

FTWW

FAIR TREATMENT FOR
THE WOMEN OF WALES

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FTWW's Pocket Endo Myth-Buster

**FTWW IS THE ONLY PATIENT-LED ORGANISATION IN WALES
DEDICATED SOLELY TO WOMEN'S HEALTH EQUALITY**

Living with ENDOMETRIOSIS ('Endo')?

If so, you've probably started to encounter fictions and misinformation which surround the condition – so here's **FTWW's Pocket Endo Myth-Buster**, with the TRUTHS you need to counter those fictions, no matter where you hear them!

✗ *Nobody's ever heard of 'Endo', so it must be rare – right?*

✓ Wrong! 1 in 10 girls / women, mainly of reproductive age, are affected, so it's as common as diabetes or asthma.

✗ *You're too young to have endo*

✓ Symptoms can begin before puberty, and some studies have shown that lesions can be present before birth!

✗ *You're too old to have endo*

✓ Endo can persist after menopause, especially if the disease has never been removed (cut out).

✗ *Pregnancy is a cure for endo*

✓ Some women's symptoms reduce during pregnancy. Others won't have the same relief. Plus, once pregnancy or breast-feeding have finished, symptoms can return...

✗ *It's just bad periods*

- ✓ If they're heavy and painful enough to make school or work a problem, then they need investigating. Plus, you may have symptoms even when you're not on your period, especially as the disease progresses.

✗ *It's just Irritable Bowel Syndrome (IBS)*

- ✓ IBS (including constipation and / or diarrhoea) can be a symptom of endo on or near the bowels. Be persistent if you think that these issues might be down to endo.

✗ *It's a urinary tract infection / sexually transmitted disease / appendicitis*

- ✓ Endo can cause symptoms that feel very much like these issues. If they've been ruled out or you've had all the treatment available for them with no relief, it might well be endo!

✗ *Changing your diet and / or avoiding chemicals will cure you.*

- ✓ Studies show that endo existed long before we started using plastics, shampoos, or eating processed foods. Reducing these may well make you feel healthier, but they won't get rid of endo!

✗ *You're taking / using hormonal treatment - any symptoms you're getting can't be endo!*

- ✓ Wrong again! It's perfectly possible to get endo symptoms when using the contraceptive pill, coil, menopause injections - even if you're not having any periods! Hormone treatments can provide symptom relief for some - but they don't treat the underlying disease!

✗ *You've had an operation for your endo, that should be the end of it!*

- ✓ Sometimes endo may not be fully removed, particularly if the surgeon has used a technique called 'ablation', where just the top of your endo is burned off. 'Excision' or 'cutting out' is a better option but, even then, it can be missed on occasions. It's a tricky disease, best treated by a specialist.

✗ *You'll be fine if you have a hysterectomy**

- ✓ A hysterectomy is the removal of your uterus (womb). Some women might get relief of symptoms afterwards, but that's often because they had a uterine condition too, such as adenomyosis. For most endo patients, it's the disease that needs removing, not healthy organs.

****Bonus Myth - endo is bits of your uterus / womb-lining sticking to other parts of your insides - uhh, no. Endo is similar to womb-lining but, when examined under a microscope, has many differences.***

✗ Nobody else seems to have this disease!

> There are lots of others feeling just like you, but many are reluctant to talk about their symptoms publicly. For more information, tips for self-management, and peer-support, join FTWW's online group on Facebook.

Useful sources of information and / or support:

<http://endopaedia.info/>

<https://www.nice.org.uk/guidance/qs172>

<https://www.endometriosis-uk.org/>

WE'RE NOT 'MAD', WE JUST WANT 'EVEN'!



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SEARCH FOR FTWW WALES

