

# QUESTIONS TO ASK AN ENDOMETRIOSIS SURGEON BEFORE SURGERY.

All the things to ask a surgeon before surgery & what to look for when searching for a surgeon.

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THE FANNY DIARIES & A CLOSED  
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FIND ON THE FANNY DIARIES PAGE



Email -

SARAH@FANNYDIARIES.COM

THE  
FANNY  
DIARIES

Sarah Victoria  
xoxo

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# JUST A QUICK NOTE...

All my downloadable E- books and everything that I write on my website and blog are from a patient (myself) point of view, not a medical one and all views are my own.

I am not a medical professional, I can never, nor will I ever give medical advice.

This is created from someone who has been through the entire Endometriosis diagnosis and surgery journey and has recognised the lack of information and guidance out there. I have created all of these so people can be as informed as possible so they can make the best decision for THEIR health. This is not to be confused for medical advice, Please always consult with your doctor about any concerns that you have.

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# INTRODUCTION.

Going for Endometriosis surgery within the UK, is a tough task. You don't get to select your surgeon if you have surgery on the NHS and reviews of doctors are not online, like they are in some other countries. Only if we pay thousands privately do we get the chance to be a bit more selective.

This is where care is dramatically lacking. Unless you know the questions to ask, what red flags to look out for and what is misinformation, we put all of our trust into medical professionals and surgeons who are not necessarily Endometriosis experts. This leads to complications and multiple repeat surgeries which can lead to more scar tissue, more adhesions and more complications down the line.

I have written this E-Book as I wish I understood all of this, I wish that I was more educated prior to my surgery and I wish that I had known to ask these questions. It might have just saved me from complications from my surgery, which I still suffer with almost 2 years on.

Endometriosis care worldwide needs to be dramatically improved ASAP. Organisations, Charities and Medical Professionals need to all do better.




# DID YOU KNOW?

**That there is currently no strict vetting systems in place within the UK, for Surgeons to operate on Endometriosis. A general Gynecologist is able to operate on someone with Endometriosis, despite not having an extensive amount of knowledge or much experience with operating on Endometriosis. This can lead to Endometriosis being missed, left behind or missed completely and a misdiagnosis.**

**We are only as good as the information that we are provided and there is a massive lack in education and correct information surrounding Endometriosis. This is why it is so important to be your own advocate and to always do your own research.**

**Proper Endometriosis Excision specialists, operate on only Endometriosis multiple times a day and have years and years of experience.**

**When we look at how this compares to the requirements for the BSGE Endometriosis Centres in the UK its quite shocking.**



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# BSGE CENTRE REQUIREMENTS

Let's look at some of the requirements for the BSGE Endometriosis centres in the UK.

## 2. Workload

It is essential that there is sufficient workload throughput to maintain surgical skills for the most complex cases. Whilst all degrees of severity of endometriosis may be treated within the service, it is a requirement that at least 12 cases of rectovaginal endometriosis which require dissection of the para rectal space, are treated by surgery each year. This is defined by a procedure to remove rectovaginal endometriosis that requires dissection of the pararectal space and must be recorded on the BSGE database. Whilst this can include open surgery it is expected that this will usually be undertaken laparoscopically.

***"At least 12 cases of rectovaginal endometriosis are treated by surgery each year"***

**This is per surgeon. That equals 1 per month which for a specialist centre is not a lot.**

**NB: Changes in criteria in 2017**

Currently the requirement is for a minimum of 12 cases annually for each centre. From January 2017, this will change to 12 cases per gynaecological surgeon annually. So the accreditation for a centre with one named Gynaecologist will be 12 cases, whereas a centre with two Gynaecologists will be 24 cases, three would be 36 cases etc.

**It is however, an improvement from before 2017. It used to be 12 annual cases per centre. As of January 2017, it changed to 12 per surgeon annually.**

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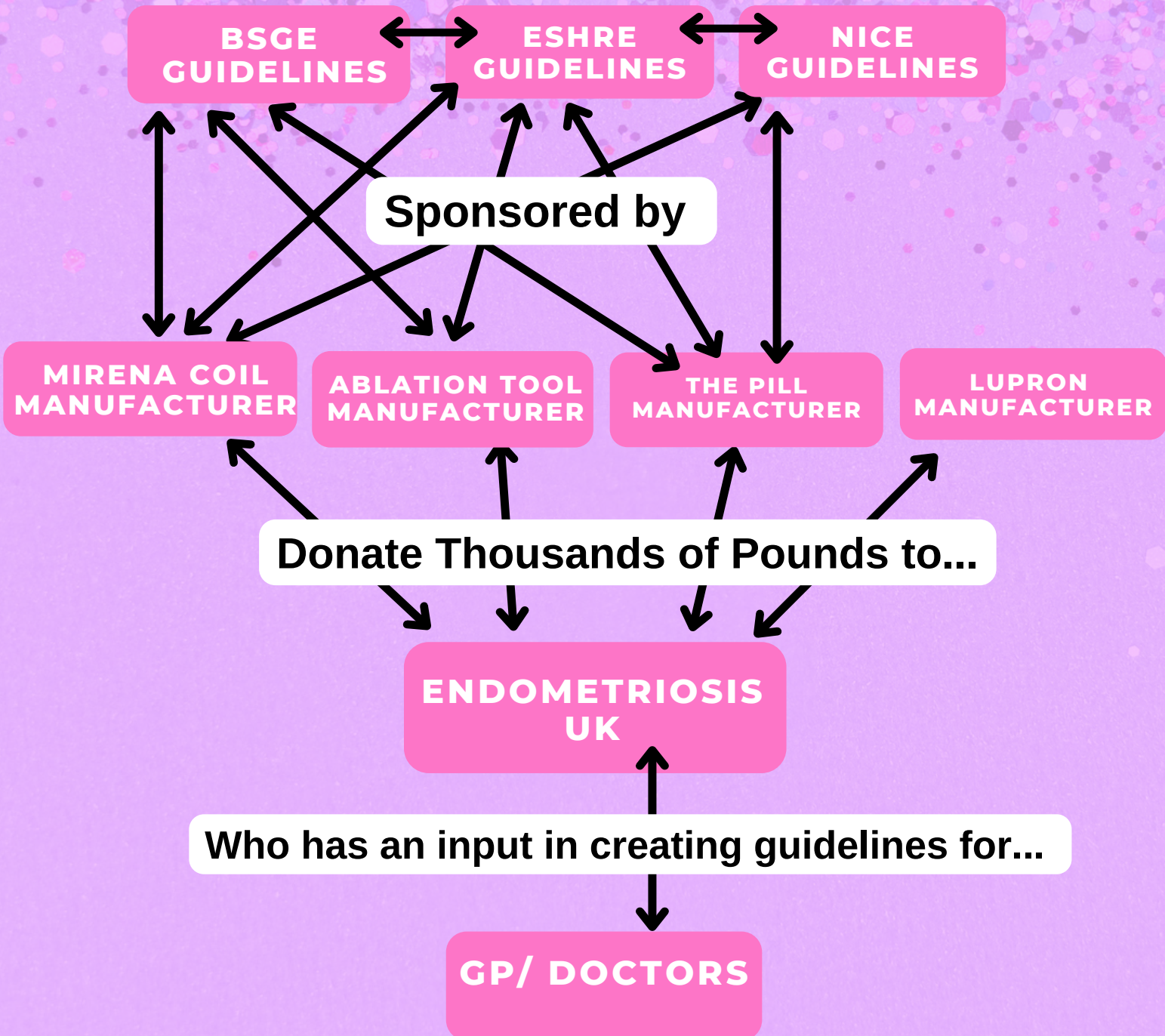
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# QUICK ENDO CARE OVERVIEW IN THE UK

## Endometriosis UK Guidelines



For a more in-depth explanation on the links to big Pharma and Endometriosis care within in the UK, and for sources please see the Endometriosis UK report on the downloads page.

# WHAT WE NEED

**We desperately need more providers such as the Center for Endometriosis care in Atlanta USA, but worldwide.**

**A proper Endometriosis Centre with surgeons just specialising in Endometriosis with extensive vetting system, training and hundreds of operating hours behind them to be able to operate there.**

**We need true Excision Endometriosis specialists available and easily accessible to everyone. We need it to be normalised and global awareness, so we all have proper access to excision from our first surgery. This is something that will give us all the best possible chance at a normal life.**

**We need more education in Endometriosis along with the real extent and devastation that it causes. This needs to be taught in medical schools and schools.**

**We need a clamp down on the misinformation that is being handed out by medical professionals, charities and organisations.**

**We need regular Gynecologists to stop operating on Endometriosis patients, when they are not properly trained to do so. We need them to stop telling people they will perform surgery, then not be able to do anything because it is too extensive for them.**

**We need Gynecologists to admit that they are not trained in operating on Endo and to refer their patients to specialists instead of attempting it themselves.**

**We need more funding and finance awarded towards training proper Endometriosis Excision Specialists.**

**Endometriosis is an all over body disease and it needs to be recognised and treated that way, a multidisciplinary team and approach needs to take it on.**







# WHAT TO KNOW...

There are two types of methods performed during surgery for endometriosis, Ablation and Excision. Please download the Ablation V Excision E-book on The Fanny Diaries website, for a more in depth explanation between the two.

This graphic below offers a quick overview of pros and cons between the two. Ablation is more widely offered however, true endometriosis excision specialists label excision Surgery as the gold standard of care when it comes to endometriosis.

<h2>Endometriosis Surgery</h2>			
<h3>Excision</h3>		<h3>Ablation</h3>	
Excision of Endometriosis is the surgical cornerstone of any high quality, multidisciplinary approach to treating endometriosis. It physically cuts out endometriosis lesions at the roots.		Ablation of Endometriosis is performed using heat energy to destroy the top layer of the endometriosis lesions where they lie. It chars the top of the lesion but does not remove deep embedded Endometriosis.	
			
Pros	Cons	Pros	Cons
<ul style="list-style-type: none"><li>Removes Endometriosis from the root, ensuring total removal of the Endometriosis lesion found.</li><li>Removes deeply infiltrated Endometriosis (DIE).</li><li>Specialist Surgeons utilising excision routinely report rates of long-term relief in 75-85% of patients.</li><li>lower rates of recurrence.</li></ul>	<ul style="list-style-type: none"><li>Not easily accessible.</li><li>Extremely expensive, not many insurances will cover it.</li><li>A lack of trained Endometriosis Specialist's in the world.</li><li>Longer recovery time.</li><li>Recurrence can still occur.</li><li>More invasive.</li></ul>	<ul style="list-style-type: none"><li>Shorter recovery time.</li><li>Less Invasive.</li><li>More accessible, more trained surgeons.</li><li>Less expensive, insurance more likely to cover it.</li><li>Provides short term relief.</li></ul>	<ul style="list-style-type: none"><li>Higher recurrence rates.</li><li>Burning tissue increases the risk of scar tissue which can increase the risk of potential damage to other organs and tissue.</li><li>Not obtaining a biopsy for pathological diagnosis.</li><li>Does not remove the Endometriosis lesions from the roots.</li></ul>
GRAPHIC BY - @THEFANNYDIARIES			



# **WHY IS A SPECIALIST ENDOMETRIOSIS SURGEON SO IMPORTANT?**

**A Laparoscopy is the standard method to visually identify Endometriosis lesions however, Endometriosis is a very complex disease that is multiple different colours. Due to the different appearance in Endometriosis lesions, they are often confused for nonendometriotic lesions which leads to endometriosis being undiagnosed. Therefore, if the surgeon is not a true Endometriosis specialist and is not aware of the multiple different colours and deep infiltrating lesions of endometriosis (that are unable to be seen visually) endometriosis can be missed during a laparoscopy. This is why it is so important to have a specialist operate.**

**Towards the back of this E-book I have included some surgical photos which show you some of the different appearances of Endometriosis.**



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# THINGS TO AVOID IN A SURGEON. 1.

The ideal situation would be to find a true Endometriosis Excision specialist who has operated on thousands of people with a huge success rate. A surgeon who understands and only operates on Endometriosis and who's excision skills are impeccable .

- If they are a regular Gynecologist, or if Endometriosis is not their primary speciality & they do not have multiple years of experience.
- If they only perform Ablation and not Excision.
- If they don't take surgical Videos or Photographs during surgery.
- If they do not recognise Endometriosis as full body disease, and say it can not be found outside the uterus.
- If they refuse or say it is not necessary to check other organs in your body for Endometriosis.
- If they say there is no need to take Biopsy's for pathological reports.
- If they are unable to look for the signs of Adenomyosis.
- If they say you will be better after your surgery the next day or within 2 days.
- If they say they only need to get rid of a bit of Endometriosis or just the bits that they can see.



# SOME THINGS TO AVOID IN A SURGEON. 2.

- If they are not aware that Endometriosis can have multiple different appearances, if they say its just black in appearance.
- If they tell you the Mirena Coil or hormones are a cure, or stop the growth of Endo. Sadly, there is no current cure for Endometriosis and hormones do not stop the growth.
- If they refuse to answer any questions or get irritated at you for asking too many questions.
- If they are dismissive, rude and not caring or compassionate.
- If they want you to use GNRH drugs (Depot, Lupron etc) months before surgery to "calm" the area.
- If you feel pressured into taking any medication that you are not comfortable taking.
- If they tell you that pregnancy or the Menopause is a cure for Endometriosis.
- If they tell you that Endometriosis is caused by retrograde menstruation.



# WHERE TO FIND AN ENDO SPECIALIST SURGEON?

There are around 200 true Endometriosis Excision Specialist's worldwide. For over 190 million people worldwide and 1 in 10, who suffer from Endometriosis, this is just not good enough.

## How would I find a specialist?

Depending where you live, what country you are from depends on where you would find an Endometriosis Excision Specialist. I know this answer isn't the most helpful but It is a very difficult thing to recommend without having every single surgeon vetted.

## As a starting point -

There is a facebook group that recommends Endometriosis Specialists however, please still do your research as I am not sure what the vetting process is for them. There are mixed reviews about the group but it can be a good starting point, as there is a list of Excision specialists all around the world. Always do your own research.

## [Facebook Group- Nancy's nook Endometriosis Education.](#)

Just a reminder that an online group is not to be confused for Medical advice. You can not be diagnosed through a Facebook group. Make sure if you see an Endometriosis Specialist, they are a legitimate and reputable medical professional. Never pay anyone online or through a group. Always speak to a trusted medical professional.

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# BUSTING SOME COMMON ENDO MYTHS. 1.

**ENDOMETRIOSIS IS THE ENDOMETRIUM.**

Endometriosis is Endometrial LIKE cells/tissue growing outside the uterine cavity. It is NOT the endometrium.

**A HYSTERECTOMY IS A CURE FOR ENDOMETRIOSIS**

There is currently NO cure for Endometriosis. Not the pill, pregnancy, eating kale, or yoga.

**HORMONES STOP THE GROWTH OF ENDOMETRIOSIS**

Hormones can potentially suppress some of the symptoms for Endo. They do NOT stop the growth.

**ENDOMETRIOSIS IS ONLY FOUND IN THE UTERUS**

Endometriosis is an all over body disease. It has been found on every organ in the body.



# BUSTING SOME COMMON ENDO MYTHS.2.

**THE MIRENA COIL IS A CURE.**

The Mirena Coil is not a cure or diagnostic tool for Endometriosis. It can possibly help with some of your symptoms but not everyone will find it beneficial.

**YOU CAN BE TOO YOUNG FOR ENDOMETRIOSIS**

Endometriosis has been found in a Fetus in medical studies. The youngest person to have Endometriosis in medical literature is currently aged 7.

**YOUR PAIN WILL NATURALLY STOP AT MENOPAUSE**

Menopause & a Hysterectomy does not cure Endometriosis. Symptoms can still persist after Menopause or a Hysterectomy.

**THE CAUSE OF ENDOMETRIOSIS IS RETROGRADE MENSTRUATION**

Sampson's theory is a theory that has been debunked. The cause for Endometriosis is unknown. Retrograde Menstruation offers no explanation for extra pelvic endo.

# THERE IS NO CURE FOR ENDOMETRIOSIS

**Sadly, there is currently no cure for Endometriosis. If a medical professional or a potential surgeon tells you that the following are cures, find a new one.**

**This is always easier said than done but we are often told multiple amounts of misinformation even by medical professionals, so keep in mind that there is no current cure.**

## THESE ARE NOT CURES

**Pregnancy**

**The Mirena Coil**

**The pill or any form of hormone contraception**

**Yoga**

**Orlissa, Lupron or any GNRH.**

**Menopause**

**A Hysterectomy**

**Surgery**

**Meditation**

**Diet**

**Exercise**

**Less stress or no anxiety**

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# WHAT COULD BE SUGGESTED AS "TREATMENT" OPTIONS AFTER YOUR SURGERY.

It is worth noting that Endometriosis is not a one size fits all disease. What works for you, might not work for someone else and vice versa. You have to do what is best for you moving forward with regards to "treatment" options.

"Treatments" aim to ease symptoms, they do not cure or stop the growth of Endometriosis.

It is very common to be offered the Mirena Coil to be fitted during your surgery. It is important that you do not feel pressured into having the Mirena fitted if it is something that you are not wanting to have. As mentioned above, the Mirena does not stop the growth but it can possibly help with some of your symptoms. Some people have benefited from the Mirena coil where as some people haven't, always do your research and what is best for you.

## YOU MAY BE OFFERED -

- *Hormone contraceptive Pill - Combined or Progesterone only Pill.*
- *The Mirena Coil*
- *Lupron*
- *Orlissa*
- *Depo Provera*
- *Advised to take nothing.*

Always consult with your doctor/ surgeon and always do your research so you understand what it is you will be taking, what it does and the full side effects involved.

Always make a decision based on what is best for YOU. You are your own best advocate and you know your body better than anyone.

Treatment option source - [www.nhs.uk](http://www.nhs.uk)



W W W . F A N N Y D I A R I E S . C O M

**Although, surgery has the possibility to provide an accurate diagnosis through a biopsy and it could possibly provide some relief it is important to remember that...**

# **SURGERY IS NOT A CURE**

**There are also risks involved with surgery so talk to your surgeon about these risks. They should explain all risks involved. That way you can make the best decision for YOU.**



**W W W . F A N N Y D I A R I E S . C O M**





# ASKING QUESTIONS CAN...

**Be daunting and advocating for yourself is super hard but you have to remember that this is YOUR health and health is priceless. You deserve to get the best out of every appointment and it is important to know these answers from your surgeon before you proceed with surgery. A thorough surgeon won't mind answering any question you have.**

**You can do it babes! I used to just sit and nod and never ask any questions now I ask loads.**

# Questions.

## QUESTIONS TO ASK YOUR SURGEON.

- IS ENDOMETRIOSIS YOUR MAIN SPECIALITY? HOW MANY PEOPLE HAVE YOU OPERATED ON WITH ENDOMETRIOSIS?
- WILL YOU BE PERFORMING THE SURGERY YOURSELF?
- WHAT SURGICAL METHOD DO YOU USE TO REMOVE ENDOMETRIOSIS, ABLATION OR EXCISION? AND WHY? CAN YOU PLEASE HIGHLIGHT THE DIFFERENCE?
- DOES ENDOMETRIOSIS HAVE MULTIPLE APPEARANCES? WOULD YOU BE ABLE TO RECOGNISE THEM?
- WILL YOU LOOK FOR ENDOMETRIOSIS ELSEWHERE ON OTHER ORGANS? IF SO WILL OTHER SPECIALISTS BE REQUIRED? E.G BOWEL, BLADDER, KIDNEY ETC.
- WILL YOU TAKE BIOPSY'S FOR A HISTOLOGY REPORT TO CONFIRM THE PRESENCE OF ENDOMETRIOSIS?
- WILL YOU DO A HYSTEROSCOPY?
- WILL YOU CHECK FOR SIGNS OF ADENOMYOSIS?
- WILL YOU CHECK THAT MY OVARIES ARE WORKING AS THEY SHOULD BE?





## QUESTIONS TO ASK YOUR SURGEON.

- WILL YOU LOOK AND CHECK FOR FIBROIDS AND POLYPS? AND SHOULD YOU FIND THEM WILL THESE BE REMOVED?
- WILL YOU TAKE PHOTOS AND VIDEOS DURING SURGERY? IF SO WOULD I PLEASE BE ABLE TO HAVE A COPY?
- WHEN WOULD MY POST OP FOLLOW UP APPOINTMENT BE?
- WHAT WOULD HAPPEN IF YOU WERE UNABLE TO REMOVE ANY ENDOMETRIOSIS?
- WILL I NEED TO DO BOWEL PREP? IF SO WHAT OPTIONS ARE AVAILABLE?
- HOW LONG WOULD YOU SAY I WOULD BE OFF WORK?
- SHOULD I HAVE COMPLICATIONS DURING THE RECOVERY HOW WOULD I CONTACT YOU?
- WILL I BE CATHETERISED WHEN I WAKE FROM SURGERY?
- DO YOU USE AN ADHESION BARRIER? IF SO WHAT ONE?
- WOULD YOU ADVISE HORMONAL TREATMENT AFTER SURGERY?
- WHAT WILL MY POST OP PAIN MANAGEMENT LOOK LIKE? WILL YOU PROVIDE PAIN RELIEF AND WHAT PAIN RELIEF WILL I BE GIVEN?

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ANY OF YOUR OWN QUESTIONS/ NOTES/

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# Questions.

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ANY OF YOUR OWN QUESTIONS/ NOTES/

# WHAT CAN ENDOMETRIOSIS LOOK LIKE?

**TW- (TRIGGER WARNING)  
ON THE NEXT SLIDE ARE  
A FEW SURGICAL IMAGES TO  
SHOW WHAT ENDOMETRIOSIS  
CAN LOOK LIKE. PLEASE  
SCROLL PAST IF YOU DO NOT  
WANT TO SEE.**

**I HAVE PUT THIS AT THE BACK AS  
NOT EVERYONE WANTS TO LOOK  
AT SURGICAL IMAGES.**



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# WHAT CAN ENDOMETRIOSIS LOOK LIKE?

HERE ARE SOME PICTURES FROM THE CENTER FOR ENDOMETRIOSIS SHOWING DIFFERENT LESIONS OF SUPERFICIAL ENDOMETRIOSIS.

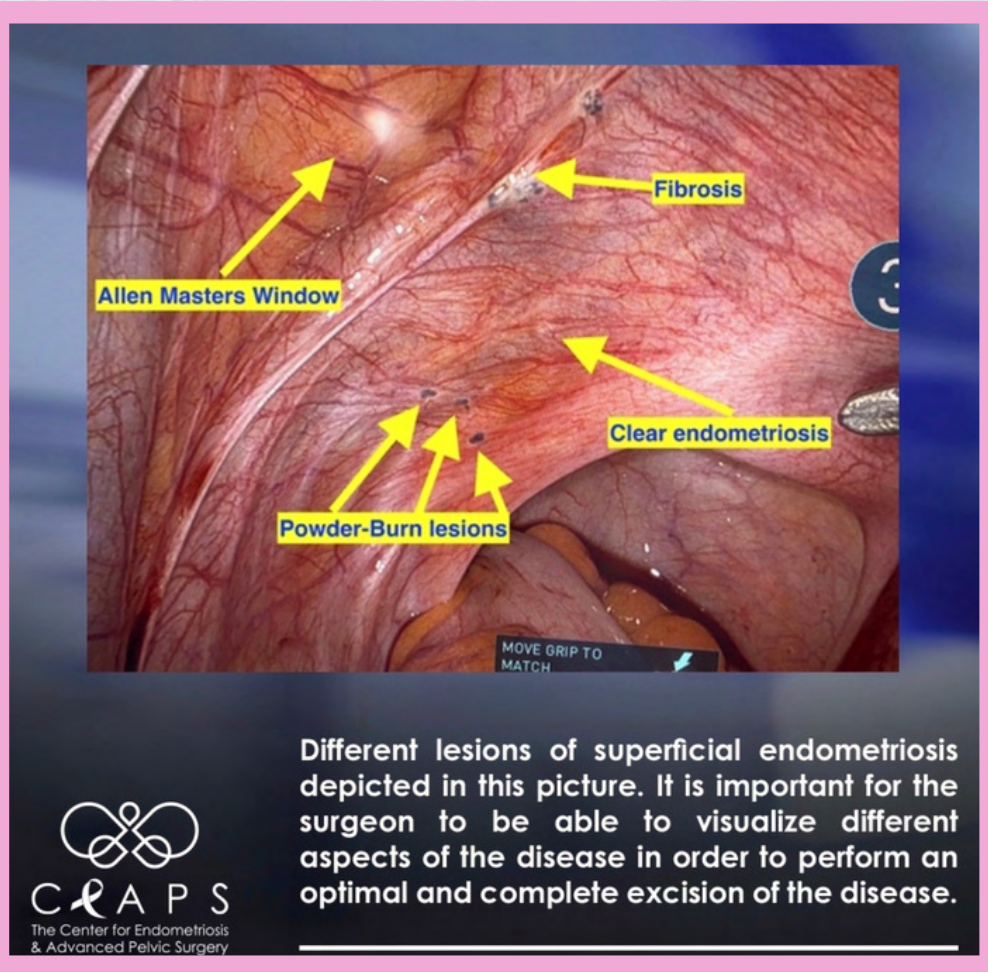


IMAGE FROM CENTER FOR ENDOMETRIOSIS INSTAGRAM PAGE.




HERE I HAVE ZOOMED IN AND CIRCLED THE CLEAR ENDOMETRIOSIS WHICH ARE NEXT TO THE POWDER BURN LESIONS. TO THE NAKED EYE IT LOOKS LIKE NOTHING IS THERE. THIS IS WHY IT IS SO IMPORTANT TO HAVE YOUR SURGERY WITH AN ENDOMETRIOSIS SPECIALIST. UNLESS YOU ARE HAVING AN ENDOMETRIOSIS SPECIALIST PERFORM YOUR SURGERY CLEAR ENDOMETRIOSIS LESIONS CAN EASILY BE MISSED.



# IF YOU ARE HAVING SURGERY PLEASE DOWNLOAD THE LAPAROSCOPY PACKING BUNDLE TO HELP YOU PREPARE.

THIS E-BOOK  
WILL HELP  
YOU PACK &  
PREPARE  
FOR YOUR  
SURGERY!

READ ABOUT  
EXCISION  
V  
ABLATION  
IN MORE DETAIL  
IN THIS E-BOOK  
X



## DOWNLOADABLE & PRINTABLE LAPAROSCOPY PACKING GUIDE.

All the things I wish I knew before going for an  
Endometriosis Laparoscopy.



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## EXCISION V'S ABLATION.

Endometriosis Surgery Explained.

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# HELPFUL INFORMATION OUTLETS.

[www.centerforendo.com](http://www.centerforendo.com) - For information.

Youtube channel - Endometriosis Summit

Facebook groups - Nancy Nook (to search for surgeons) Please also do your own research as I am not sure of the vetting process.

If you are in the USA - ICarebetter.com Website- To search for specialist surgeons.

## Where isn't the best information?

Endometriosis UK Charity Website & Youtube.  
Their information leaflets were last updated in 2010/2012 & their youtube channel is full of misinformation webinars.

## SOURCES.

[HTTPS://WWW.BSGE.ORG.UK/ENDOMETR  
IOSIS-CENTRES/](https://www.bsg.org.uk/endometriosis-centres/)

[WWW.FANNYDIARIES.COM](http://www.fannydiaries.com)

[HTTPS://WWW.NCBI.NLM.NIH.GOV/PMC/  
ARTICLES/PMC4334056/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4334056/)

[HTTPS://WWW.NCBI.NLM.NIH.GOV/PMC/  
ARTICLES/PMC4233437/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4233437/)

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SPECIALIST/](https://drseckin.com/why-is-it-so-hard-to-find-an-endometriosis-specialist/)



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