is a neuropathic pain, often described as burning or electric. For example, deep infiltrating endometriosis affecting the sacral nerve roots (S1–S3) may cause buttock pain, while lower back pain corresponds to L5 and S1 dermatomes.



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Perianal, genital, or perineal pain is linked to S3 and S4 involvement via the pudendal nerve. Pain in the anterior and inner thighs corresponds to the femoral and obturator nerves. Visceral pain, on the other hand, is often vague, poorly localised, and associated with autonomic symptoms such as nausea, vomiting, pallor, and tachycardia. It may arise from superficial endometriosis or damage to the inferior hypogastric plexus (IHP), leading to phantom pelvic pain. Understanding the distinction between somatic and visceral pain is the first step in achieving an accurate diagnosis and effective management of endometriosis-related sciatica.

Endometriosis and Pelvic Nerve Involvement

Endometriosis is common, but it is rarely recognised as a cause of sacral radiculopathy. That said, endometriosis affecting pelvic nerves is not a new discovery. The first documented case of intrapelvic nerve entrapment due to endometriosis was reported by Denton and Sherill in 1955, with further significant contributions by Possover et al. in 2011. Symptoms often begin as cyclical in nature and gradually progress to constant, debilitating pain. Sciatic or lumbosacral trunk endometriosis (ISE) is a rare but definite cause of sciatica. The lesions are typically found in the suprapiriform region, causing symptoms such as sciatica, gluteal pain, muscle atrophy, and, in some cases, foot drop.

Careful observation during consultation can provide critical diagnostic clues. For example, noting how a patient walks or sits, and observing whether they require a special cushion, such as a donut pillow, can offer valuable information. Another form of endometriosis-related sciatica involves the sacral nerve roots (SNRE). These cases often include sciatica alongside pudendal pain and pelvic organ dysfunction, as the affected nerves supply multiple regions of the body. For instance, lesions involving S3 and S4 can lead to bladder hypersensitivity or sexual dysfunction. These cases require a meticulous surgical approach due to the intricate anatomy of the sacral nerves.



I extend my gratitude to my mentors, Mr. Shaheen Khazali and Professor Marc Possover, for their guidance in this field and their invaluable contributions to Neuropelveology and, most importantly, for helping our patients.

Diagnosing Sciatica in Endometriosis

Diagnosing sciatica caused by endometriosis can be challenging due to the complexity of pelvic nerve anatomy and the overlapping nature of symptoms with other conditions. A thorough and systematic approach is essential, combining a detailed clinical history, physical neuropelveological examination, and advanced imaging.





The first step in diagnosis is to carefully listen to the patient's symptoms. Patients may report a combination of sciatica-like symptoms (pain radiating down the leg, gluteal pain) along with pelvic pain, potentially accompanied by neurological signs such as muscle weakness or foot drop. During the clinical examination, careful observation of the patient's posture, gait, and sitting comfort can provide important diagnostic clues.

A neuropelvic examination should assess motor strength, reflexes, temperature changes in the affected area, muscle atrophy, and sensory changes to identify nerve involvement. Advanced imaging is crucial to confirm the diagnosis and map the extent of the disease. Magnetic resonance imaging with specific protocols for endometriosis remains the gold standard.

In my practice, we often use MRI Neurography, which can be particularly helpful for diagnosis and pre-operative planning. It can identify deep infiltrating endometriosis affecting the sacral plexus, lumbosacral trunk, or sciatic nerve.

In some circumstances, transvaginal ultrasound performed by a specialist trained in endometriosis imaging can also be helpful for assessing the sacral roots, particularly if there is suspicion of neurovascular conflict. It is important to note that diagnostic laparoscopy may not be particularly useful for diagnosing nerve involvement. Deep lesions often lack obvious peritoneal features, and occasionally only a small dimple in the pelvic peritoneum is observed, with the bulk of the disease located entirely retroperitoneally. This creates a typical "iceberg effect." Dissecting the nerves without planning to excise the disease is not advisable, as it can lead to significant intraoperative complications and complicate subsequent surgeries due to scar tissue formation.

Treatment Options

The gold standard for managing endometriosis-related sciatica is laparoscopic or robotic surgery. Radical excision of endometriosis and fibrosis is essential, and in some cases, partial nerve resection may be required. However, the success of these procedures depends on an in-depth understanding of pelvic anatomy to avoid complications. Incomplete excision not only risks persistent symptoms but can also make subsequent surgeries extremely challenging.



From adolescence to menopause:

Modern management of
endometriosis and uterine disorders

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STAY CONNECTED

Dr Charles Nagy

Complications of deep infiltrating endometriosis of the bowel

Deep infiltrating endometriosis (DIE) is a complex and frequently debilitating condition that profoundly impacts the quality of life for many women. While endometriosis itself is characterized by the growth of endometrial-like tissue outside the uterus, DIE specifically refers to a more severe form that penetrates deeper into surrounding tissues, including the bowel. In this article, we'll explore what bowel endometriosis entails, the potential consequences of leaving it untreated, atypical presentations, and the associated risks of bowel obstruction and chronic inflammation. Understanding these complications is crucial for raising awareness and promoting timely diagnosis and treatment.

Understanding deep infiltrating endometriosis of the bowel

Endometriosis affects approximately 10% of women of reproductive age, and DIE is a more advanced stage of this disease. Deep infiltrating endometriosis of the bowel primarily affects the rectum and sigmoid colon but can infiltrate other sections of the gastrointestinal tract as well. Unlike superficial endometriosis, which can be managed more easily, DIE involves more profound tissue penetration and can lead to severe symptoms. Management of deep endometriosis of the bowel requires a multidisciplinary approach of an experienced pelvic surgeon, colorectal, urology specialist, gastroenterologist and dietician to ensure best outcome.



Dr Charles Nagy is the first surgeon in the Middle East & the second globally, to be accredited & recognized by the SRC as a Master Surgeon in multidisciplinary endometriosis care.

He currently practices at Medcare Women & Children Hospital in Dubai as the head of a multidisciplinary endometriosis centre but has worked at hospitals all over the world. Dr Nagy has a long list of impressive credentials & experience of over 20 years of specialization in Endometriosis.

He is on the General Medical Council GMC Specialist Register & member of the American Association of Gynecologic Laparoscopists, the British Society of Gynaecological Endoscopy the European Society of Gynaecological Endoscopy & the Academy of Medical Educators.

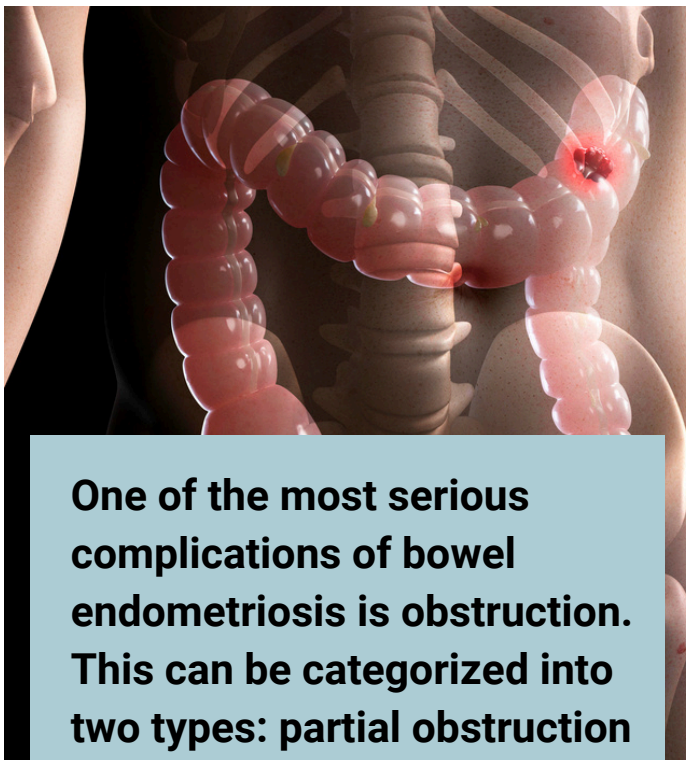


Bowel Involvement and Symptoms

The infiltration of endometriosis into the rectum, sigmoid colon and other sections of the gastrointestinal tract can cause a range of symptoms, including:

- **Abdominal Pain:** Often worsens during menstruation or after prolonged periods of sitting.
- **Changes in Bowel Habits:** Constipation, diarrhoea, or alternating bouts of both, complicating the diagnosis and management.
- **Nausea and Vomiting:** Particularly during painful episodes.
- **Bowel Obstruction:** In severe cases, the endometrial tissue can cause partial or complete bowel obstruction, a medical emergency requiring immediate intervention.
- **Rectal Bleeding:** In very few cases; it can be alarming and requires thorough investigation.

These symptoms often mimic other gastrointestinal conditions, such as irritable bowel syndrome (IBS) or inflammatory bowel disease (IBD), making diagnosis challenging and often requiring imaging or laparoscopy for confirmation.



One of the most serious complications of bowel endometriosis is obstruction. This can be categorized into two types: partial obstruction and complete obstruction.

Partial Obstruction: This occurs when the bowel is narrowed but not completely blocked. Symptoms may include abdominal pain, bloating, and irregular bowel habits. Partial obstruction may be managed with conservative treatment options such as dietary changes or medication.

Complete Obstruction: This results in complete inability to pass stool or gas. Symptoms often escalate to severe abdominal pain, vomiting, and a swollen abdomen. Complete obstruction is the more dangerous of the two types and typically requires immediate surgical intervention.

Risks Associated with Bowel Obstruction

The risks of bowel obstruction are significant and include:

- **Increased Pain:** As pressure builds in the bowel, pain can become excruciating.
- **Ischemia:** Prolonged obstruction can restrict blood flow to the affected area, leading to ischemia, where the tissue becomes deprived of oxygen.
- **Necrosis:** If left untreated, the affected bowel tissue can die (necrosis), necessitating surgical removal of the necrotic section.
- **Perforation:** Severe cases can lead to bowel perforation, a life-threatening condition that can result in peritonitis (inflammation of the abdominal cavity).

Chronic Inflammation and Cancer Risk

Another complication of bowel endometriosis is chronic inflammation. The presence of endometrial tissue in the bowel can lead to persistent inflammation, which can exacerbate gastrointestinal symptoms, disrupt normal bowel function and contribute to long-term health issues related to gastrointestinal disorders.



Endometriosis and Cancer Risk

Recent studies have indicated that women with endometriosis may have an increased risk of certain cancers, including ovarian cancer. While the link between bowel endometriosis specifically and cancer is still under investigation, there is some evidence suggesting that chronic inflammation and the presence of endometriosis can increase the risk of malignancy in affected tissues. However, more research is needed to clarify this association and determine the exact risks involved.

Strangulation and Necrosis

Strangulation can occur when tight adhesions formed by endometriosis compromise the blood supply to the affected bowel. This condition is more severe than a simple obstruction:

- **Necrosis:** When blood supply is cut off, the affected bowel tissue can become necrotic (dead). This necessitates surgical intervention to remove the affected section of the bowel and prevent further complications.
- **Obstruction vs. Strangulation:** While both conditions are critical, strangulation carries a higher risk of mortality and severe complications, making it an emergency.

Diagnosis and Management

Diagnosing DIE of the bowel often requires a combination of medical history, imaging studies, and sometimes surgical exploration. Transvaginal ultrasound and magnetic resonance imaging (MRI) are common diagnostic tools that help visualize deep infiltrating lesions. Once diagnosed, treatment options vary depending on the severity of the disease and associated symptoms. Management may include medication, surgical intervention or pain management.

Conclusion

DIE of the bowel presents a complex array of challenges. The physical symptoms, potential complications and emotional toll underscore the importance of awareness and timely intervention. By understanding the implications of this condition, we can foster a supportive environment and promote early diagnosis and comprehensive care that addresses both the physical and psychological aspects of living with deep infiltrating endometriosis. Women should advocate for their health, seek help, and connect with others facing similar challenges, as they navigate the often treacherous waters of this debilitating condition.





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The pelvic spaces and other locations where endometriosis can be detected

Endometriosis is frequently seen in the pelvis, which is the area within the body between the hips, from the belly button to the vagina. Most of the time the disease effects the gynecological organs, such as ovaries and fallopian tubes. If endometriosis grows in more distant areas to the pelvis, where it's not supposed to grow, this refers to extra-pelvic endometriosis. This can include areas like the lungs, diaphragm, intestines, bladder, and, in rare cases, the brain or other organs.



Ezgi Darici Kurt, MD

Although it's less common, extrapelvic endometriosis can be just as debilitating as pelvic endometriosis and can lead to severe symptoms that affect various aspects of daily life. As in the pelvis, these tissues are hormone sensitive so during the periods these tissues may grow and thicken and eventually break down by causing symptoms in the related organs. In some cases, the symptoms are cyclical, meaning they may flare up during menstruation. The symptoms of extrapelvic endometriosis are like a puzzle, often mimicking other conditions, making diagnosis a true challenge for both patients and doctors. Since these symptoms can resemble those of other conditions, such as irritable bowel syndrome (IBS), respiratory infections, or pelvic inflammatory disease, diagnosis can be delayed or missed altogether.

Extrapelvic endometriosis often plays a game of hide-and-seek in the body, making it even harder for patients to find answers and for doctors to uncover the cause of their symptoms.



Diagnosing the disease can be challenging. Imaging tests like ultrasound, MRI, and CT scans can sometimes show signs of the disease, but the only definitive diagnosis usually comes through laparoscopy or biopsy. This involves surgically removing a sample of tissue for examination.

The most common site of extrapelvic endometriosis is bowel.

Presence of the lesions may cause persistent or intermittent symptoms which worsen by the menstruation. Abdominal pain, bloating, constipation, diarrhea and blood in stool are the most frequent symptoms. Bowel endometriosis is frequently misdiagnosed as irritable bowel syndrome (IBS) due to the presence of digestive or gastrointestinal pain among its symptoms. The difference between these two conditions may be done by assessing the frequency and severity of the pain. A patient with IBS or most other gastrointestinal diseases may have discomfort several times per week over the course of a month, whereas bowel endometriosis produces significant pain during the menstrual cycle.

The second most common type of extrapelvic endometriosis is the urinary tract.

It may affect the parts of the urinary system such as bladder, ureters, kidneys and urethra by causing symptoms like pain during urination, frequency in urination, blood in urine and urinary incontinence. An important point to highlight here is the silent kidney loss. Endometriosis can silently kill function in one or both kidneys. If endometriosis wraps around one or both ureters, it can cause edema in the kidneys and, if this situation is left untreated, it can lead to renal failure. From 100,000 endometriosis patients diagnosed with ureteral endometriosis, researchers predicted that 25–50% will experience renal function decline and an unknown number will then have loss of the kidney.

As endometriosis specialists, we need to check kidneys during a routine ultrasound scan.

Another form of extra-pelvic endo is abdominal wall endometriosis or so called skar endometriosis. Although this is a rare condition affecting around 1.5% of the cases, it is gaining importance nowadays due to the increasing number of cesarean sections. A swelling on the c-section scar tissue and discoloration or hyperpigmentation of the abdominal wall during menstruation may be suggestive for this condition.

Thoracic endometriosis also has caught a lot of attention among endometriosis specialists in recent years. One of the challenges in diagnosing thoracic endometriosis is determining whether or not a patient's symptoms are related to their menstrual cycle. Coughing fits, shortness of breath, and chest discomfort are some of the symptoms that a person may occasionally encounter and since these symptoms don't seem to be connected to menstruation, they might not even consider the possible connection so diagnosis may take several years .

Treatment for extrapelvic endometriosis is often tailored to the specific symptoms and the location of the disease. In many cases, hormonal therapies such as birth control pills, GnRH agonists, or progestins can help suppress the growth of endometrial tissue. For women who experience severe symptoms or who are not responding to medication, surgical options may be necessary to remove the affected tissue. This is particularly true when the condition affects organs like the lungs or bowel.

Living with extrapelvic endometriosis is not only a physical burden but also an emotional one, as women are often left feeling isolated, misunderstood, and unheard. In some cases, the disease can recur, and ongoing management may be necessary. For women with extrapelvic endometriosis, every breath, every movement, can be a reminder of the invisible struggle they face. Multidisciplinary care, including input from specialists in surgery, pulmonology, gastroenterology, and pain management, may be required to address the various symptoms of extrapelvic endometriosis and improve quality of life.





ENDOMETRIOSIS AND THE PHENOMENON OF MEDICAL GASLIGHTING

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Medical negligence is an underreported phenomenon, that takes place when healthcare professionals fail to provide appropriate care, which can lead to delayed diagnosis, worsening symptoms, and even long-term physical and psychological damage. An often-overlooked form of neglect is symptom minimization, which translates into misdiagnosis and, by implication, far-reaching consequences for patients' quality of life and health.

Oana Sidorencu-Ștefăniță
Cognitive-behavioral psychotherapist



In case of women with endometriosis, medical negligence translates into discouragement, rejection, invalidation, as it is a diagnosis that is given with difficulty. Endometriosis is a chronic condition that affects approximately 10% of women worldwide, causing severe pain, heavy periods and fertility problems, all of which interfere with the ability to maintain quality of life in all areas, from professional to marital. However, diagnosis can take an average of 7 to 10 years, as symptoms are often ignored or downplayed by healthcare professionals, prolonging patients' suffering.

“

An aggravating factor for women with endometriosis is the phenomenon of medical gaslighting, a form of psychological manipulation in which their symptoms are dismissed or considered only in their imagination.

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Gaslighting causes people to doubt their own perceptions and accept the doctor's interpretations, even when they are wrong. This phenomenon contributes to the delay in diagnosis and to the worsening of the physical and emotional condition of the patients. For example, they may leave the doctor's office feeling they overreacted, have a negative self-image, and believe that since all women suffer from period pain as they're constantly told, they should just accept their condition and suffer in silence with persistent pain. As a result many women redefine their perception of what constitutes normal pain and are deprived of adequate treatment to relieve severe symptoms.

Women who experience medical gaslighting are forced to manage emotional consequences such as anxiety, depression, and even post-traumatic stress syndrome and associated avoidant behavior. They go through cycles of frustration and helplessness, constantly feeling that their pain is not acknowledged. For example, patients may be misdiagnosed with emotional or anxiety disorders rather than having their actual physical symptoms investigated. This constant invalidation can make them doubt their own sanity.

Another painful aspect is a result of being labelled as "hypochondriac", "anxious", "sensitive", "exaggerated", "victims", "not real women", "pretending", "pretentious", "not they've matured" which advances a mixture of sexism and lack of consideration for people's experiences, both within the medical system and among those close to them who do not adequately understand endometriosis. Women who insist are labeled as "aggressive" or even "crazy," each label taking its toll on self-image and well-being.

Lack of empathy leads to social withdrawal, lack of confidence, hopelessness, feelings of abandonment, helplessness and confusion. If the patient has the feeling that they cannot find understanding anywhere, they develop a state of hopelessness, leading to depression and the erosion of the relationship with those close to them, as well as trust in the medical system. Patients may end up self-sabotaging their healing efforts.

Healthcare professionals should receive ongoing training to be able to recognize and diagnose gynecological conditions such as endometriosis, but above all, have an empathetic approach, validate patients' experiences and actively listen, allowing them to fully describe symptoms without interruption or to minimize their pain.



To recognize if you are a victim of medical gaslighting, there are some signs to consider:

01. Ignore your symptoms

A common aspect is when the doctor ignores the patient's symptoms or trivializes their described pain, refusing to take it seriously.

02. Frequent interruption when talking

Also, another sign is the frequent interruption of the patient without allowing them to fully express their symptoms, which creates a feeling of frustration and invalidation.

“ Sometimes the doctor may adopt a dismissive or sarcastic attitude, suggesting that it is all in the patient's mind, classic gaslighting behavior. ”

03. Lack of empathy

A lack of empathy from the doctor, manifested by a detached attitude or indifference to the patient's pain, indicates an environment in which the patient's suffering is not acknowledged.

04. Attributes symptoms to psychological causes

Another sign of gaslighting is when the doctor attributes the symptoms to psychological causes without doing proper medical investigations.

In cases of medical negligence, patients may emphasize assertiveness in medical discussions. Assertiveness involves expressing firmly and clearly the need to receive further investigations, without allowing patients to be intimidated by indifferent, sarcastic attitudes or the initial refusal of doctors to take them seriously. Patients have the right to ask for clarification, to request tests or a second medical opinion when they feel they are not being given enough attention. This is not about being aggressive, but about trusting your own health assessment and respectfully asking for treatments and investigations. Structured symptom monitoring can be helpful to present as much data as possible and use it as support for maintaining perspective in the face of impulsive behavior. Cultivating an assertive attitude can help endometriosis patients protect both their physical and mental health.



Medical gaslighting is not only a barrier to proper diagnosis for women with endometriosis, but also a subtle but deeply damaging form of underestimating suffering. It is necessary that educational efforts be amplified, both among patients and among medical professionals. For patients, education is not only about better knowledge of their condition, but also about developing skills to deal with a medical system that can be hostile or uncaring despite positive intentions. There is a need for health professionals to recognize and correct biases that may lead to dismissing patients' symptoms, as well as an empathetic and informed approach to gynecological syndromes.

Discussions about endometriosis and menstrual health can no longer be considered a taboo subject. By increasing public awareness, patients could ask for help without fear of being stigmatized, and this would pave the way for earlier diagnosis and more effective management of the disease. In addition, psychological counseling can support women who are dealing not only with the physical symptoms of endometriosis, but also with the psychological effects of delays in diagnosis.

In therapy, patients can be supported to develop coping mechanisms, rebuild self-confidence, and get help reducing anxiety, depression, or post-traumatic stress symptoms that may occur during this difficult process.

Thus, an integrated approach, which combines medical treatment with psychological support, provides the necessary resources to cope with both the disease and related challenges. Last but not least, each of us can be a promoter of change, through empathy and openness to aspects of menstrual health.

Here are some sources where you can learn more about the challenges of people with endometriosis within the medical system and gaslighting:

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Chronic fatigue, endometriosis and nutrition

The connection between all of them and the role of nutrition in endometriosis and fatigue



Dr. Conor Kerley

PhD, BSc, H. Dip

Doctor of nutrition, award winning nutrition researcher, leading dietitian and patient (with MS + asthma).

Founder at Phytaphix

Instagram: [conorkerley.nutrition](https://www.instagram.com/conorkerley.nutrition)

Chronic fatigue syndrome (CFS) is a serious, disabling illness. Often long-lasting illness that prevents people from doing their usual activities. Fatigue can lead to issues in everyday such as education, work, hobbies, family life and more. A 2011 study found that chronic pelvic pain was over 10 times more common in females with chronic fatigue syndrome than in similar females who did not have chronic fatigue syndrome.

A more recent study from 2019 reported that almost 40% of women with chronic fatigue syndrome, also had endometriosis. A 2002 US study reported that females with endometriosis had 15 times more chronic fatigue syndrome than the average female.

General fatigue and endometriosis

Chronic fatigue syndrome (CFS) is a separate medical issue in itself. As we can see above, many with CFs also have endometriosis. However, general fatigue can be a major issue for many with endometriosis, even in the absence of CFS.

A 2020 Spanish study found that a huge 50% of surveyed women with endometriosis had severe fatigue while 33% had moderate fatigue. Therefore, only 17% had minor or no fatigue, meaning fatigue was a major issue for 8 in 10 women with endometriosis.

A small 2020 study reported that women with endometriosis related fatigue had increased fat mass, and physical deconditioning, including decreased strength, flexibility, balance, and overall functional capacity. Further, the women with endometriosis related fatigue also had decreased fitness, decreased sleep quality and decreased quality of life. Separate studies in 2022 and 2023 found fatigue to be the most common symptom reported by female with endometriosis. A 2018 study from Switzerland, Germany and Austria studied over 1,000 women, of which over 500 had endometriosis. This study reported that endometriosis related fatigue was NOT related to:

- Age;
- How long a person had been diagnosed with endometriosis;
- What stage their endometriosis was.



In other words, fatigue can affect those with endometriosis regardless of their age, how long they've had endometriosis or how severe their endometriosis is.

Causes of chronic fatigue in endometriosis

Despite being a very common issue in a very common disease, there is relatively little in the scientific literature about fatigue and endometriosis.

Therefore, the exact cause(s) of fatigue and endometriosis are not fully understood. However, a 2020 Spanish study⁴ found that in endometriosis, fatigue was associated with

- higher anxiety and depression
- poorer sleep quality
- poorer sexual functioning
- worse gastrointestinal health
- higher anger/hostility scores
- lower quality of life

A study of females with endometriosis from 2024 reported that fear of progression was associated with both worse fatigue and worse insomnia.

How to help manage chronic fatigue in endometriosis through diet

Decreased appetite
Decreased appetite is common among those with endometriosis⁷ and seems to be related to pain, nausea and fatigue. The problem is that decreased appetite leads to decreased energy intake which leads to decreased energy.

If someone is struggling with decreased appetite, eating smaller but more regular meals and snacks can really help. For example, a small breakfast, morning snack, small lunch, afternoon snack, small dinner and an evening snack.

B vitamins
There are eight B vitamins, including vitamin B9 which is folate in foods or folic acid in synthetic supplement form. All the B vitamins are important, for everybody to consume as part of the diet daily.

Vitamin B9
Vitamin B9 (folate or folic acid) is particularly important for females of child bearing age. This is because vitamin B9 helps protect against neural tube defects and other complications of pregnancy.

Great sources of vitamin B9 including green and beans so think broccoli, Brussel sprouts, cabbage, kale, spinach as well as chickpeas (garbanzo beans) and kidney beans. These are very healthy foods, for all and it is a good idea to consume these foods every day – whether you have endometriosis or not and whether you have fatigue or not. Official recommendations for females of child bearing age is to take a supplement containing 400micrograms of folic acid daily.

In humans, folic acid must be converted to the active form of folate, called 5-methyltetrahydrofolate (5MTHF) by a series of enzymatic reactions. There is evidence from 4 separate human research studies that folate and folic acid metabolism can be faulty in endometriosis.

Indeed, a 2018 study reported a supplement containing 5MTHF could help reduce endometriosis symptoms. Therefore, the active form of folate, 5MTHF, is worth considering. 5MTHF is more expensive than standard folic acid and is only found in some, premium supplements such as [EndoHormone Phix](#).

Vitamin B12
Vitamin B12 is absolutely crucial for energy production in all humans, including those with endometriosis. Vitamin B12 is not made by humans or by animals but by microorganisms in the soil and in the intestines of mammals. It is found in all animal products, including red meat, poultry, dairy and eggs. Some people with endometriosis may choose to avoid these foods as they contain saturated fats and dietary cholesterol and have been linked with overall inflammation as well as endometriosis symptoms. Other good source of vitamin B12 include fortified foods: plant milks, breads and cereals as well as supplements. In humans, absorption of vitamin B12 is complicated but vitamin B12 levels are easy and cheap to measure.



Vitamin D

Vitamin D is known as the sunshine vitamin as humans can produce vitamin D in their skin when exposed to ultraviolet B (UV-B) irradiation, mostly from sunshine. In fact, vitamin D is unique as a vitamin as most humans get most of their vitamin D from the sun as opposed to the diet.

The problem is that we spend less time outdoors in the sun, wear sunscreen and perhaps live in colder climates (I'm writing this article from cold, dark Ireland!). Therefore, over 1 billion people are estimated to have vitamin D deficiency. Indeed, there is evidence that vitamin D deficiency is common in endometriosis.

A 2020 review which put together the results of existing research in endometriosis reported that:

- Women with endometriosis had lower vitamin D levels compare to women without endometriosis.
- Higher vitamin D levels meant lower endometriosis symptoms, while lower vitamin D meant higher endometriosis symptoms.

This is important because vitamin D has been linked to general fatigue as well as disease related fatigue. Further, vitamin D is relatively rare in foods with the only food containing decent levels of vitamin D being fatty fish such as salmon, sardines, mackerel etc.

With this in mind, it can be a good idea to take a supplement containing vitamin D3 and to ensure you take any vitamin D supplement with a meal (vitamin D is fat soluble so if you take it on an empty stomach, you will not absorb it efficiently).

Iron

Iron is an important mineral that has many functions, including transporting oxygen in the blood. Iron and its transport of oxygen in the blood is crucial for energy.

Iron deficiency is common in endometriosis and is related to heavy periods (blood contains iron, more blood loss means more iron loss). There are two main types of dietary iron; **heme iron** and **non-heme iron**. Heme iron is better absorbed and found in red meat, offal. Some people with endometriosis may choose to avoid these foods as they contain saturated fats and dietary cholesterol and have been linked with overall inflammation as well as endometriosis symptoms. Non-heme iron is found in nuts, seeds, legumes and leafy green vegetables such as spinach, as well as iron-fortified foods such as cereals.

Although non-heme iron is not as well absorbed as heme iron, consuming vitamin C along with foods rich in non-heme iron increase its absorption. For example, have berries, a kiwi or an orange with nuts as a snack or add bell peppers to a stir fry with spinach and legumes. Thankfully, vitamin C which is a powerful antioxidant has been reported to have direct benefits for endometriosis too.

Iron is a crucial mineral but too much iron is bad for anyone. Before taking an iron supplement, it is a good idea to make sure you are consuming iron rich foods. Even then, consider getting a blood test. If you have heavy periods and fatigue, ask your doctor for a blood test to include:

- serum iron levels – which measures the amount of iron in the blood but also and more importantly.
- complete blood count, which includes haemoglobin (the oxygen-carrying protein in red blood cells) and haematocrit (the amount of red blood cells in the blood).
- ferritin measures how much iron is stored in the body.
- total iron-binding capacity (TIBC) - measures how well iron attaches to transferrin and other proteins in the blood.
- transferrin saturation – transferrin is a protein that moves iron throughout the body.



Magnesium

Magnesium is another crucial mineral, involved in hundreds of key chemical reactions in the body, including many reactions related to energy production. Fortunately, magnesium is found in many healthy foods. A 2012 study reported that a magnesium rich Mediterranean diet could decrease endometriosis-associated pain. Specific foods high in magnesium that were recommend in this study included brown rice, oatmeal, wheat germ and sees such as sesame, flaxseed, sunflower and pumpkin seeds.

Sleep

It seems obvious but disrupted sleep can lead to fatigue, Indeed, we see that research reports a link between disrupted sleep and endometriosis. I used to work in a clinical sleep lab so I am well aware that sleep is crucial for overall health, including energy and reduced fatigue.

For anyone with fatigue, sleep should be a priority. Some simple tips include:

- Get in and get up out bed at roughly the same time everyday.
- Try to avoid eating heavy meals or snacks in the evening e.g. after 6pm.
- Try to limit bright light in the late evening, especially right before bed.
- Avoid caffeine or energy drinks after midday.
- Alcohol can help you fall asleep but decreases the quality of sleep.
- Some physical activity during the day can help you sleep at night.

Some foods which seem to help sleep include kiwis, cherries and pistachios (see melatonin section below).

Melatonin

Melatonin is a powerful hormone produced by the human pineal gland in the late evening when we are exposed to darkness. This is one reason why it is important to try sleep in the dark – meaning you should not be able to see past your nose. Practically, this means sleeping with black out blinds and/or a face mask.



The single food with the highest amount of melatonin is pistachio nuts – therefore a small handful of pistachios in the evening is a great way to boost melatonin as well as antioxidant and healthy fat intake. There is even research demonstrated that in women with endometriosis, melatonin can improve sleep quality and decrease endometriosis symptoms, including decrease pain and decreased pain killer use. Practical strategies for managing endometriosis fatigue.

- Consider batching cooking when you have the energy to ensure you have healthy meals for when you don't have the energy. For example, make double portions for dinner and freeze on portion. This will help stop you reaching for a ready meal or takeaway.
- Rest when you need it but try to build small amounts of physical activity into your daily routine – think short walks etc.
- Keep healthy snacks available where you spend your time – at your desk in work, on the kitchen table, in your bag etc. My go to for my sports bag is some dried fruit and nuts. – these won't spoil but mean that if you get hungry or need some energy, the energy drink or chocolate bar won't be as tempting.

Summary

Make good sleep and physical activity a priority. Monitor your appetite and if you feel there is an issue, see a registered dietitian.

Consider getting a blood test for vitamin B12, vitamin D and iron levels once a year.

Every day, consume foods rich in vitamin B12, iron and magnesium.

Consider supplement with activated folate (5MTHF) and vitamin D3.



Effect of Endometriomas on Fertility and Therapeutic Options: An Updated Medical Perspective

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Endometriosis is a complex gynecological pathology, which affects approximately 10-15% of women in the reproductive period, and is frequently associated with the formation of ovarian endometriomas. Endometriomas are ovarian cysts that negatively influence fertility through complex mechanisms, being associated with the reduction of the ovarian reserve and the creation of an unfavorable inflammatory environment for conception. The therapeutic approach must be personalized, taking into account both the patient's desire to achieve pregnancy and the risks and benefits of each method.

Effects of Endometriomas on Fertility

Ovarian endometriomas affect fertility through multiple mechanisms. The reduction of the ovarian reserve is one of the most important consequences. Low serum levels of anti-Müllerian hormone (AMH), a marker of ovarian reserve, are frequently observed in patients with unilateral or bilateral endometriomas. For example, a large study demonstrated that AMH levels are significantly lower in women with endometriomas compared to those without endometriosis. In addition, the inflammatory environment caused by endometriomas contributes to the deterioration of oocyte quality and reduces the chances of fertilization.

Locally released pro-inflammatory mediators can also affect sperm motility and the ability of the embryo to implant, complicating the process of natural conception.

Excision of Endometriomas and Benefits

Surgical excision of endometriomas is a frequently used intervention, with the aim of improving symptoms and reducing the size of cystic formations. However, the effects on fertility are controversial.

An essential aspect is the negative impact of surgery on the ovarian reserve. Studies show that excision of endometriomas, especially bilateral ones, can lead to a substantial reduction in AMH levels. For example, a decrease of 39% for unilateral and 57% for bilateral endometriomas was observed 9-12 months after the intervention.

In addition to reducing the ovarian reserve, surgery can also result in the formation of pelvic adhesions and anatomical changes, which can affect the patency of the fallopian tubes. These are consequences with long-term effects on fertility. Therefore, the choice of surgery should be made with a careful assessment of the risk-benefit ratio

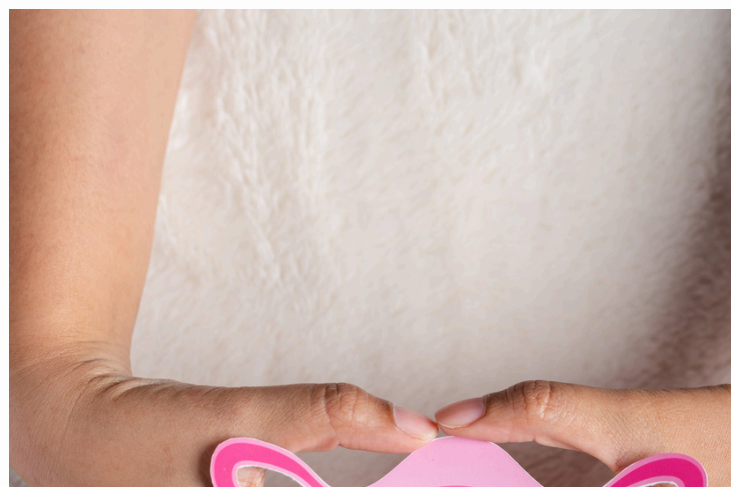


Minimally Invasive Techniques: Alcoholization of the Endometriosis Cyst

A conservative alternative to surgical treatment is alcoholization of endometriotic cysts. This minimally invasive technique involves ultrasound-guided puncture of the cyst and injection of ethyl alcohol to induce sclerosis of the cyst walls. The procedure has the advantage of reducing the size of the endometrioma while maintaining ovarian function.

Benefits:

- Preservation of ovarian reserve, essential in women of childbearing age.
- Short recovery time compared to classic surgery.
- Reducing pelvic pain associated with endometriosis and improving quality of life.



Alcoholization is not without disadvantages: cyst recurrence is a possibility (the risk of recurrence is similar to the one after cystectomy), and complications such as post-procedural infections can occur in rare cases. It is essential that this method is performed by experienced specialists to minimize the risks and maximize the benefits.

The impact of endometriomas on fertility is significant, and the choice of appropriate treatment must be personalized according to the patient's goals regarding ovarian reserve and desire for pregnancy. Although surgical excision has long been considered the gold standard, conservative options such as ablation offer promise for preserving ovarian reserve, particularly for young women who desire children.

Adopting a healthy lifestyle, complemented by minimally invasive interventions and the support of an infertility specialist, is crucial for optimizing therapeutic results and increasing the chances of conception. Continued advances in the understanding of pathological mechanisms and the development of personalized therapeutic techniques promise to improve the management of this complex condition.

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Extrapelvic endometriosis, a frequent but underestimated form

Wendy Bingham, DPT

Executive Director
Extrapelvic Not Rare (501 c3)

Endometriosis is the culprit of many ills I endured that were dismissed, underappreciated and misdiagnosed for less sinister conditions (eg. IBS, Groin Strain, Pleurisy, Asthma, and Primary Spontaneous Pneumothorax). It was the culprit that had doctors convinced to be physical conversion of stress and anxiety, or low tolerance for benign aches and pains.

I consider endometriosis to be one of, if not, THE most misrepresented and disrespected diseases that can be experienced.

My impression is that lesions are only one trait of the disease, and inflammation is an inherent part of the disease; not limited to be *in response to*, or *between it* and endometriosis lesions.

I save space for the potential that the proximity, roles and migratory patterns of cells destined to develop the reproductive, immune and vascular systems in early development of the embryo, may explain (at least) a portion of disease and immune dysfunction (or its predisposition for). It's a disease that can occur anywhere in the body, though most common in the lower abdomen and pelvis. It's a disease that directly and indirectly disrupts the function of organs and their systems by way of infiltration, development of adhesions and inflammation at local and systemic levels.



In your experience, living with endometriosis and engaging with so many sufferers, given that there are multiple chronic diseases that can impact one's life, why do we get less facilities for endometriosis? Is it because it's considered a gynecological disease? Do you reckon that saying it causes heavy menstrual pain can be a minus in how some perceives it?

Endometriosis is still classified as a benign disease of and limited to gynecological structures despite evidence to the contrary. Continued classification as such is myopic and, to be blunt, disrespectful to the destructive capacity of endometriosis and the experiences of people who had, have, and will have it. Accumulated observations, experiences and conclusions have shaped this perception, and now dogma, that perpetually reinforces the same direction and lines of research and treatments. Perception can change but requires willingness to consider new information and other points of view without preconceived biases. Advances to research technology, increased accessibility of literature, and voices of people with endometriosis are the catalyst: new tools, information and views to shift perspective. The willingness to depart from dogma will influence the quality, quantity and access to care.

To most people, endometriosis is a 'benign disease'. However, the history of endometriosis raises the risk of gynecological cancers. Pelvic endometriosis, particularly ovarian disease, has a small risk for malignant conversion. Conversion of lesions at extrapelvic locations are documented (ie. diaphragm, ascending colon, liver body), but probabilities of risk aren't established.

Painful, heavy periods aren't exclusive, nor the dominant symptoms for everyone who experience endometriosis; some have 'normalized' symptoms, others have none. Lesions don't need to be in direct contact with a tissue or organ to impact its function or create symptoms, and complications. A few examples include IBS, Urinary Frequency, Radiculopathy. Like pelvic endometriosis, lesions among other tissues and organs (extrapelvic) may or may not be symptomatic.

To shift perception that endometriosis is a benign, gynecological disease, necessitates recognition the current classification is restrictive and an incomplete representation (locations and symptom heterogeneity, complications and systemic mals). New data must be gathered from valid tools that identify aspects of the disease that support a shift from this perception. One of these tools is the International Classification of Diseases (ICD), which is developed and monitored by the World Health Organization (WHO). The WHO and other agencies (ie. Center for Disease Control) monitor death rates, disease and injury. Data collected from the ICD platform is used to create and monitor action plans to reduce morbidity and mortality. It is the most common reporting system used by countries across the world.

Most countries are using the 10th Version. Prior to most revisions, the locations available to report at the time of each incident (1 person=1 incident) near exclusively limited to reproductive organs are nearby areas. The addition of a few of the more common extrapelvic locations has been added, and available to report incidence by, but not all countries (ie bladder, ureter). The 11th version has added the number of itemized locations with greater detail. This version also collates information that identifies relations between presence of lesions, locations and complications (ie. ureter endometriosis = hydronephrosis; chest wall=spontaneous pneumothorax; bowel endometriosis = obstruction).

Tell us three severe complications of extrapelvic endometriosis that can endanger life?

A history of endometriosis increases the risk of overall premature death. Review of data collected by the ICD platform attributed 1.31 to 3.67 deaths per year to endometriosis between 1980 and 2021. No other details are available.



Transition of countries to the 11th version of the ICDs will collect data that provides a clearer picture of the incidence and location of endometriosis to complications that endanger life, and death. Prior to the advent of soft tissue imaging, one death was reported due to a large stromal lesion within the heart. The patient died from heart failure.

A handful of cases with compression of both ureters developed bilateral hydronephrosis that resulted in non-functional kidneys. Despite renal dialysis, they died shortly after it was initiated.

Despite the development of soft tissue imaging, a lack of awareness and knowledge about extrapelvic endometriosis combined with other factors continues to place people at risks of severe complications. Three locations of extrapelvic disease that, if left untreated can be life threatening: intestinal tract, ureter and chest wall.

Bowel Endometriosis: Obstruction due to infiltration through the bowel wall or development of adhesive disease that narrows the lumen that prevents waste from passing from the body. Obstruction can lead to ischemia of the intestine or perforation of the bowel, raising the risk of infection and sepsis.

Ureter Endometriosis: Lesion(s) near or among the ureter wall can lead to hydronephrosis; urine made by the kidney is unable to drain. This leads to dilation of the kidney and may lead to death of the organ. One ureter is far more common than two, but it does occur. People can live with one normal kidney. Not everyone has two kidneys. The disease process and ultimately death of a kidney can go undetected, in part due to a lack of pain fibers in the ureters and kidneys.

Chest Wall Endometriosis: Lesions may create accumulation of bloody fluid (hemothorax) and/or air (pneumothorax) between the lung and chest wall.

It is important to note the isolated cases in the literature and mortality rates above suggest mortality associated with endometriosis are isolated incidents. Data gathered from the 11th Version of the ICD platform will provide more information on this matter. Episodes are often small to medium but, left untreated, recurrent episodes may become large enough to create 'tension'. Tension is buildup of air and/or fluid that impedes distribution of oxygenated blood from the heart to vital organs.

You have your own story with lung endometriosis. When did you find out you have it and did it manifest?

I started experiencing digestive, urinary and respiratory systems during high school (17 yrs). A pattern emerged as I got older. I was 29-30 at the time of my first documented lung collapse (spontaneous pneumothorax-SPT). I worked in a rehabilitation hospital at the time. An OT who had experienced recurrent SPT's told me about an association with the menstrual cycle and SPT. At the time, the quantity of literature and access to it was limited; the internet was still an infant. Two years later I had a second confirmed SPT. I was 3 months postpartum following the birth of our only child. It occurred 1 day before my menstrual cycle resumed. Between 32 and 46 yrs, symptoms progressed from bimonthly (a few days at ovulation and 7-10 days building to day 1 of menses) to a constant presence, which a crescendo at ovulation and Day before/Day 1 of my periods. I finally had a diagnostic lap at 46 yrs and multidisciplinary surgical care at the Center for Endometriosis Care in Atlanta, GA, at age 48.

Although I had countless visits to the ED and a few hospitalizations for abdominal pain and pneumothoraxes that required intervention, far more episodes were spent at home. In part because I didn't have the physical and emotional capacity to endure drawn out saga's notorious for Emergency Department visits; nor potential gaslighting when I was most vulnerable. Over the years I consulted primary care, gastroenterologists, urologists, gynecologists, pulmonologists, cardiologists and cardiothoracic surgeons. Not one asked about or connected the relationship of my symptoms and recurrent SPT's to my menstrual cycle.



I identify my recurrent SPT's as 'catamenial'. I was finally diagnosed with endometriosis by a local gynecologist at age 46. At age 48 I had surgery for diaphragm disease of the right leaf and pericardial area of the central tendon and left chest.

Extrapelvic Not Rare is a not-for-profit organization you founded. What made you dedicate your time to such activity?

Less than a year after life-changing surgery at a center for excellence, I attended a conference on endometriosis. I wanted to further my knowledge about the disease, landscape of practice and players of the disease. I also hoped to identify an area where I could make a positive impact from my personal experience and interest, for the benefit of others who do not fit the established disease profile. I knew the existence, and my experience with extrapelvic endometriosis was not rare. By the end of that conference, I had identified the niche and my purpose where my firsthand experience as a person with disease, education and background as a healthcare practitioner could make an impact. It would be a few years before Extrapelvic Not Rare transpired from a #hashtag, social media channels, and FB group, into a 501 c3 nonprofit.

One of your recent projects is a book with places where endometriosis was found. What can you tell us about it?

I am delighted you've had the opportunity to peruse The ABCs of Extrapelvic Endometriosis ebook. At this time, there are (4) versions of the book: English, Spanish, French and German. No timeline or predetermined limit in translations has been set and I am committed to generate more versions of the book. I've had positive feedback from laypeople and medical professionals about the books' layout, content, layout and oversized font and simplified language. We're looking for volunteers fluent in an additional language, who would like to assist with translations. All language versions can be accessed for free and accessed through a link at our website. Our goal is to acquire funding to cover costs associated with a publishing company that targets community public libraries and academic institutes (middle schools upwards through universities and professional healthcare programs), starting with the English version. We have not solidified an action plan to acquire funding but anticipate we will begin the process early in 2025.



What other projects have you done?

This past summer, EPNR hosted a Doctor of Occupational Therapy at The University of the Pacific, for her Capstone Project. Our students interviewed specialty providers and practitioners for endometriosis and surveyed people with the disease. She also presented a.) an online webinar (2 parts) for people with endometriosis, b.) provided an in-service to peer students, faculty and licensed OTs associated with the program and c.) created an outline on content for the development of a post-professional continuing education course. Data from the interviews and surveys were presented at the 2024 Occupational Therapy Association of California in November.

EPNR also worked with a high school student. The (inaugural) Endometriosis Edu-Walk was part of her Senior Project. The student contributed to the development of displays, marketing, procurement of raffle prizes and event management. Ongoing projects include representation of EPNR at public events. We are dedicated to participating in a range of events and their target audiences to bring awareness about the disease to people regardless of their socioeconomic position. In 2025 we will expand our participation at events from Washington and Oregon to Northern California and Connecticut, USA.



I've been blessed to formally present the topic of extrapelvic endometriosis to the Icelandic Minister of Health and members of Parliament through invitation of The Endometriosis Association of Iceland and presentations at The Endometriosis Summit: Bowel Endometriosis-2022, collaboration with Dr. Abhishek Mangeshkar, and Updates to Thoracic Endometriosis (2024). Other projects include Virtual Webinars and an Animated Video Series (both housed at the website).

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

I'd like to see an international endometriosis action plan with universally agreed targets and values. Targets should set minimal levels for disease competency and management. A few countries have rolled out action plans in recent years. National action plans play an important role in moving endometriosis forward but each must be tailored to the specific needs and barriers of that country (eg. private or public payor source, guidelines, school programs). They should also include the minimal target values (or more stringent) set in an international plan.

Action Plans that involve and prioritize people with the disease have historically been successful (eg. heart disease, diabetes, breast cancer, and HIV). Any action plan will require input of people steeped in knowledge and experience with endometriosis. Given the history of slow, often stagnant processes, playmakers must be expanded to include a diversity of medical specialties and scientific fields in addition to organizations that represent diverse populations with the disease that can bring new information and perspectives. Disclosure of all conflicts of interest (COI) should be compulsory. And reviewed by a third party. The history of service by those with COI should be reviewed. Any decisions made by the individual while in a position to benefit directly as a result of the decision (research, diagnosis, treatments) should be scrutinized. In regard to a mandated post-professional course. This should apply to all healthcare professionals to maintain licensure. (ie. HIV and Covid-19). A smaller set of professionals to complete a second course that contains content relevant to their area of practice should also be mandated.

Albeit not specific to endometriosis, nationwide menstrual leave policy exists for residents in China, Indonesia, Japan, South Korea, Spain, Taiwan and Vietnam. Excused absences can be paid or unpaid; 1 to 3 days per month. It's a good start to reducing menstrual stigma, and a policy that can build awareness of the conditions and diseases that lead to painful periods. There are pros and cons to developing endo specific policies from scratch or piggyback from established, or easier to enact menstrual leave policies.

How do you see the future of endometriosis care?

In general, I believe things will improve. In part, because people with endometriosis are shining a spotlight on the disease and, to be honest, nobody wants to go backward. I anticipate the number of Centers of Excellence for endometriosis care will increase. Centers offer multidisciplinary teams of healthcare providers equipped with the knowledge and experience to provide surgical intervention, and/or medical management, with informed consent of the patient as priority. Centers may also have in-house or close relations with outside allied health professionals.

Diagnostics: I think the average delay will shrink but will plateau at 2-3 yrs unless a simple noninvasive tool becomes available. Imaging for detection of endometriosis, some forms and locations, will become more commonplace. Although the technology of soft tissue imaging has improved in recent years, long held generalizations about the capacities of imaging still negatively impact people with endometriosis (eg. normal imaging=no disease). Global acceptance will depend upon the training of sonographers to perform, and radiographers to read and imagine. To ensure validity of imaging as a diagnostic large, international studies that include sonographers and surgeons from all countries that follow guidelines that include imaging as a diagnostic standard must be completed and periodically recur to assess comparatives of imaging to surgical measurements of identified disease and presence of undetected disease. Laparoscopic surgery will continue to have a role in diagnosis. Accessibility to the highest standard of care will not improve unless surgeons receive financial compensation representative of the skills, procedures and time to exercise disease. The number of centers can't grow without surgeons filling them. Government and Private Insurers who reimburse for services must acknowledge that laparoscopic excision is not the same as laparoscopic ablation.



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I have had 14 surgeries, with varying degrees of success

I believed the pain I was experiencing was normal, that all women had this pain

Karen Louise
endometriosis patient
Group support administrator
National Endometriosis Survivors Support



My story began a few months after my 10th birthday.

I was horrified to get my period, years ahead of my peers. The pain was dreadful, I was constantly drained & exhausted, but I just thought that was the type of person I was. By the age of 15, my periods crippled me. For 2 weeks a month, I could barely do anything. I was admitted to hospital on a number of occasions with a suspected appendicitis, such was the extent of the pain. Nothing was ever found, as endometriosis can't be detected on scans, unless it has formed large cysts, but even that is a fairly recent & unreliable development.

I was occasionally shouted at by doctors, calling me dramatic, malingering, time wasting & insinuating I was lazy. I believed the pain I was experiencing was normal, that all women had this pain, that to feel like you have the flu & can barely stand up for 2 weeks before your period was normal. I believed that I just had a low pain threshold, that I just wasn't a very motivated or energetic person, that I was lazy. This was the mental impact the dismissal of my pain by the medical profession had had on me. I had very little confidence in myself & was so unhappy for a lot of my life.

I finally received a diagnosis at the age of 28. I had managed to keep going, successfully achieving the grades & qualifications I needed, at school & university, to become a secondary school teacher. Teaching is a hard job, but I was exhausted. I picked up every infection, cold, flu, stomach bug from the kids, as endometriosis weakens your immune system. I started to see a new GP & decided to bring up my continued back, abdominal, leg, pelvic pain once again, having been too scared to mention it to doctors for a long time, for fear of being branded mentally ill & time wasting again. Luckily, a diligent GP recognised the symptoms as endometriosis, but the only way to formally diagnose this, is through a diagnostic laparoscopic procedure. This was done & I was told I have endometriosis. I couldn't even say it, let alone know what it was! They told me to go on the pill, without the usual week break & that should sort me out. It didn't, I continued to bleed throughout & the pain became worse. Again, I tried to keep going, trying to keep my job, my social life, to be a normal young woman in my 20s. However, I missed out on so much, I had so many HR meetings at school about my absences (school have been amazing & so supportive & I know I'm lucky there).



I lost friends, because they got sick of me cancelling all the time, relationships broke down, as for 2 weeks a month I was crippled in pain & I could barely do anything.

I was so used to the pain, that when I had tickets for a Kings of Leon gig, I dosed myself up on painkillers & kept going because I had been looking forward to it for so long. I didn't want to miss out, I dragged myself into work the next day, but was then taken into hospital as an emergency case. I actually did have appendicitis, but it felt so similar to the normal pain I just didn't really notice it, until it burst, making me incredibly unwell. I learnt from that, that endometriosis pain feels like appendicitis.

They found that endometriosis had covered my pelvic organs, but because it was just emergency surgery & endometriosis requires a specialist surgeon, they mopped up the mess from my appendix & stitched me back up, leaving me in more pain than ever before & no plan to move forward. It's so hard to find a good endometriosis surgeon in the UK. I was left on waiting lists for months on end, only to find that the surgery would be done by another surgeon, who wouldn't manage to get all the endometriosis, because they weren't comfortable working with bowels/kidneys/bladders/livers/diaphragms, wherever it had made its way to.

“

I have had so much surgery to remove the endometriosis, I have lost my uterus, ovaries, had a stent put between my kidney & my bladder, my bladder is damaged & I frequently pass blood in my urine & it is incredibly painful to empty my bladder, my bowels are scarred & stuck together with adhesions.

”

I would come round from the anaesthetic, to be told that some of it had gone & hopefully it would be good enough to feel some improvements, but it never was. The scar tissue that forms around our internal organs from the endometriosis covering them, will hurt forever & my organs will stick together with adhesions forever. I lost my fertility, as my Fallopian tubes had been destroyed by endometriosis. I went through futile, painful cycles of IVF, until I was told there was no way I would ever be able to have children, as my body was so ruined by endometriosis.

Hysterectomy did not help

My hysterectomy was done badly. I bled so much that I needed a transfusion. The blood was not drained & it formed adhesions so extensive that I was unable to stand up properly & without pain for a year. I was unable to use HRT, had no support with the overnight, surgical menopause, at 37 years old. The endometriosis grew back. I was unable to go back to my full time job & my marriage broke down, as he was unable to cope with the person I became. It was a really difficult time in my life.

It is frustrating & sad to see that nothing has changed, that women are still not believed about the extent of their pain & symptoms. It's frustrating & sad that the help is still not out there for women experiencing these symptoms. I feel like the state of the NHS is such that all but the most serious, emergency cases, are not being dealt with. With early intervention, support, and a range of therapies currently not offered by the NHS, women would not have their careers, relationships, and mental health as severely impacted as they clearly are at the moment. Women are left to navigate a really confusing system, are left to advocate for themselves, which is so hard when trying to work, trying to look after themselves, at the same time as writing to, calling, various places to get the help they need, often finding GPs, who should be advocating for them, really unhelpful. Many women are experiencing considerable financial hardship as a consequence.



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Premature Ovarian Failure:

A challenge for young women's health



Dr Virginia Lazăr

Consultant
Obstetrics and Gynecology
Gral Medical

The age threshold at which ovarian function ceases, both from an endocrine and reproductive point of view, is essential, because the earlier this process occurs, the greater the risks of developing various diseases, both in the short term and in the long term. Cardiovascular disease, obesity, type II diabetes, neurocognitive disorders, osteoporosis are just some of the challenges faced by women with early menopause or premature ovarian failure.

At the same time, women diagnosed with premature ovarian insufficiency also have to manage the difficulty of staying in labor and everything that follows from this, with consequences on both physical and emotional health, a situation that does not affect them only, but also their partner and married life.

Throughout life, women experience significant hormonal changes. The phases of this process begin with the onset of puberty and the first menstruation and end with menopause, i.e. the definitive cessation of menstruation and the end of reproductive life. Menopause involves the absence of menstrual bleeding for 12 consecutive months, in the absence of pathological causes, and may occur naturally or be medically induced.

Physiologically, menopause sets in around the age of 51 for most women. Installation of this process between the ages of 40 and 45 means early menopause, and earlier than 40 means premature ovarian failure.

Neither early menopause nor premature ovarian failure are considered physiological, both requiring medical intervention. The incidence of premature menopause is about 10% in the general population, and of premature ovarian failure is about 3.7% in the 30-40 age group and about 1/1000 in the 20-30 age group.

I also want to emphasize the expression "**difficulty in getting pregnant**", because when we talk about this pathology, although small, there is the possibility of intermittent resumption of ovarian function, and therefore, occasionally there may be ovulation.

The medical literature cites numerous factors that influence the age of onset of menopause, such as genetic, family, ethnic factors, age of first menstruation, reproductive history, body mass index, alcohol consumption and smoking, exposure to pollutants and endocrine disruptors, socioeconomic status. The causes of premature ovarian failure and early menopause can be genetic, autoimmune, metabolic, infectious or iatrogenic. We have up-to-date investigative guides, but most of the time we will not be able to identify a cause.



A separate category of patients is represented by those in whom these two pathologies are medically induced. This category includes survivors of childhood cancers, who have an incidence of premature ovarian failure between 2.1-82.2%, young women (under 40) diagnosed with breast cancer who have undergone or are undergoing oncological and endocrine treatment, who have an incidence of premature ovarian failure between 35.5-63.3% and women who have undergone ovarian surgery, both for endometriosis and other cysts, independent of the amount of ovarian tissue removed.

The diagnosis of premature ovarian failure involves a combination of clinical analysis and laboratory tests.

Perhaps as important as these, is the awareness of the fact that a young woman can face "menopause" long before the time. This should be considered by both women's health practitioners and women.

Symptoms of premature ovarian failure are varied and may include: irregular periods or absence of periods (amenorrhea) for at least 4 months, hot flashes, night sweats, sleep disturbances, fatigue, lack of concentration, memory problems, mood swings, decreased libido, vaginal dryness, recurrent urinary infections, infertility or difficulty conceiving a child. Among the most common investigations are the evaluation of the hormonal profile, the measurement of the follicle-stimulating hormone (FSH) level, the estrogen level, the evaluation of the ovarian reserve by transvaginal ultrasound and the dosage of the anti-Müllerian hormone (AMH) level.

Neither premature ovarian failure nor early menopause can be cured, but there are strategies to alleviate the symptoms and impact of these pathologies.

Hormone replacement therapy is essential to restore hormonal balance and improve or even eliminate symptoms. Ideally, this will be done until the average age of onset of menopause, i.e. 51 years, and involves the administration of the hormones estrogen, progesterone and testosterone in doses as close as possible to the physiology of the age, different for example from 30 to 40 years. In the case of women who do not want a pregnancy, we emphasize the fact that substitution therapy is not contraceptive, rare cases of pregnancy in these women have been cited. In this situation, the administration of contraceptive pills can be chosen, taking into account the age and the amounts of estrogen and progestin in the pills. We will pay special attention to bone health.

We will pay special attention to bone health. Assessment of bone density – osteodensitometry is important to know what level we start from, and whether, over time, our strategy to manage hypoestrogenism is effective. Fertility support is most often provided by in vitro fertilization, when possible with your own oocytes and as a secondary option with donated oocytes. Although it seems last on the list, lifestyle has a significant impact on health. The food and exercise choices we make every day have the potential to improve or worsen our health. Weight gain is not inevitable during this period, but it is very common. Studies have shown that the risk of developing abdominal obesity increases 5 times postmenopause, along with the slowing down of the metabolic rate. HIIT or High Intensity Interval Training and weight lifting, pilates and yoga appear to be the physical activities with the best results in maintaining weight, mobility, joint flexibility and bone strength.

In conclusion, premature ovarian failure is a complex condition that requires a personalized approach, and awareness and access to information are crucial for early diagnosis and adoption of an appropriate treatment plan.



Lisa and Robyn from Ireland, fighting endometriosis and helping others to use their voices. Together they are:



Her Voice Project

They say googling your symptoms it's often bad as you never know what you will come across. But in your case, it helped find out that your symptoms were caused by diaphragmatic endometriosis, something that no doctor that you saw was able to pinpoint. How did you feel when you realised that you finally have an answer?

L: When I realised that diaphragmatic endometriosis was the cause of my symptoms—especially the persistent, unexplained shoulder pain—I felt a mix of relief and validation. For so long, I'd been dealing with this confusing pain that no one seemed able to explain. I'd seen multiple doctors, but none of them connected my shoulder pain to endometriosis, so I was left feeling lost and, at times, even doubting my own experience.

Finding out on my own was empowering but also frustrating. On one hand, I finally had an answer; I wasn't imagining things, and there was a real, specific reason for my symptoms. It felt like a weight lifted off my shoulders knowing I could now look for ways to manage the pain that made sense for my actual condition. But on the other hand, I felt a bit let down by the process—it shouldn't have taken so long or so much effort to figure this out.

In the end, though, I'm grateful I trusted myself and kept searching. Now that I know diaphragmatic endometriosis is the cause, I feel more confident in advocating for the care I need and hopeful about finally finding some relief.

You were told that maybe you have a low pain threshold. A phrase often heard by many sufferers. How did it make you feel?

R: It made me feel weak and less than - I really began to think maybe it was true. It makes me angry now knowing what was happening inside my body and that I actually had a very very high pain threshold!

One of the doctors that you saw told you that you were too young to have endometriosis. How old were you then and at what age did your symptoms start?

L: When I finally discovered that diaphragmatic endometriosis was the cause of my symptoms, it was a huge relief and, at the same time, an emotional moment. My symptoms had started way back when I got my first period—they were extremely painful.



Then in 2015, I began experiencing this odd shoulder pain, which only worsened over the years, gradually spreading to cover larger areas. None of it made sense, and none of the doctors I saw could piece it together either. It was frustrating and exhausting to feel something was wrong without having any answers.

Finally learning that my shoulder pain was linked to diaphragmatic endometriosis felt like I could breathe again. For so long, I had felt dismissed and confused, wondering if I'd ever find the reason behind it all. To realize that it was a real condition and that there was a specific explanation for what I'd been going through was incredibly validating. I was relieved to know I wasn't imagining things and grateful I'd trusted myself enough to keep searching for answers.

Knowing what's causing my symptoms gives me hope that I can manage this condition better now, and it has given me confidence to advocate for my health going forward.

It takes years until one gets a diagnosis and many many doctors visits. How long it took you?

R: For me it took over 10 years to receive an official diagnosis due to each doctor explaining away my symptoms on my fitness levels, my diet, my iron levels and also my mental health to name a few! I was made to believe it was all in my head.

At your recent surgery, what did they discover? In an interview of yours, you mentioned liver endometriosis. Is that what you have?

L: At my recent surgery, they found that my endometriosis had progressed to stage 4, affecting multiple areas beyond my reproductive organs. The disease had spread significantly, attaching my bowel to my abdominal wall, infiltrating my liver, and deeply affecting my diaphragm. It was both shocking and validating to see just how extensive it had become, explaining so many of the symptoms I had been dealing with for years. Yes, liver endometriosis was confirmed, along with the diaphragmatic involvement I'd long suspected, which helped explain my shoulder and neck pain.

After surgery, I went through induced menopause to help manage symptoms, but unfortunately, my first period returned in October 2024, bringing the shoulder and neck pain back with it. It's been a tough realization that there's still more to address, but now I'm scheduled for two additional surgeries with a thoracic specialist in Oxford to examine my diaphragm more closely and assess my lungs for any further involvement. It's been a challenging journey, but knowing the full extent of the condition has given me a clearer path forward, even if it means more surgeries ahead.

From the start of your symptoms until surgery what was your medical journey like?

R: After years of suffering, you had your diagnostic surgery that turned into a proper surgery. It seems that your low pain threshold was actually stage 4 endometriosis. What was that a validation for you? The validation was bitter - I was so happy to have the validation and an answer after 10 years but the reality sunk in that I would have to deal with this disease for the rest of my life and that was frightening - There is still so much work to do to help women have good quality of life with Endo and this needs to change now!

You are not just a sufferer, you used your experience to create a space for women. What made you do so?

L: Creating a space for women with endometriosis and other complex gynaecological conditions became a mission for me because I knew how isolating and overwhelming the journey could feel. For years, I struggled with unexplained symptoms, bouncing between doctors who couldn't give me answers, and dealing with pain that was often dismissed. I felt alone in my experience, and there was a point when I realized that so many other women were going through the exact same thing.

What pushed me to act was the realization that, beyond medical treatment, we need support, understanding, and a sense of community. It can be incredibly empowering to hear from others who understand what you're going through, to share knowledge that goes beyond medical jargon, and to create a space where women feel seen and heard.



Now, this space is more than just a place for sharing information; it's a community where we advocate for each other, push for awareness, and support each other through the ups and downs. Knowing it can make even a small difference in someone's life makes every challenge I went through feel like it has a purpose.

You had hysterectomy as well. How are you now? Did it work?

R: I did yes, I had a hysterectomy in September this year after I exhausted all other avenues. It was a very emotional decision as although I had said I was finished expanding my family this was permanent and I worried I would change my mind in a year or two. Ultimately I went ahead with it so I could try to move forward. Thankfully I have recovered well and it was discovered I had adenomyosis also which thankfully a hysterectomy is a cure for. I was worried I would feel like less of a woman but I actually feel more womanly than ever!

What is advocacy for you?

L: I don't see myself as an endometriosis advocate. I see myself as a women's advocate—a source of emotional support and a comfort blanket for other women. My goal is to be there for women who are going through difficult journeys, whether they're dealing with endometriosis, PCOS, or any other health struggle that leaves them feeling unheard or alone. It's about creating a safe, compassionate space where women feel validated, understood, and empowered to advocate for their own health.

Her Voice Projects what does it mean?

L and R: Her Voice Project is a space built on compassion, connection, and community, created for women to feel they truly belong. Our mission is to offer a supportive, judgment-free environment where women can openly discuss all aspects of their lives, from health struggles and personal challenges to celebrating their successes and joys.

Through Her Voice Project, our goal is to create a safe, inclusive space for all women to be heard, celebrated, and supported.

Her Voice Project what does it mean? What are your values and mission?

L and R: Her Voice Projects is a space built on compassion, connection, and community, created for women to feel they truly belong. Our mission is to offer a supportive, judgment-free environment where women can openly discuss all aspects of their lives, from health struggles and personal challenges to celebrating their successes and joys. We want every woman who joins us to feel like she's talking to her best friend—a place where she can be vulnerable, feel understood, and find strength in the shared experiences of others.

Our values are at the heart of everything we do. Compassion is the foundation, driving us to support each woman's unique journey with empathy and respect. Connection means building real, lasting bonds, encouraging women to share their stories and learn from each other's journeys. And community is our strength—a collective of women coming together to lift each other up, empower one another, and remind each other that they're never alone.

You joined Lisa's efforts in making a change. What made you step in help?

R: I really admired Lisa for all the amazing work and change she was making with the page and I wanted to be a part of the change. I have amazing support but meeting women who know exactly how you feel and are going through is a bond like no other. I feel so grateful Lisa trusted me to step in.

We plan to continue holding events that focus not only on raising awareness but also on providing education, resources, and emotional support. Our goal is to expand the community and host more interactive events—whether they're workshops, online discussions, or wellness retreats—where women can learn, share, and grow together. We also hope to partner with healthcare professionals and organisations to offer better access to resources and care for women dealing with chronic conditions. Ultimately, we want to build a network that empowers women, strengthens our voices, and fosters an environment where women's health issues are not only discussed but prioritized.



Adenomyosis in teenagers

Diagnosis, Manifestations and Treatment



Dr Diana Mihai

Primary Physician

Obstetrics-Gynecology

Specialist in Vaginal Rejuvenation and
Infertility

Ladies Excellence Clinic

“Dragile mele, nu este normal să aveți dureri severe la menstruație, să nu puteți merge la școală sau să ajungeți la spital din cauza lor. Multe dintre voi știu că vă simțiți neînțelese deoarece nu găsiți o soluție și cei din jur poate nu iau în serios aceste dureri menstruale sau sângerările abundente. Cunoscând că există această patologie numită “endometrioză” și “adenomioza”, vă recomand să căutați un specialist în acest domeniu și să mergeți la o consultație. Un diagnostic cât mai rapid vă ajută durerile dar și va încetini/stopa progresia patologiei și agravarea ei”.

Although adenomyosis is commonly diagnosed in middle-aged women, it can also occur in teenage girls. Symptoms of adenomyosis can significantly affect the quality of life of teenage girls, causing school absences and anxiety. Adenomyosis can also be associated with other conditions such as endometriosis.

Diagnosing adenomyosis in teenage girls
Diagnosing adenomyosis in teenage girls can be challenging because the condition is less common in this age group and the signs can be non-specific. However, there are several diagnostic methods that can be used:

- **Clinical assessment:** A detailed history is taken to identify the patient's symptoms and medical history. An enlarged and tender uterus may be detected on physical examination, although this is less common in adolescent girls.
- **Transvaginal ultrasound** is a non-invasive method and often the first line of diagnosis for adenomyosis. However, identifying this condition in adolescent girls can be difficult because ultrasound signs can be nonspecific.

For the ultrasound evaluation of a patient with dysmenorrhea, including suspicion of adenomyosis and endometriosis, a protocol structured in four steps can be followed, as follows:

1. Routine evaluation of the uterus and adnexa.

- Evaluation of ultrasound features for adenomyosis (direct and indirect signs, according to MUSA criteria).
- Determination of the presence or absence of endometriotic ovarian cysts.

2. Evaluation of "soft" transvaginal ultrasound markers.

- Ovarian mobility: It is checked whether the ovaries move freely or are fixed by adhesions.
- Presence of adhesions: Pelvic adhesions may indicate endometriosis.
- Localized tenderness: Ultrasound palpation to assess specific pain points.



3. Evaluation of the pouch of Douglas.

The dynamic option is used to check the sliding sign. This involves mobility between the uterus, ovaries, and other pelvic structures, which helps assess the presence of adhesions and deep endometriosis.

4. Evaluation of foci of deep endometriosis.

Foci of deep endometriosis in the anterior and posterior pelvic compartments, such as the bladder, bowel, rectovaginal septum, and vaginal walls, are evaluated sonographically.

This detailed ultrasound evaluation can help identify causes of severe menstrual pain, such as adenomyosis and endometriosis, providing a structured and accurate approach to correct diagnosis.

As far as adenomyosis is concerned, ultrasound signs are divided into direct and indirect:

Direct ultrasound signs:

- Hypoechoic areas in the myometrium;
- Echogenic radial striae;
- Myometrial cysts;

Indirect ultrasound signs:

- Thickening of the anterior or posterior myometrium;
- Irregular contour of the junction between the endometrium and myometrium;
- Enlargement of the uterus;
- Inhomogeneous echogenicity of the myometrium;

Within the IDEA (International deep endometriosis analysis) protocol, adenomyosis is included as part of the evaluation of the uterus, because adenomyosis and endometriosis are frequently associated.

Types of adenomyosis

Adenomyosis can be classified into two types:

- **Focal adenomyosis:** When invasive endometrial tissue is located in a specific area of the uterus, it can form distinctive nodules.
- **Diffuse adenomyosis:** When invasive endometrial tissue is evenly distributed throughout the uterine wall.

Treatment of adenomyosis in adolescent

- **Drug treatment:** Nonsteroidal anti-inflammatory drugs (NSAIDs) can help reduce pain. There are suppositories, oral tablets or transdermal patches that reduce pain.

It is important to start taking them daily 1-2 days before menstruation and pains appear.

Various types of hormonal contraceptives: reduce pain and menstrual flow and in most cases stop or slow the progression of adenomyosis while they are administered. They are recommended to be administered continuously, under monitoring, until the patient wants a pregnancy. Then she can stop them and try to get pregnant from the very next month.

Treatments rarely used in adolescents: dienogest, rilpivirine, danazol, tranexamic acid, GnRH agonists, aromatase inhibitors, hormonal intrauterine device. Surgical treatment such as endometrial ablation, uterine artery embolization or hysterectomy: considered only exceptionally in adolescent girls. These treatments will never allow the patient to get pregnant again.

Alternative therapies:

- **Curcumin (Turmeric):** The recommended dose is 1000 mg twice a day. Curcumin is known for its anti-inflammatory and pain-reducing properties.
- **Zinc:** Helps repair intestinal permeability, normalizes immune function and acts as an anti-inflammatory. The recommended daily dose is 30 mg taken with food.
- **NAC (N-Acetyl Cysteine):** An amino acid that works as an antioxidant and immune modulator. It can reduce inflammation and pain, showing promising results in clinical trials. The recommended dose is 600 mg three times a day.
- **Melatonin:** A hormone involved in regulating the sleep/wake cycle, which also has a role in supporting the immune system and reducing inflammation.
- **DIM (Diindolylmethane):** Support for the initial phase of estrogen excretion, important in the hormonal balance of women with adenomyosis.



iCareBetter, a platform where patients can find video vetted endometriosis specialists

Dr. Saeid Gholami
Founder of iCareBetter

Understanding Endometriosis Patients: Challenges and Behaviors

The list of shortcomings in endometriosis care is prolonged. The long delays in diagnosis and treatments, failed treatments and surgeries, traumas, gaslighting, and many other issues exist. If there is one thing that has minimized the challenges, it is working with the right endometriosis expert early in the treatment journey. In today's digital age, innovative methods are being introduced to enhance patients' knowledge and access to high-quality care. However, it is not easy for a patient to know the surgical skills of a surgeon when they plan to do surgeries. They typically use proxy methods such as reviewing Instagram channels and Google reviews, talking to other patients, and looking at advocacy groups. They use these proxies to validate a surgeon's skills, and we all know how easy it is to game the system and manipulate the outcomes of these proxies. For example, hundreds of tools and companies exist to help surgeons look good on Google Reviews, regardless of their true outcome and skills. Advocacy groups recommend doctors primarily based on their personal relationships, and they do not vet surgeons. So, patients cannot confidently trust these resources and are looking for new resources.

Building Trust Through Video Vetting in Endometriosis Care

In endometriosis care, where patient trust is key, video vetting is a helpful way to build confidence and openness. This innovative approach not only showcases a surgeon's expertise but also helps patients make more informed decisions about their care. The video vetting process offers a transparent and comprehensive means of assessing a doctor's skills and expertise. By the end of this article, you'll understand what video vetting is, why it's significant for specialized fields like endometriosis surgery, and how it's changing patients' behaviors in finding their surgeons.

What is the Video Vetting Process for Endometriosis Surgeon Verification?

The video vetting process for endometriosis surgeon verification is a comprehensive and specialized approach designed to assess and validate surgeons' skills. This process goes beyond traditional credentialing methods, offering a more nuanced and accurate evaluation of a surgeon's capabilities.

- **Submission of Surgical Videos**

The process begins with surgeons submitting videos of their endometriosis surgeries. These videos typically showcase procedures demonstrating the surgeon's ability to handle stage II or higher endometriosis cases.

- **Accompanying Documentation**

Surgeons are required to submit corresponding operative and pathology reports along with the surgical videos. These documents provide crucial context to the procedures shown in the videos, offering insights into the surgeons' decision-making process and the outcomes of their interventions.

- **Expert Review Process**

Once submitted, the videos and accompanying documents undergo a rigorous review by a panel of expert endometriosis surgeons. This review is conducted anonymously to ensure objectivity. The experts assess various aspects of the surgeon's performance, including:

- Surgical technique and precision
- Decision-making during complex situations
- Adherence to best practices in endometriosis surgery
- Management of potential complications



• Specialized Verifications

The video vetting process can also lead to specialized verifications. These specialized verifications provide a more granular view of a surgeon's expertise, allowing patients to find specialists who closely match their specific needs.

Why Video Vetting is Important for Endometriosis Surgeons

The importance of video vetting for endometriosis surgeons cannot be overstated. This approach to surgeon verification addresses several critical needs in endometriosis care, benefiting both patients and doctors.

Elevating Standards of Care

Video vetting raises the bar for endometriosis surgery by setting a new standard for skill verification. It encourages surgeons to continually refine their techniques so they can successfully pass the vetting.

Addressing the Complexity of Endometriosis

Endometriosis is a complex condition that can present in various forms and severity. Video vetting allows surgeons to demonstrate their ability to handle this complexity in each specific disease region, such as bowel, diaphragm, ovaries, ureters, bladder, and other organs. By showcasing their skills in managing different types of endometriosis lesions and associated complications, surgeons can prove their readiness to tackle even the most challenging cases.

Enhancing Professional Development

The process of preparing for and undergoing video vetting can be a valuable learning experience for surgeons. It encourages self-reflection and critical analysis of one's surgical techniques. This introspective approach can lead to continuous improvement and professional growth, benefiting the surgeon and their future patients.

Building a Network of Excellence

Video vetting creates a community of verified endometriosis specialists. This network can facilitate knowledge sharing, collaboration on complex cases, and the advancement of endometriosis treatment techniques. Such a community of excellence can drive innovation and improve the overall quality of care globally.

Facilitating Patient-Surgeon Matching

For patients, finding the right surgeon for their specific endometriosis case is crucial. Video vetting facilitates this matching process by providing detailed insights into a surgeon's areas of expertise. Patients can more easily identify surgeons who have demonstrated proficiency in endometriosis. This will lead to more targeted search and effective treatment plans.

Steps to Go Through Video Vetting Process as an Endometriosis Surgeon

For endometriosis surgeons looking to undergo the video vetting process, there are several key steps to follow. This structured approach ensures a comprehensive and fair evaluation of surgical skills and expertise.

Selecting the Right Platform

The first step is choosing an appropriate platform for video vetting. Currently, [iCareBetter](#) stands out as the primary platform offering transparent double-blind video-vetting verification for endometriosis surgeons.

Preparing Surgical Videos

The core of the [video vetting process](#) lies in the surgical videos surgeons submit. Here are key considerations for preparing these videos:

1. Focus on Representative Cases:
2. Highlight Key Techniques
3. Include Specialized Procedures
4. Ensure Video Quality

Compiling Supporting Documentation

Along with your surgical videos, you'll need to provide supporting documentation:

- Detailed operative reports for each submitted surgery
- Corresponding pathology reports.

Submitting Your Materials

Once your videos and documents are prepared:

1. Use a secure cloud storage system to share your content.
2. Organize all materials in a clear, easily navigable format.
3. Ensure all patient-identifying information is properly redacted to maintain privacy.



Undergoing the Review Process

After submission, your materials will undergo a rigorous double-blind review process:

1. Three expert reviewers will anonymously evaluate your surgical videos and documents.
2. The review focuses on surgical technique, decision-making, and adherence to best practices.
3. You may receive requests for additional information during this process.

Receiving and Implementing Feedback

Upon completion of the review:

1. You'll receive detailed feedback on your submitted materials.
2. Use this feedback as an opportunity for professional growth and improvement.
3. Consider implementing suggested changes in your surgical practice.

Promoting Your Video Vetting Designation

Once successfully vetted:

1. Update your professional profiles and website to reflect your new designation.
2. Inform your patients about the significance of this verification.
3. Consider sharing your experience with colleagues to encourage wider adoption of video vetting in the endometriosis surgery community.

Video Vetting as a Vital Tool for Building Patient Relationships

It is an invaluable approach for endometriosis surgeons to build rapport and provide crucial information to patients early in their decision-making journey. This innovative process not only confirms a surgeon's expertise but also elevates trust and engagement. This trust lays the foundation for strong patient relationships.

Enhancing Transparency and Trust

By participating in video vetting, surgeons demonstrate a commitment to transparency and excellence. This openness can significantly boost patient trust, as it provides tangible evidence of a surgeon's skills and expertise.

Facilitating Informed Decision-Making

Video vetting empowers patients with detailed information about a surgeon's capabilities. This information enables them to make a more informed decision about their care.

Creating a Personal Connection

Although patients don't directly view the surgical videos, the knowledge that their surgeon has undergone this rigorous process can create a sense of personal connection and trust.

Addressing Specific Patient Concerns

Video vetting allows surgeons to demonstrate proficiency in specific areas of endometriosis surgery, directly addressing common patient concerns.

Encourage Patient Engagement

The existence of a video vetting process can encourage patients to be more engaged in their healthcare decisions.

Facilitating Referrals and Second Opinions

Video-vetted surgeons can more confidently claim endometriosis expertise and offer second opinions, knowing their skills have been objectively verified.

In conclusion, video vetting is a vital tool in building strong, trust-based relationships between endometriosis surgeons and their patients. By undergoing this process, surgeons not only validate their skills but also demonstrate a commitment to patient-centered excellence in care. This approach aligns perfectly with the evolving healthcare landscape, where informed patients seek transparency and excellence in their medical care. As the field of [endometriosis surgery](#) continues to advance, video vetting will likely play an increasingly crucial role in ensuring high-quality care and facilitating positive patient outcomes.



ENDORO-ONLINE

**WEBSITE FOR ENDOMETRIOSIS,
ADENOMYOSIS AND FIBROIDS**



ENGLISH ROMANIAN

Information from various medical
sources

Endometriosis

Adenomyosis

Fibroids

Infertility

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ASSOCIATION OF PEOPLE WITH ENDOMETRIOSIS

HELPING TO CONSTRUCT A BETTER WORLD



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