



So...What IS *ENDOMETRIOSIS*, and how might it affect **ME**?

- **Endometriosis** (aka '**ENDO**') is a disease which is thought to affect ONE IN TEN women across the world! Despite it having little 'exposure' it is as common as diabetes or asthma, and affects girls and women of ALL ages!
- **Endo** is when tissue that is somewhat similar to the lining of the womb, is found elsewhere in the pelvis, on the internal organs, & sometimes farther afield. The inflammation from these lesions causes swelling, irritates the surrounding areas, and causes localised bleeding. Over time, scarring & adhesions can develop. Hormone fluctuations often affect the symptoms.
- **Adhesions** (bands of scar tissue) can make organs inside the abdomen stick together & sometimes stop them working properly. They can also cause pain.
- **Endo** can cause pelvic pain at any time, not just during periods.
- **Endo** may cause heavy, painful, irregular bleeding.
- **Endo** can cause bloating, fatigue, bowel & bladder problems, rectal bleeding, aching back, legs, pain during sex / internal exams, and infertility.
- Most of the time **endo** doesn't show up on ultrasound scans, CT scans, MRIs or endoscopies (camera investigations up the back passage).
- A laparoscopy is the only way to definitively diagnose **endo**. This is a keyhole operation performed to spot the lesions & adhesions that make up disease.
- The current gold standard surgical treatment for **endo** is called **EXCISION**. This is where the lesions are properly removed - cut out, rather than just burned.
- In Wales, the lack of specialists means many sufferers will have repeated ineffective surgeries to burn the **endo** - comparable to only taking the tip off an iceberg. The disease remains below the surface & often symptoms persist.



So...You want to know more about *ENDO* and its treatment?

- Burning of **endo** is also known as diathermy ablation.
- Burning **endo** only affects the top of the disease, leaving most of it behind and creating painful scar tissue.
- Subsequent operations may be more difficult after burning has been performed. This is because adhesions and scarring reduce visibility and make surgery more complex.
- Pregnancy is *NOT* a cure for **endo**. Some women will experience relief during pregnancy because of increased progesterone levels – but many won't experience any relief at all. Afterwards, the symptoms often return.
- Some women find that **endo** has affected their fertility and they can't get pregnant or maintain a pregnancy. If disease is properly removed (**excised**) their chances of conceiving improve.
- Hysterectomy (removal of the uterus) is *NOT* a cure for **endo**. Even removing the ovaries won't necessarily help. This is because **endo** creates its own hormones to survive. Accredited endo specialists should try just to remove disease, not the reproductive organs.
- Right now, **EXCISION** is the best treatment we have. Hormone medicines (like the Pill, the Coil, or menopause-inducing injections) might ease symptoms for some women but they don't cure the disease.
- Most general gynaecologists do not have the expertise to excise **endo**. Across the UK, there are specialist multi-disciplinary centres accredited by the BSGE (British Society for Gynaecological Endoscopy) where **endo** can be excised and to which all patients should, ideally, be referred.

