

ASK ESIG – September 2016

The [ASK ESIG](#) question for September came to ENZ from a concerned Mother for her teenage daughter. Thank you to Dr Susan Evans (Adelaide), Dr Simon Edmonds (Auckland), and the ENZ Facebook members for your responses. You can read all about ESIG members by [clicking here](#).

Question:

I'm the mother of 16 year old Abby and I am desperate to know what to do about Abby's bad periods. Abby has at least 2 days off school every month and is now having pains at other times. Her periods started at 12 and they have always been bad. I have a diagnosis of endometriosis which was a real battle to have treated and I still suffer. But to see my daughter now heading down the same path, is so upsetting. We have been to two GP's and the story seems to be the same – take the pill and it will settle. Well, we've tried that for several years and her periods are regular but the pain and other symptoms are still bad. She tried taking the pill continuously and even when she's not getting a period, she still has awful pain. She's frightened about going to the toilet now because it hurts so badly. The doctor has said we probably won't get into the health system and even if we do, nothing can be done and surgery never works. I'm sure Abby has endometriosis but I don't know what to do. We don't have health insurance and I can't afford to see someone privately. I'd love you to help us by offering advice.

PS. Abby hasn't had a boyfriend yet and spends most of her time at home where she used to be a really outgoing and sporty girl. The doctor has put her on anti-depressants.

Dr Susan Evans response:

Regarding Abby: for a start, this is what I would suggest:

- Norethisterone instead of the pill, 5mg one daily continuously starting in day 3 of her period to minimise periods more effectively than the pill and keep any endo quiet. If it doesn't suit, then Visanne 2 mg instead. This may not be available in NZ yet.

For the muscle pain she will also have at this time:

- Keep moving and do the stretches on the website <http://www.pelvicpain.org.au/information/women/yoga-poses-relax-pelvis/>
- A diazepam suppository 5mg made up in a fatty base inserted in the vagina or rectum for severe pain. Only for occasional use and must not drive using these.
- A walk every day
- Download the audio file from Patricia Neumann website <http://www.patricianeumann.com.au/buy>
- Change her anti-depressant to duloxetine if you have it available in NZ now

For her parents:

- Read the ten tips for parents of teens with pain in PPFA website <http://www.pelvicpain.org.au/information/teens/tips-parents-teens-pain/>

The book available here will be very helpful. <http://www.nzendo.org.nz/how-we-help/resources>

Dr Simon Edmonds response:

It can often be very distressing for women who have been given a diagnosis of endometriosis, to then see their daughters go through some of the same problems with their periods and pelvic pain.

There is certainly a familial/genetic linkage with endometriosis, but this is not always the case. If Abby has tried the pill and also taken it continuously, without improvement in her pain, then referral to a gynaecologist would certainly be appropriate. There may be other causes for the continuous pain throughout the month and the gynaecologist will take a careful history and exclude these.

There is no 'correct' time to perform the 1st laparoscopy to try and diagnose or exclude endometriosis, but we try to explore more conservative options in younger girls as this often works.

If not, then laparoscopy at least gives an answer as to the way forward, but it would be unusual to see severe disease in this age group. Insertion of a mirena coil at the same time, is also another option as this can give better control of the periods. Improving diet and exercise regimes can also help in this age group.

If you do not have private cover, all public hospitals should offer this service and a least a consultation to discuss the way forward.

ENZ response:

There's a lot we don't know about endometriosis but one thing we all agree on is - endometriosis starts early! Ignore it at our peril.

Abby's pain is beginning to be experienced on other days of the month rather than only with her period which means that her pain is showing signs of becoming persistent with other challenging symptoms. Developing a persistent pelvic pain condition at the tender age of 16, must be taken seriously and managed effectively. Abby's symptoms are now affecting her mentally and socially as well as physically and emotionally.

We urge you to contact ENZ and ask for one of our teenage menstrual diaries so that Abby can 'keep a track' of her symptoms. This is useful information to show your GP. You may be able to change your GP to someone who understands women's health and pelvic pain, however we realise this is not always possible if lists are full and doctors are not taking new patients. If this is the case, return to your GP and ask for a referral to a gynaecologist who specialises in endometriosis. Take ENZ resources and her pain diary with you. The letter from the GP to the hospital must be quite specific and stress how Abby's life, well-being and schooling are compromised because of her symptoms. If a generic letter is sent, the team who are responsible for triaging patients at the DHB, may not consider her symptoms to be bad enough for gynae review on a public waiting list. You can request to see a particular gynaecologist but it's not always possible to have your choice granted. If its possible, you can see a gynaecologist with expertise in treating endometriosis privately (as a paying patient) and go on their public list which they can arrange for you. However, you need to make sure that the gynaecologist you see privately also works in the DHB as most are in private practice only.

Abby's pain needs to be managed better, together with re-assessment of OCPs. With exercise, It's always hard to 'get off the couch' when you're feeling miserable and in pain, but we recommend a daily walking routine. Kirstie James (ENZ athlete) has some tips for exercise when you're feeling totally unmotivated. Have Abby read Kirstie's story [here](#). See if the school can guide and help. There may be a social sports team Abby can join – through the school or a club. Abby is only 16 but she can take some responsibility for doing the things she can to feel better. There may be

some help you can access for her around this and once again, the school will hopefully be able to advise. It would be a good idea to have an appointment with Abby's school and in particular the Dean of her year group. Falling behind in her studies or assignments can put further pressure on her and the more behind she gets, the worse things can become generally.

Next step is to have a think about health insurance. There will be a stand down time for Abby as, even without a diagnosis, her symptoms would be considered a pre-existing condition. Adelphi Insurance (<http://www.adelphiinsurance.co.nz/>) will be able to advise you about this at no charge and with no pressure to 'sign up'. If you do proceed to get health insurance for her, even with a stand down time of 3 years, Abby will still be under 20 and can access the specialists with expertise to treat and manage with gold standard best practice. It may not be as expensive as you think and it's only a phone call to find out.

The '[me' program](#) in schools addresses these problems and we are advocates for early intervention so that girls and women's lives are not compromised. We're working with government and the clinical directors to develop clinical pathways to ensure symptoms are recognised early and timely intervention is sought. Is 'me' in Abby's school? There will be others like her suffering similarly and the school can contact us to make arrangements.

Reponses from ENZ Facebook members (names omitted):

- We had to save for it but my mum sent to a private person for the initial first appointment and when he suggested surgery for endo diagnosis, my mum requested to have me put on the public system. It took a little longer but it worked.

- Go and see another GP. My doctor spent years telling me I was fine. I knew for a long time something was wrong, and thought it was endo. He finally sent me to a specialist when it got so bad he was prescribing me tramadol. You could also try family planning. Keep trying, eventually somebody will send you to a specialist. I have been, and am going through the public system and they made sure I saw a psychologist, pain specialist, physio and gyno.

- I would recommend getting health insurance for her in case she has problems later in life. She is at this stage only having painful periods. I luckily had health insurance before developing Endo. I am stage 3 and take a supplement which is the only thing that has helped (apart from surgery which has helped a lot but it is a battle keeping on top of the growth with multiple surgeries) for pain & balancing my hormones, Oestrogen feeds Endo so you need to get her hormones levelled out so she doesn't develop it & also to stop the pain.

- So sorry to hear about Abby's pain and your own battles.
The continuous pain is concerning. I would recommend medical insurance and a specialist gynae who is experienced treating Endo, understands pain management and treating young adults.
Not all GPs have a good understanding of Endo - my previous GP thought I had appendicitis and after treatment failures took the initiative to get training for the medical team.
It is natural that a young person would feel depressed when their body is out of control. Find out as much quality info as you can (not crap off Google) and talk closely with Abby about options to manage her feelings, particularly anxiety and self-esteem. If Abby is still at school her School Guidance Counsellor or Nurse may be able to help with strategies to keep up with

her school work and stay connected with friends.

There could be many reasons for pain going to the toilet. My own experience was scarring that 'glued' my bowel to my pelvic floor and distorted my anatomy causing other related problems and bleeding.

Not getting on to adequate pain management and treatment can lead to vestibulitis and psychological trauma, all totally treatable but unnecessary.

The FODMAP diet can also help with pain relief, as well as regular gentle exercise and activities with a 'flow' element where you focus on something else instead of pain.

Get on to a good specialist recommended by NZ Endo as soon as you can.

- Dear Abby's Mum, I have seen my Mum in the same position that you are, as she has had Endo for a long time and was struggling trying to get anyone to listen to get me diagnosed between the ages of 14 and 20 (I'm 23 now). I'm not sure whereabouts in NZ you live, but my best suggestion is to do some research on the internet, read up about different Gynaes and try to find one that has an interest in Endo. If you can find someone who works in both the private and public systems, you could see someone privately for the first appointment (if you can afford to), and then ask them to refer you to their public list for surgery and ongoing care. I've been in the public health system for almost 3 years, and it can be a battle, so try to get continuity of care if you can and request to see the same Gynae every time you go so that you don't get shunted around seeing different doctors all the time. Also, try and find her a new GP that is supportive of her and will be more proactive about helping her get to the next stage in diagnosing and treating her Endo. It's a hard lesson to learn, but you have to 'shop around' and find the Doctor that you feel comfortable with and know is going to be of help to you and your daughter. Perhaps look at websites of GP Practices in your local area and look for someone with an interest in Women's Health? Other natural things that help me are using heat packs (heat sometimes helps my pain more than pain meds) and trying to keep active throughout the month with gentle exercise such as walking, yoga and swimming. Maybe work with your daughter to try and find a more gentle form of exercise that she can gradually build up to doing on a regular basis. Having Endo can be so hard, as you can feel like you lose a part of yourself as you struggle to do the things that you used to, but you will figure out what works for her with medical help. Most importantly, support her to try and show her body love and care, even on the days when it is causing her pain. I remind myself that it's not my body causing the pain, but the Endometriosis, and that helps me to support my body both physically and mentally. Sending you both big hugs.
- My biggest mistake was not getting a second opinion. Once we changed Dr, who was pro endo we had much better results. When the Drs at the hospital gave up our Dr would fight for her to be seen again. So my advice would be second opinion. Also since being diagnosed with gluten and dairy allergy on top of it, which apparently is common with endo patients. She has had much less hospital time. She is also in the depo injection to stop her periods all together which she gets 8 weekly. Getting on top of it quickly is the answer for a better outcome for sure.