A collection of personal stories from Veterinary Nurses suffering from a Chronic Illness or Condition.

A personal story by Alex Taylor

Endometriosis (pronounced en- doh – mee – tree – oh – sis) and adenomyosis (pronounced ad-eno-my- oh- sis) are a bit of a mouthful, aren't they? For the sake of everyone reading this blog I will call them 'endo', and 'adeno'. They are both invisible illnesses, making it particularly challenging for those affected to be believed, understood, and taken seriously.

The charity Endometriosis UK describe endo as:

'The condition where cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. Each month these cells react in the same way to those in the womb, building up and then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape'

The pelvic pain support network defines adeno as:

'The finding of endometrium (the tissue that normally lines the inside of the uterus/womb) within the myometrium (muscular wall of the womb)'
Endo affects 1:10 adult females in the UK. Yet it isn't discussed enough, people are not aware of its existence, and more importantly there is no known cure.

Symptoms of endo/adeno include:

- Chronic abdominal pain. This can be experienced at any time during the woman's cycle, but often worsens during menstruation
- Heavy, prolonged periods with clots and spotting between cycles
- Chronic fatigue
- Bowel and bladder problems

- Fertility problems (affects 30-50% of endo sufferers)
- Back and leg pain
- Painful sex
- Feelings of isolation, anxiety, and depression

My story

Even in my teenage years, I always had heavy and painful periods, which I accepted as normal. Although some cramping can be normal, if it is bad enough to affect your daily life it is not. I wish I had known this when I was younger!

Fast forward ten years and I was visiting the doctor several times a year, for what I now know were endo-related issues e.g., spotting between periods, abdominal pain. I was put on the contraceptive pill when I was quite young, which masked and lessened my symptoms a little. I had various tests and examinations, but nobody ever suggested endo, it wasn't mentioned, not once.

Ten years later, I met my husband and was looking to start a family. I came off the pill and almost immediately my symptoms worsened. Endo and adeno had reared their ugly heads and boy did I know it! At this stage I still wasn't sure what it was but was referred (privately) to a gynae specialist, who immediately suggested endometriosis. I had a laparoscopy, which confirmed and temporarily treated my endo.

I had a diagnosis, but by this point my symptoms were starting to become debilitating. I was always in pain, always had an 'endo belly', as particularly cruel symptom, as it makes you looks six months pregnant, which is tough if you are trying to conceive (and failing).

I was now in my mid-thirties and I tried various treatments, including medication to induce a pseudo menopause, which made me feel awful. I had a second laparoscopy, which gave me some relief for about six months, but then the pain started up again, just like before. That's the problem with endo, it's an insidious disease and has a habit of creeping back.

Accepting infertility

I was also having various tests to see if I could conceive and if I was suitable for IVF treatment. As it turned out I wasn't, because endo had caused such severe scarring and inflammation on my ovaries they didn't work properly. I had no follicles and no eggs.

If I am honest, I was sad for a little while when I discovered I would not be able to have children, but I eventually accepted that having children was just not the path I was supposed to take. However, I was sad for my husband, who I think would have been a great dad.

Final surgery

Eventually, because of the relentless pain and fatigue I decided to have a hysterectomy. The doctors were not keen on this at first, but after a lot of discussion I went ahead and had the surgery. This was the best thing I ever did as it truly changed my life. Luckily, most (but not all) of my pain was from adeno, which was cured when I was 'spayed'. I do still get pain and fatigue, but it is nowhere near as severe as before. I honestly feel like a different person now, I feel free!

Advice for other endo warriors

My advice for another veterinary nurse with endo would be to surround yourself with people who listen, understand, and support you. Do not be fobbed off by people who think you are making your symptoms up – you are not. Do not be made to feel guilty if you cannot attend social events or need time off work – it's not your fault. Most of all, I would say look after yourself, take the medication you need to function, rest when your body demands it and do not make yourself feel bad about having endo, it does not define you as a person. As the famous Stephanie Bennet-Henry quote says, 'life is tough my darling, but so are you'.

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