



Endometriosis

Genea eBook

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It can take as long as a decade for a woman with pelvic pain to be diagnosed with endometriosis. Sadly, those 10 years are often likely to be smack bang in the middle of a woman's prime reproductive years and she may not realise that endometriosis could be seriously impacting her chances of conceiving. What is often worse, some women experience only mild symptoms and are not aware that they have endometriosis which is impacting their ability to conceive.

In this ebook we want to share information about the causes, symptoms and treatments for endometriosis. We have also spoken with two women who have had first hand experience of the condition. They are passionate about increasing awareness of endometriosis and what can be done to treat it. We, as they do, believe the number one most important thing for women and girls to know and remember is that it is not okay to have severe period pain. If the pain you experience during your period, or in fact pain in the pelvic region at any time, is so severe that you need to miss work, school or other activities - you should ask for help.

Explaining endometriosis

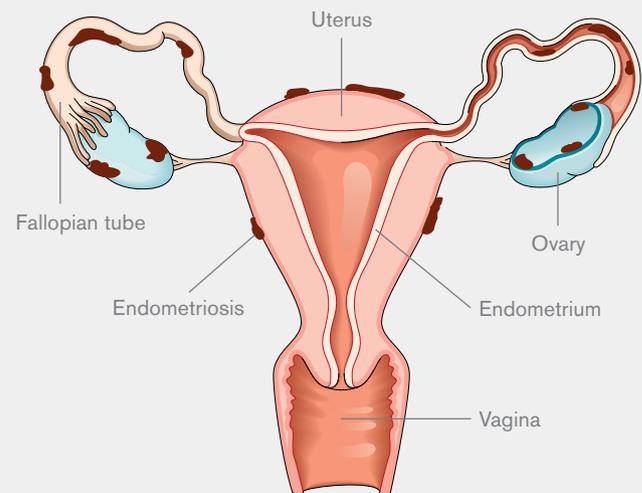
Around the world it's estimated that endometriosis affects 176 million women and girls. It is a chronic condition that can involve the entire pelvic region and can impact a woman anytime from when her periods first start through to menopause.

The issue arises when tissue that normally line the uterus (the endometrium) move beyond the uterus and begin to grow in abnormal places around a woman's pelvis and, more rarely, other parts of the body. In fact, endometriosis has been found in all parts of the body - including the liver and lungs and even scars.

Most often, these endometrial tissue cells stick to organs in the pelvis and then start to grow and multiply. The pain can arise when they begin to undergo the same cyclic changes as they would in the uterus; bleeding at the same time you have your normal period.

What causes endometriosis?

Endometriosis isn't contagious but that's about the only thing we're absolutely sure of when it comes to the cause of the condition. It is most commonly thought to be caused by what's called retrograde menstruation. Plainly speaking, that means that the fluid and tissue that is shed from the uterus during a period flows back along the fallopian tubes and into the pelvis where it attaches and grows.



It is also thought that a family history could be key with numerous studies showing an increased risk of endometriosis for women with mothers or sisters with the condition. While the exact level of increased risk is difficult to determine, one study cited a three to nine times increased risk of developing the disease.

What are the symptoms of endometriosis?

Endometriosis can be a contradictory condition with some women suffering severe pain and others experiencing no symptoms at all, often unaware of the condition until they have difficulty conceiving.

Symptoms

Pain - the pain may be linked to the menstrual cycle or there may be no association whatsoever. Pain can be felt in the pelvis, stomach or back and endometriosis can also cause pain during bowel movements, sex and urination.

Heavy bleeding - endometriosis can cause clots as well as irregular bleeding, spotting before a period or long periods.

Bowel and bladder problems - the condition can cause constipation or diarrhoea, the need to urinate more frequently and bloating.

Reduced quality of life - excessive tiredness and generally feeling unwell and unable to get on with day-to-day life may be a symptom of endometriosis.

Doctors generally use a system developed in the United States to grade or assess the severity of the condition as either minimal, mild, moderate or severe. They consider the extent and depth of the endometrial tissue throughout the pelvis, the extent of adhesions and the presence of ovarian disease.

How does endometriosis cause infertility?

Between one third to a half of women with endometriosis will struggle to conceive or be diagnosed with infertility.

All stages of endometriosis can cause infertility.

While there are no obvious reasons why infertility occurs in someone with minimal or mild endometriosis, it is believed that there may be some body chemicals released from the endometrial cells that interfere with the ability to conceive or affect normal early development of the embryo.

In moderate to severe forms of endometriosis, scarring may cause interference with ovulation and the passage of the egg along the tube because of damage or blockage. It can also prevent the sperm from reaching the egg.

Regardless of the level of the condition, the message to all women experiencing endometriosis or even simply suspecting that's what is happening to them. Seek help - you're not alone.

Taking control when it feels like you have none

Sylvia Freedman, co-founder of EndoActive recently “came out” as someone who has endometriosis and since then has had a very public experience with the condition. Read what she has to say about taking back control where you can.

It's funny how much we take fertility for granted until we're threatened with losing it. In primary school my girlfriends and I would make long lists of all the names we'd give to our children. The question was never if we'd have children but rather how many. I spent my senior high school years and late teenage years desperately trying NOT to get pregnant. I was hyper-vigilant, pretty much believing that unprotected sex = baby. I had never even considered the possibility that I wouldn't be able to conceive.

I'd never pictured a life without kids. I just assumed that whenever I was ready, out they'd pop. All of a sudden everything changed.

At 21 I was diagnosed with endometriosis and was warned that I may never get the opportunity to fall pregnant or carry a baby to full term. I learned that it's not so easy to get pregnant and that creating a new life is such a complicated process it's a miracle that there are so many of us.

“I'd never pictured a life without kids. I just assumed that whenever I was ready, out they'd pop. All of a sudden everything changed.”

At first, I felt robbed of my dream to have children. Thinking about it completely broke me. I cried every time I saw a woman with a big, beautiful pregnant belly. I cried every time I saw a baby. Any baby! I lay in my bed and wept for the little ones I ached for. I began plotting unconventional ways I could create a family and how soon I could get going in case I was infertile by my next birthday. I had several plans in the pipeline without even considering that I was young, single, jobless and so not ready to have kids. I still needed to backpack through South America! In hindsight, I was driving myself insane trying to plan a future I wasn't prepared for.

But the more I learned about Endo, the more hope I had restored. I stopped worrying. It's true that girls with Endo may have their fertility compromised but so many women have written to me telling me their stories, full of optimism and babies. I adjusted my frame of mind from passively allowing my imagined fears to torment me to actively taking control.

That's when I thought about freezing my eggs. Refusing to torture myself with what ifs anymore, I listed the facts and considered my options.

Facts:

- I have Stage 4 Endo that may compromise my fertility in the future
- I'm 23, single and not ready to have kids yet

Options:

- Wait and see what happens in the future and possibly regret not preserving my precious 23 year old eggs
- Freeze my eggs now and create a back-up plan for future Syl. Just in case.

Egg freezing really began as a wild idea but quickly seemed like the obvious thing to do. Just by having the initial consultation with my Fertility Specialist made me feel like I was reclaiming control over my life. Once I had made the decision to freeze my eggs, I felt strong and empowered.

Egg freezing was such a positive, interesting experience. The sadness of losing control of my life was swallowing me whole but making this decision was the first step to putting my sassy pants back on and reviving my spirit. The best thing was learning that I have a secret stash of inner strength.

More about Sylvia

In late 2014, Sylvia and her Mum Lesley mounted a massive public campaign to get a dedicated endometriosis treatment introduced to Australia.

After just a month they had collected 74,500 signatures on their petition and convinced a multi-national pharmaceutical company to bring the medication to Australia.

In the process they launched EndoActive and now continue to campaign for community support, communication and information on endometriosis.

One of their aims is to raise the profile of this disease and they want to change the way it's referred to to help that cause.

In Sylvia's words: We realised that if we are to raise the profile of Endo in the community then we have to use a word people can easily pronounce – so we use the term Endo instead of endometriosis wherever possible. For example – Multiple Sclerosis is now generally referred to as MS. A small change but it makes a difference when communicating with the public and not sound like we have something infectious.

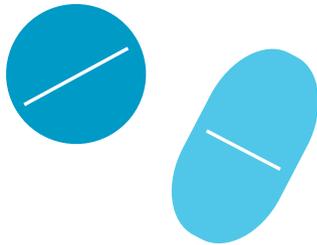
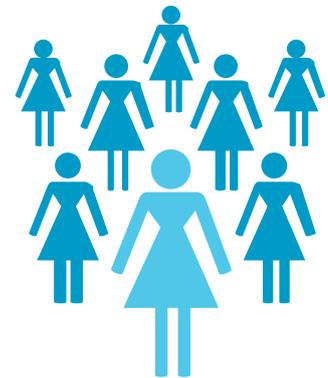
Myths about endometriosis

When it comes to fertility, there are a multitude of myths you've undoubtedly heard. A large number of myths exist about endometriosis as well. To help debunk some of these myths, we've spelt out the truth about various aspects of endometriosis.

Special diets, herbal remedies or exercise WILL NOT cure endometriosis



Endometriosis is quite common, NOT rare



Endometriosis CAN'T BE prevented



Endometriosis is NOT caused by an STI



Endometriosis CAN cause pain at any time in your cycle



Endometriosis does NOT always lead to infertility

Turning silent suffering into meaningful action

Early diagnosis can be key in good management of symptoms and pain. Genea team member Debbie explains her journey after the contraceptive pill masked her symptoms for many years and she ignored some other tell-tale signs.

After suffering with painful and heavy periods from day one, I was prescribed the contraceptive pill in my teens to try to ease some of the symptoms. It brought me some relief - I still had pain and heavy bleeding for the first few days of each period but I figured that was a normal part of being a woman. After all, women complain of period pain all the time, how was I to know mine was not quite the same?

After years of being on and off various pills, I felt at age 33 it was time to have a break. That was when I had the first real inkling that something wasn't quite right.

Almost as soon as I stopped taking the pill and got my first period I experienced many of the textbook symptoms of endometriosis - I just

“Each day was a struggle to do anything, I couldn’t function normally and grew to dread the time my periods came around.”

didn't know that's what it was. I was constantly constipated, had sharp pains around my stomach and I felt very sluggish and drained all the time. I ate lots of fibre rich foods but nothing would relieve the agonizing pain of trying to go to the toilet and on top of that I also had pain when urinating; the pain was so unbearable I dreaded every time I needed to go to the toilet. I would be crouched over every time I needed to go, clenching my fists, and no pain relief tablets would help either.

Each day was a struggle to do anything, I couldn't function normally and grew to dread the time my periods came around.

“The pill had helped relieve some of the pain but also masked these symptoms.”

I made an appointment to see my GP who sent me for various ultrasounds but nothing was detected. I asked my GP to send me to have a colonoscopy but constantly got the reply that I was “too young to have a colonoscopy”. I went to see my gynaecologist who couldn’t come up with an answer to my symptoms and referred me on to a urologist.

This is the point where the picture finally began to form clearly. The urologist performed a flexible cystoscopy in his rooms and saw a very large nodule - endometriosis the full thickness of my bladder wall. He said he could see by the size of the nodule that I must have been in enormous pain and told me that surgery was the only option to remove this nodule and relieve the pain. As he explained the surgery I began to freak out. Essentially he would be removing part of my bladder and after the surgery I would need to urinate more frequently as my bladder would be a lot smaller than normal. Thankfully he explained it would go back to normal size with time.

A million questions and worries ran through my mind - Will this prevent me from having kids? What are the implications on my future fertility? Why didn’t I know about this earlier?

Because I work at Genea I decided to get a second opinion from Dr Geoff Reid. I told him my symptoms and he sent me straight away to have a colonoscopy. He also took into consideration my concerns about my future fertility.

The colonoscopy results came back and Dr Reid informed me that I had endometriosis in my bowel (large intestine) and would need to have 20cms of my large intestine removed to get rid of the disease – again I freaked out! And the questions came back again. After all these years having painful periods and my constipation issues and this was the cause!

The pill had helped relieve some of the pain but also masked these symptoms.

I was in total shock but reassured by my doctors that they would remove the endometriosis and they were confident that the disease wouldn’t reappear.

Surgery was arranged ASAP – I had a combined case with Dr Geoff Reid and my Colorectal surgeon. Together they performed a laparoscopy and bowel resection to have the 20cms of my large intestine removed. It was decided that the bladder surgery would be a separate procedure.

I went into the procedure knowing I was in good hands, with two fabulous doctors who really cared about my wellbeing and future fertility.

Surgery went very well. I was in hospital for five days, recovery was slow, but each day I could see an improvement so that was reassuring. It took a good four weeks at home recovering before I felt I was back to my normal self. My work was very supportive, it was great to know I had their support in this treatment and my recovery.

I had three months break and then it was time to deal with the next stage of my endometriosis, the bladder. I had mixed emotions about this surgery even right up to the last minute when they were wheeling me into the operating theatre as it wasn't that common but my urologist was very confident so I trusted his judgment.

My surgery was performed all laparoscopically with a partial cystectomy (removal of the nodule in my bladder), again Dr Geoff Reid was present at my surgery with my urologist.

And again I am lucky to say, it was another successful surgery thank goodness.

My original gynaecologist called me weeks after my bowel surgery after he received the doctors' reports of my diagnosis and the procedures they performed. He wanted to apologise for not picking up my symptoms.

I feel there needs to be more awareness about endometriosis and young women need to take action about any changes they notice with their body.

The human body is an amazing thing, when you notice a change or are unsure of what is going on it is good to get it checked out - trust your instincts. I have been through a lot in one year but am thankful for the wonderful support from my doctors, family and friends around me, I couldn't have done it without them.

Dr Natasha Andreadis,

a **Fertility Specialist with Genea** is in complete agreement as to the important role that support and holistic care play when dealing with fertility issues such as endometriosis. Here she explains her thoughts on the condition.

Put simply: endometriosis is a chronic condition and as a result, you should have a team of people looking after you. This team may include a GP, Gynaecologist, Fertility Specialist, Massage therapist, Nutritionist, Physiotherapist, Psychologist, Naturopath or even a Chinese Medicine Practitioner. If I've left anyone out, please let me know.

What is so good about a team?

A team means there are people seeing you from a different perspective; they can come together to ensure you are getting the best, holistic care.

But, as with any team, they are only as good as the understanding they give each other. It is important to ensure that you encourage them to **communicate** with each other – as this is vital to your care. Ask them to write letters to each other, perhaps even phone each other. This way you know they are all on the same page; and no treatments clash. Everything is in check, it should not be up to you to remember the technical treatment details advised by every person you see, they can do this for you.

Yet, always remember, the best person to tell you how it's all going – is of course you.

So you have endometriosis. What more can you do for you ?

- I encourage you to read. Read lots.
- Be proactive.
- Educate yourself. You may end up knowing more about your condition than your team put together!
- Share this information with others.
- Ask questions; never apologise for this. No question is too silly.
- Remember that you are a whole person - everything within us is linked, not separate.
- Hormones, nerves and the immune systems are the three major conductors – they are constantly interacting with each other. In endometriosis, hormones are often out of balance, nerves are extra sensitive, immunity impaired.
- Your doctor may prescribe you medication - as long as you agree with the treatment, it is your responsibility to take it.
- Your doctor may operate on you - it is your role to understand the procedure and give informed consent.

On a day to day basis though, there is so much you can do for you, to help you. I recommend you take control of four things:

1. Eat right – some general and sensible principles. Eat organic, wholefoods that are seasonal and fresh wherever possible. Avoid anything processed, in a can or pack.

Avoid sugars. There are no benefits to heaping sugar into your coffee or having cans of coke. Sugar is inflammatory and this will feed the inflammation that is your endometriosis.

Some patients also benefit from going dairy, and gluten free (these are also pro-inflammatory). Why not give it a try? We are all BIO-INDIVIDUALS. No one size fits all.

2. Have an exercise plan. Exercise has numerous benefits and the feel good hormones it produces will serve you in a positive way, every day. Whether it be yoga, running, pilates or pole dancing – please remember to move it.

3. Reduce your toxin load. Every day we ingest and expose ourselves to chemicals. Whether it's through pesticides in food (hence best to eat organic) or through the moisturisers and lipsticks we use. These chemicals interfere with hormone function and have been linked to endometriosis. One group is called Dioxins – a group environmental pollutants. A study on a colony of monkeys found that animals spontaneously developed endometriosis a decade after their first exposure to the pollutant dioxin. The greater the female monkey's exposure to dioxin, the greater the severity of disease.

4. Take time out to slow down, relax. Meditation is scientifically proven to be of huge benefit in the treatment of pain.

There are so many things you can do, to help you. Your team will love you for it.

Next steps

Endometriosis is a medical condition, and like other conditions, no two people are likely to experience the same symptoms, or require the same treatment. Some people will want to treat the condition to alleviate the pain, and others, will want to know that they are taking steps to protect their future dreams of having children.

If you know or suspect you have endometriosis, and would like to learn more about your options for treatment, we would encourage you to get in touch. By filling in a [quick form](#), you can take the first step on a path to taking control of your health. Alternatively, reach out and call us on 1300 361 795.