

an e-booklet for women girls and families

PELVIC PAIN 2014



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Introduction

How to use this book

Thanks for reading our e-booklet!

We know it's hard to get the information you need when you have pelvic pain. A bit awkward at times, and really annoying if no one seems to know what's wrong with you.

Don't worry. We see women just like you every day and want you to be well. You are certainly not alone.

The first step is to learn more about pelvic pain and we hope this ebook will help.

Where do I start?

To work out what you need, we suggest that you first think about how many days a month you have pain:

- Some women have pain with periods but are otherwise completely well. They have what doctors call '*dysmenorrhoea*' and often have a medical condition called Endometriosis. The section in this ebook on '*period pain*' may be all you need.
- Other women have a mix of different pains with pain of some kind almost every day. They may also be tired, anxious or worn down by pain. They have what doctors call '*chronic pelvic pain*'. There is a section in this ebook on all the different pains you may have.

At the beginning, it's a good idea to make a list of your problems. By keeping a list, you can look back later and work out which treatments helped you most. You can also see how you have improved and feel good about yourself.

If you have lots of problems, you might like to think about which problem bothers you most right now and work on that.

The mix of pains we have included is the 'bigger picture' of pelvic pain. It can include an irritable bowel, a painful bladder, painful sex, pelvic muscle pain, anxiety, low mood, fatigue, pelvic nerve pain, headaches, general ache, or stabbing pains on one side.

But isn't there one thing that will help everything?

Unfortunately, not yet.

It is true that for many women, surgery through a telescope (called a **laparoscope**) can make a big difference to their pain. It is an important part of pelvic pain management, especially if your major problem is period pain.

However, there are some types of pain you can't see at a laparoscopy and can't fix with surgery. These pains are just as real as pains you can see, but are treated in different ways.

You may have been told that 'everything looks normal', but your pain remains. You may have worried that you are weak in some way.

If you find this ebook useful, you are welcome to send it to friends, boyfriends and family. There are millions of women in the world with pelvic pain.

The Pelvic Pain Foundation of Australia at www.pelvicpain.org.au has information and events you can attend

If you like the e-booklet, there is much more in our full size book!

The e-booklet is a great start, but you may still have questions and want to know more. Our full size book, '*Endometriosis and Pelvic Pain*' has much more information on all the different pains and it's really easy-to-read. There are stories of real women just like you, information on fertility, and everything you need to know before deciding whether or not to have an operation. The book is available for \$25 Australian dollars at these websites:

www.pelvicpainsa.com.au

www.drsusanevans.com.au

www.nzendo.co.nz

With our best wishes

Susan Evans and Deborah Bush

Period Pain

Dysmenorrhoea

Period pain is the commonest type of pelvic pain, but what's normal?

None of us know what another woman's pain is like, and you may have wondered if your bad period pain is really normal and you are weak in some way.

What is normal period pain?

Well, period pain should only be considered 'normal' if:

- The pain is only there on the first 1 or 2 days of your period, *and,*
- It goes away if you use the Pill or take period pain medications

If not, it is *not* normal.

Severe period pain in young women is a bigger problem now than it was in the past. Our grandmothers often had their first baby before they were 20 years old. After that came years spent pregnant or breast-feeding until menopause arrived. Even if their periods were painful, at least they didn't have many of them.

Girls start their periods earlier now and become pregnant later. They may have 300 to 400 periods ahead of them before menopause.

I don't think my pain is normal. What could it be?

Painful periods can be due to:

- Pain in the uterus (womb), especially if pain is on the first 1-2 days of a period, or,
- Pain from endometriosis, especially if pain is there for more than 1-2 days or doesn't get better with the pill

Many women with bad period pain have both these problems, and we know that women with endometriosis have a more painful uterus than other women, even if it looks normal.

Am I too young to have endometriosis?

Endometriosis used to be thought of as an uncommon problem of women in their 30s and 40s. We now know that it is a common problem that usually starts in the teens.

Endometriosis in teens often looks different at a laparoscopy and can easily be missed. In older women it is often a dark brown colour. In young women it may look like tiny clear bubbles that can be hard to see.

Teens often worry about being different from other girls. In fact, a study of 1000 girls aged 16-18 years in Canberra, Australia (MDOT study) found that 21% of the girls had severe pain with periods and 26% had missed school because of period symptoms.

It's really important that teenage girls get good care so they can live normally.

Period pain doesn't have to be 'just part of being a woman'.

You may have been told that your period pain is normal, just part of being a woman, or that you should have a baby.

There is much more that can be done now

If simple treatments don't help, you may have endometriosis

What can I do about period pain?

Could I have endometriosis?

Simple things first

Period pain medications work best when they are taken before the pain gets bad, so keep some with you all the time and take them regularly during periods. The commonly used medications include ibuprofen 200mg, naproxen 275mg, or diclofenac 25mg. Take two straight away then one, three times a day with food. All these medications can cause stomach irritation, so are best taken with food.

The Contraceptive Pill is often helpful. Ask your doctor for a pill with more progestogen than estrogen for the best effect. Many women skip periods on the pill because fewer periods means less pain. To do this, you need to be on a pill where all the hormone tablets are the same colour. Plan a period only every 2-3 months or preferably not at all. Ask your doctor or pharmacist how to do this. If pills don't suit your mood, try one called Qlaira.

A Mirena® intrauterine device (IUCD) is currently the most effective treatment for pain from the uterus and lasts up to 5 years. It slowly releases a progestogen medication to the uterus that makes periods lighter, less painful and it is also a contraceptive. Remember that it is common to have irregular bleeding and crampy pains for the first few months, but these problems usually settle.

If you have not had children, or have a tender pelvis you can ask to have it inserted under an anaesthetic if you wish. The best time is just after a period, sometimes at the same time as a laparoscopy.

Complementary therapies that can help include acupuncture, Vitex Agnus Castus (1000mg daily) and magnesium (100-200mg every 2 hours at period time for 2 days only).

If simple treatments for period pain don't help, you may have endometriosis. This is where tissue like the lining of the uterus grows in places outside the uterus around the pelvis. Most endometriosis can't be seen on an ultrasound.

When simple things don't help

Laparoscopy. A laparoscopy is an operation where a doctor puts a telescope through a small cut in your umbilicus (belly button) to look inside your pelvis. He or she can then:

- Diagnose if endometriosis is present
- Remove the endometriosis if possible

There are different types of surgery available to treat endometriosis. Sometimes the endometriosis is *excised* which means cut out and sometimes it is *cauterised* (diathermied) which means burnt.

Some laparoscopies for endometriosis are fairly short and straight forward, while others take much longer and are more difficult. It depends on where the endometriosis is and how severe it is.

We know that the amount of endometriosis found at a laparoscopy doesn't fit with the amount of pain. So, you may have a little bit of endometriosis and a lot of pain, or a lot of endometriosis and very little pain. Remember that even if you have endometriosis, that a lot of your period pain may also be from the uterus, even if the uterus looks normal.

This is why a good combination of treatments to consider is a laparoscopy to remove any endometriosis and a Mirena IUCD inserted at the same time. The Mirena can easily be removed later by your doctor without an anaesthetic if it doesn't suit you. After a laparoscopy aim for as few and as light periods as possible to reduce the chance of new endometriosis lesions developing.

Remember that even if you do have endometriosis, a lot of your pain may be due to other things such as a painful bladder, painful nerves or painful pelvic muscles.

Progestogen medications such as norethisterone or dienogest taken continuously are a good way to avoid periods and keep endometriosis quiet.

An irritated bowel or bloating

An Irritable or Sensitive Bowel

An irritable or sensitive bowel is a good example of a pain you can't see. It looks normal at a laparoscopy or ultrasound but certainly doesn't feel normal.

Women feel bowel pain low in their abdomen, in the same place that they feel period pain, pelvic muscle pain, ovary pain, bladder pain and endometriosis pain, so it's easy for all these pains to get confused.

The most typical feature of bowel pain is that the pain gets better after wind or a bowel action has been passed, and there are usually other bowel symptoms too, such as diarrhoea, constipation or bloating.

Bloating

Doctors often think of bloating as an inconvenience rather than a major problem. This is because bloating rarely means a serious illness. The trouble is that bloating makes women feel unattractive and uncomfortable. It also makes any other pelvic pain worse. Luckily, there is lots you can do to feel better.

Before you do anything about bloating, you should see your doctor. Sometimes women feel bloated because they have an ovarian cyst. Your doctor can check this for you.

If this check is normal, then think about what type of bloating you have.

The first type of bloating is where the abdomen swells up and your stomach *looks* big. Women often feel like this near period time, but it is also aggravated by certain foods. These foods are described further below.

Cutting down on these foods often makes a big difference to pain.

The second type of bloating is a *feeling* of being bloated, when you look normal. This is often due to a change in the way nerves work causing abnormal sensations such as bloating, and sensitivity to touch. You may find your clothes uncomfortable or dislike anyone touching your abdomen.

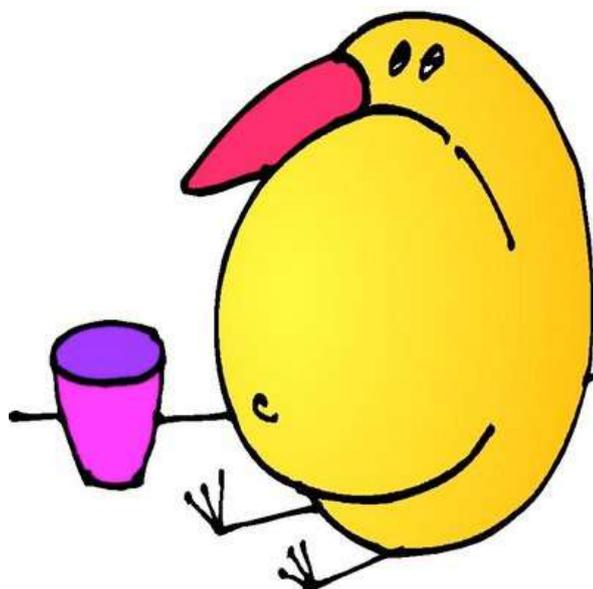
This type of problem is described more on page 17, but other useful treatments include:

- Peppermint oil capsules taken 3-4 times daily or peppermint tea
- Iberogast liquid 20 drops from a chemist, drunk in warm water as tea 2-3 times daily

Many women with pelvic pain have a mix of both types of bloating.

Remember to tell your doctor if you have:

- bleeding from the bowel
- undigested food in your bowel action
- bowel incontinence, or
- unexplained weight loss.



What can I do about bowel pain?

Sometimes it's my worst problem

Which foods might be a problem?

Some of the foods most likely to cause problems are a special group of carbohydrates, sometimes called FODMAP foods. Common FODMAP foods include lactose, wheat products (bread, pasta, pizza etc), onions, corn syrup, apples, and artificial sweeteners, but there are many others.

Most people absorb these foods quite quickly in their 'small bowel' (small intestine). This means that very little of those foods reaches the 'large bowel' further down.

Some people absorb these foods slowly, which means that more of these foods reaches the large bowel undigested. In the large bowel, the food is fermented by bacteria to form gas and other substances that irritate the bowel and cause pain, diarrhoea and bloating. A small amount of these foods may be no problem at all, but a larger amount can cause lots of pain. If they also have a sensitive bowel, which many women with pelvic pain do, then they will really suffer.

This means that while your friends may be able to eat any food and feel fine, your bowel will be painful unless you are careful.

Should I just go 'gluten-free'?

A gluten free diet is a special diet for people with Coeliac Disease. Women with coeliac disease need to be on a strict 'gluten free' diet for the rest of their life.

Women with an irritable bowel often feel much better on a 'gluten free' diet, because by cutting out gluten they are also cutting out wheat, a major FODMAP food. They do not have a problem with gluten and may be able to tolerate small amounts of wheat.

Before you change your diet, ask your doctor for a blood test that checks for coeliac disease. This test isn't reliable if you have already cut out wheat from your diet, so it's much easier to get it done first.

Are there other problem foods?

Yes, definitely, but everyone is different. You might have a problem with rich or fatty foods (cream, takeaway, animal fats), alcohol, coffee, fizzy drinks, and spicy food.

A low fat, low salt, high fibre diet is good for everyone, but even more important if you have bowel problems.

If you find it all too hard to work out, a dietitian may be able to help.

Constipation

We have been brought up to think that it's important to have a bowel action every day. Actually, it's OK to have a bowel action every couple of days or so, as long as it is soft and easy to pass when it happens.

It is easiest to open your bowels when the bowel motion is soft and your bowel is contracting strongly enough to pass it easily.

You can make the bowel action softer by:

- Drinking enough water
- Increasing the fibre in your diet
- Taking a fibre supplement such as Sterculia (normafibe®). This supplement is useful as it causes less wind than most other supplements

You can increase bowel contractions by:

- Regular exercise, brisk walk every day
- Allowing *unhurried* time to go to the toilet after breakfast in the morning
- Avoiding medications such as codeine
- A herbal treatment such as slippery elm

But my constipation is really bad. Nothing works for me.

Some women have severe constipation, even when they do everything right. It is very unfair. They feel bloated and uncomfortable most of the time. If so, it is time to talk to your doctor, or maybe a gastroenterologist (bowel physician).

Painful Sex

Dyspareunia

Painful sex is distressing. As well as the physical pain, there is the emotional pain women feel when they are unable to enjoy sex with their partner. No one feels like sex if it hurts, but it is easy for him to feel you don't care.

What causes painful sex?

There are lots of possible causes but with some help, you and your doctor can usually work out what the problem is.

To make it easier, it's a good idea to think about where your pains are before you go, and see if you can help your doctor find the problem.

If you find a sore area, think about whether this feels like the pain you have with sex, or whether it is a different pain. A common cause of painful sex is painful pelvic muscles.

Painful pelvic muscles

The pelvic floor muscles are the ones you tighten when you want to stop passing urine quickly. They can become tight, strong and painful.

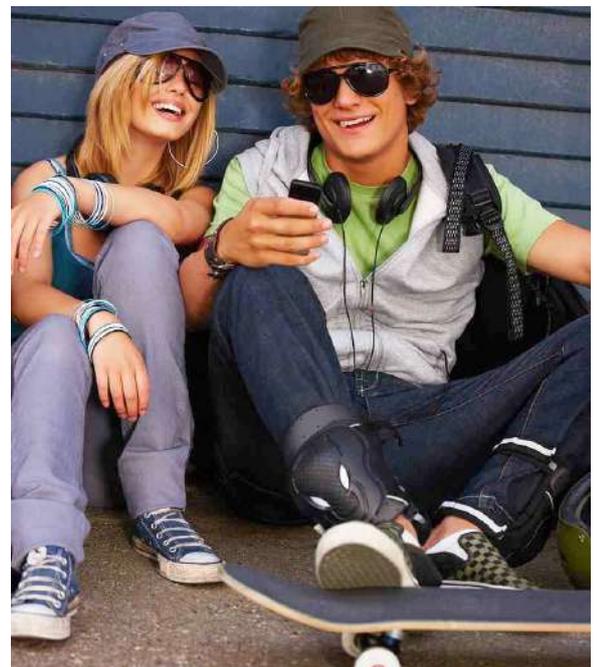
Often there is an ache in the pelvis much of the time, sometimes with sudden crampy spasms. Intercourse, examinations, or using tampons are very painful and sometimes the pain lasts for hours or days afterwards. There may be sudden sharp or stabbing pains up the vagina or bowel when the muscles cramp. Pain is often worse with exercise and isn't helped by normal pain medications.

You can check your pelvic muscles yourself by inserting one finger just inside the vagina. Push backwards towards the bowel with your finger, then push sideways towards your hip

on each side. Does pushing these muscles cause the same pain you get with intercourse? Useful treatments:

- Use a heat pack or a hot bath when the pain is severe
- Do the easy stretches for women (twice daily) at www.pelvicpain.org.au
- Download the pelvic muscle relaxation mp3 tape (it comes with instructions) at www.thepelvicfloorclinic.com.au
- See a specialised womens physiotherapist to help the muscles re-learn how to relax and move normally.
- Keep moving, but avoid exercises that hurt you. Core exercises such as pilates may aggravate the pain. Avoid prolonged sitting.
- Explain to your partner that you should avoid vaginal intercourse until the muscles improve. Sexual activity without penetration is fine.

Even if sex is too sore right now, you can still keep closeness and happiness in your relationship



Painful Sex

What can I do about Painful Sex?

- Use a vaginal trainer (dilator) to slowly teach the muscles to relax. This is best taught by a woman's physiotherapist.
- Use a small dose (5-25mg) of amitriptyline early each evening, or duloxetine (30-60mg) in the morning. Your doctor can arrange this, with instructions on how to use these available at www.pelvicpain.org.au
- Continue regular gentle exercise, such as walking
- Treat other causes of pain so there is less need to hold muscles tightly
- Think about how you hold yourself and avoid holding tension in your pelvis

If the muscles are so painful that physio is difficult, then a botox injection to the pelvic floor is often helpful. The botox is injected as day surgery under anaesthetic, lasts 4-6 months and stops the muscles cramping. It also makes physiotherapy easier.

It is best to avoid intercourse until your muscles have recovered.

If you do have intercourse then:

- Use a water based vaginal lubricant such as KY Jelly®, a fruit based lubricant like Sylk®, or olive oil if you find lubricants irritating
- Ask your partner to go slowly and wait until you are ready. Using the relaxation CD each day for a couple of weeks beforehand can teach you how to relax these muscles. Using a slow gentle finger first allows you to get past the initial muscle spasm, before penetration
- Try to avoid the time around periods when you are more sensitive

A painful bladder

If pushing the front wall of the vagina causes pain and you have bladder troubles, then the pain may be due to painful bladder syndrome.

Treating the bladder problems (page 10) often helps.

The pain is deep inside and worse at period time

Endometriosis can cause painful intercourse deep inside, especially if it lies between the uterus and the bowel. However, this is difficult surgery, and you will need a gynaecologist skilled in difficult laparoscopic surgery. A laparoscopy will not fix pain from pelvic muscles

Sore vulval skin

The vulva is the area between your legs and the labia are the folds of skin near the opening of the vagina. If the skin is sore, good ideas include:

- Use sorbolene and glycerine cream instead of soap when you wash.
- Avoid waxing the hair on the labia
- Ask your doctor to check for a vaginal or thrush infection. If you have a lot of trouble with thrush, then a weekly tablet of fluconazole 150mg for 6 weeks or longer if needed often helps
- Try a low dose of amitriptyline
- Use a 2% amitriptyline cream if you are tender just at the opening of the vagina
- See a 'vulval dermatologist' (skin doctor) if you still have problems

I was sexually abused in the past

Sexual abuse was once thought to be a major cause of pelvic pain. We know that most women with pelvic pain have *not* been sexually abused. Even so, sexual or physical abuse is common, is always wrong, is not your fault and is something that can make getting better more difficult.

'Physical or sexual assault is always wrong and never your fault'

Bladder troubles

Why am I always in the bathroom?

You may know all about **cystitis**. If so, you probably mean bacterial cystitis, which is the medical word for a bladder infection (urine infection). The word 'cystitis' really only means an irritated bladder. It does not say what caused the irritation.

Women with pelvic pain often have another type of bladder irritation called either **Interstitial cystitis (IC)** or **Painful Bladder Syndrome (PBS)**. This type of cystitis is different from a urine infection. There is irritation of the bladder wall but no infection. It is another pain you can't see at a laparoscopy.

If you have endometriosis, bladder troubles and pain on most days, then it is quite possible that you have PBS. Sometimes it is the bladder which causes most of the pain.

What problems does painful bladder syndrome cause?

The common symptoms include:

- **Frequency.** (Needing to go to the toilet a lot)
- **Nocturia.** (Needing to get up to the toilet at night)
- **Urgency.** (Needing to rush to the toilet and finding it difficult to 'hold on')
- **Pain.** Which gets worse as the bladder fills, and improves once the bladder empties
- **Pain with intercourse.** Especially in positions that put pressure on the front wall of the vagina (near the bladder)

Many women with a painful bladder describe having 'frequent urine

infections'. Sometimes there *is* a bladder infection, but often it is a flare up of their painful bladder that feels like a urine infection. If urine is sent to a laboratory, it often shows some blood but no infection.

Simple things first

A urine test with your doctor to check for infection or other problems is a good idea. They can also check for a chlamydia infection of the urethra if a sexual infection is possible.

Make sure you are drinking enough (but not too much) fluid each day. For most women, this will be around one and a half, to two litres of mostly water daily. If you drink a lot more than this, that may be part of the problem.

If you still have problems, think about whether any of the foods or drinks on the next page trigger your bladder problems. Use the 'bladder first aid' treatment if your pain flares up, and try a bladder medication such as amitriptyline from your doctor.

The Evil Twins:

Endometriosis and Interstitial Cystitis are so commonly found together, they are sometimes called the 'Evil Twins'

Dr Maurice Chung



What can I do about my bladder troubles?

Sometimes they are my worst pain

Dietary changes. There are many foods that can make bladder pain worse, but most women only have problems with some of these. They include:

- **Foods high in acid** such as citrus fruit, cranberries, vitamin C, some herbal or green teas or tomatoes. A plain mint/ chamomile tea or just water is best
- **Foods that stimulate nerves** such as caffeine, chocolate or cola drinks
- **Foods high in sodium or potassium** such as bananas
- **Artificial Sweeteners** including aspartamine etc
- **Fizzy drinks** (including mineral water)

Diet cola drinks are probably the worst as they contain acid, caffeine and artificial sweeteners. Cigarettes can also affect the bladder.

If you eat these foods, remember how you feel afterwards. If you feel worse, this may be a trigger food for you. You may also find trigger foods of your own.

Medications are really useful but you may need to try a few different ones with your doctor to find the right one for you:

- **Low dose amitriptyline** from your doctor. This is a good first choice as it helps frequency, urgency, pain and the number of times you pass urine at night. It can also sleep, bloating and headaches. A dose starting at 5mg *taken around 3 hours before bed* and increasing slowly to between 5 and 25mg daily suits around half the women who try it. Sleepiness in the mornings usually wears off in a week or so, but start with a small dose.
- If amitriptyline makes you feel too sleepy, then you can try tolterodine 1-2mg daily, oxybutinin 5-15mg daily or solifenacin 5-10mg daily.

- Hydroxyzine 10-50mg at night is often helpful but not available in Australia. This is an anti-histamine so especially useful for women with allergies.
- Pentosan polysulphate sodium (Elmiron®) 100mg three times daily. This is the only medication specifically used for painful bladder syndrome. It helps about half the women who take it but is expensive and may take up to six months to work.

Bladder First Aid

If there are times when your pain or urgency comes on suddenly, you may be able to help it quickly by:

- Drinking 500ml of water mixed with
 - o 1 teaspoon of bicarbonate of soda, or
 - o a sachet of Ural ® or Citravescent ®.
- Then take 2 paracetamol tablets (1g) and drink 250ml water every 20 min for the next few hours
- If you are no better, have a urine test for infection. Only take antibiotics if an infection is found.

Remember that if your bladder problems continue, you should discuss this with your doctor.



Fatigue, anxiety and low mood

Sick and tired of feeling sick and tired

Pelvic pain can affect your life dramatically, and it's understandable if you are just *'sick and tired of feeling sick and tired'*.

You may have had pain for a long time, been told that everything was normal, or not been taken seriously. You may have had treatments which haven't really helped and been disappointed.

It's hard to feel positive when this happens, but even so keeping a positive attitude is one of your best defences against pain.

You have lots to look forward to.

What is your coping style?

Everyone copes with pain a little differently. Maybe you put on a brave face at work or with friends, when inside you feel far from well. Maybe you have struggled on, trying to cope alone.

You might recognise some of your own feelings and behaviours in the *Pain Cycle* chart below.

These coping strategies are common, but maybe it's time to review how you manage your pain, and work towards being the woman you'd like to be.

'Choosing to live well with pelvic pain doesn't mean you have to be a superwoman, but it does mean choosing not to be a victim'

Best practice treatment is not just about what your doctors, and health care team can do for you. It's also about self-help, and what you can do for yourself.

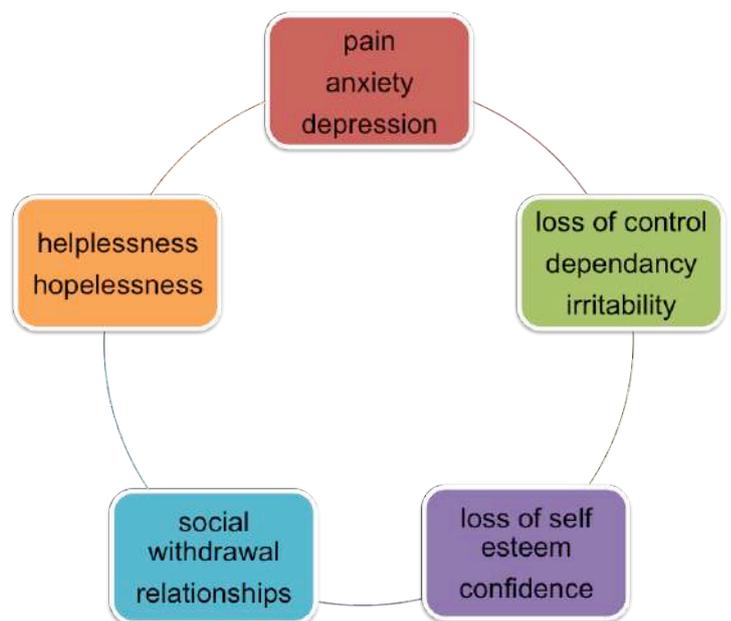
Doing things for yourself can help you feel *'back in control'*. This can be daunting in the beginning, but the more you do things for yourself, the more you will build confidence and the easier it will become. Remember, setbacks are normal and not a reason to give up.

'Fit, happy people have less pain'

The Pain Cycle

While you may put on a brave face at work or with friends, inside you may feel far from well.

Can you relate to any parts of the pain cycle?



Fatigue, Anxiety and Low Mood

I'm so over it!

Simple things first

- Take some time to think about what it is that worries you most about the pain and ask your doctor about your concerns. Often these fears are unnecessary
- Think about the things that trigger your stress, and problem-solve them one at a time
- Accept that you might need help. Others will be glad to help, especially when they see you making positive steps for your own well-being.
- Prepare for visits with your doctor by writing down your symptoms and the questions you'd like to ask.
- Plan time for fun and leisure, and keep active. Being outdoors is a great way to manage pain and stress. Do things you like which take your mind off the pain and keep you busy. Singing and music are a great start. There are many things you can still enjoy.
- Look after your body. Smoking, alcohol, drugs and being overweight make people feel sluggish and tired. You don't need it.
- Start regular gentle exercise, which tones the body and releases 'feel good' hormones. Walking is wonderful. If you have pain, then exercise is essential. Even a 10 minute walk each day is a useful start. If exercise causes you pain, read pages 8 and 14. It's OK to start small and build up
- Get regular sleep. Simple remedies include lavender oil on your pillow, chamomile tea before going to be and regular, calm bedtime routines.
- Consider relaxation or meditation to send positive energy to the mind

- Ask your doctor if your Vitamin D level may be low, or whether a course of iron tablets would be helpful.
- Learn to love your body. Replace unhelpful thoughts with helpful ones.

These things help you make pain a smaller part of your life. There will be some things you can't do, but look for things you enjoy that you can do, even if still have some pain, to keep happiness and activity in your life.

When simple things don't work

If you still feel low, it's really important to seek help. Depression and anxiety are common if you have had a lot to cope with.

These problems didn't cause your pain, but they do make it harder to get better and you deserve to be well. Keep up with the things on the 'simple things first' list and get help. It's really important. Useful services to help you include:

- Your doctor or a psychologist. Explain how you feel and ask if you could be depressed. There is no need to feel uncomfortable talking with your doctor about this
- The really useful, *free* 'Pain Course' at www.ecentreclinic.org which can teach you how to manage your pain, anxiety or depression.
- Online information on depression at www.beyondblue.org.au, www.depression.org.nz
- a telephone information line at **1300 22 4636 (Australia)**

'I can be well, and this is my plan'

Stabbing pains and ache

Often the problem is muscle spasm

Everyone knows that muscle cramp is painful, but imagine what a muscle cramp on the inside of your hip bones might feel like.

Many women with pelvic pain describe a sudden pain that can come on at any time, sometimes wakes them at night, makes them want to curl up in a ball, may go down into the legs and isn't helped much by normal pain medications. They may have trouble walking when they have the pain and exercise often makes it worse.

Women with this type of pain often find getting the help they need very frustrating. Nothing shows at a laparoscopy, or on an ultrasound scan but they are exactly right. It's bad pain.

A careful examination with 1 finger in the vagina, feeling high on the inside of the hip bones can find the muscle. Usually it is a muscle called Obturator Internus, or one nearby called Piriformis. Often the pelvic floor muscles are tight and painful too.

What can I do about spasm in these muscles?

The treatments for painful pelvic floor muscles described on page 8-9 help this type of pain too and there is lots more information in our book. Botox is especially useful for this type of pain.

What else could cause sudden pain on one side?

Other common causes of pain on one side include:

- Appendicitis (right side. Not usually a long term pain)
- Ovulation pain (2 weeks before a period starts when not on the pill, and only once each month)
- A ruptured ovarian cyst (less common if you are on the pill)
- An ectopic pregnancy (a pregnancy test will be positive)
- Bowel pain
- A kidney stone (there will be blood in your urine. Not usually a long term pain)

Core Strength and muscle pain

This type of pain may be worse with exercises that build 'core-strength'



Pudendal Neuralgia

Pain where you sit

This is a pain you may not have heard of before, and it's a pain that men can get too (!) especially if they spend a lot of time cycling.

The pudendal nerve is the nerve that goes to the muscles and skin between our legs where we sit. Some people call this the 'saddle area', which means the part of you that would touch a saddle if you were riding a horse.

The nerve travels through some tight places around the inside of your pelvis, where it can get irritated or be put under pressure.

What causes pudendal neuralgia?

The common causes include childbirth, injuries, cycling, long term constipation and tight, overly strong pelvic floor muscles. Sometimes no cause is found.

What are the symptoms of pudendal neuralgia?

There are many different symptoms but they are usually worse when sitting. The symptoms include:

- pain in the area of the pudendal nerve anywhere from the clitoris or penis back to the anal area. It may be on one side or

both sides, near the front, or further back. This pain is usually a burning or sharp 'electric' feeling

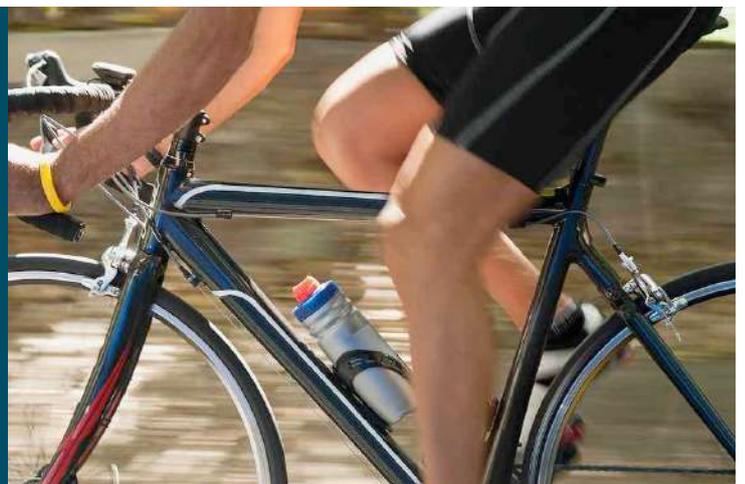
- sexual problems with less feeling in the penis or clitoris
- difficulty opening your bowels

What can I do to help the problem?

To help the nerve recover, you should:

- avoid activities that put pressure on the nerve, such as sitting, or cycling
- when you do sit, use a 'U-shaped' foam cushion with the front and centre area cut out, or sit on 2 towels rolled up under each buttock so there is no pressure in the centre
- see a pelvic physiotherapist to learn how to relax and lengthen your pelvic muscles, to take pressure off the nerve
- avoid straining when you pass urine or open your bowels, and avoid overly strengthening your pelvic muscles
- some centres offer botox to the pelvic floor muscles or pudendal nerve blocks for this problem

Pudendal Neuralgia is so common in cyclists, it is sometimes called 'Cyclists Syndrome'



Bad Headaches and Migraines

Are they related to my pelvic pain?

You may be surprised that we have included headaches in this e-booklet, but they are really common in women with pelvic pain, especially at period time.

It's always best to talk about your headaches with your doctor first, but once they are happy that there is no serious illness present, we suggest you try one of these treatments.

None of these treatments suit everyone, so you may need to try more than one to find something that suits you best. It is worth the effort, though. Your headaches are unlikely to go away by themselves and life is better without headaches.

Headaches with periods

A headache that comes each month with a period often improves with one of these options:

- A mirena iucd in the uterus
- A diclofenac 100mg suppository
- A 'triptan' nasal spray available from your doctor, or,

- An estrogen hormone patch used at period time

A low grade headache for several days each month

Sometimes they may be severe, while at other times just a nuisance. It is definitely worthwhile trying a preventer medication taken every day. Helpful medications in young women include:

- Amitriptyline 5-25mg 3 hours before bed each day
- Cyproheptadine (Periacten), 2 to 4mg each night
- Other medications from your doctor, or explained in our book

Try each one for 2-3 months and keep a headache diary, so you can decide if it has helped.

Migraines at other times

Make a plan with your doctor and ask about a 'triptan' nasal spray. There is much more information on headaches in our book, and at www.migraineclinic.org.uk

Remember to tell your doctor straight away if:

- Your headaches have changed or become worse
- A headache comes on suddenly
- You have a stiff neck or fever
- Your headache started after an injury
- You have new sensations, weakness or abnormal movements



The Chronic Pain Condition

Neuropathic Pain

If you have pain on most days, or several different pains, you may have wondered why your body is so sensitive. Someone may have told you 'it's all in your head'.

You don't need to worry that you are weak, or that the pain is imaginary. It's real, but it may be something you haven't thought of.

Often it is a change in the way the nerves, spinal cord and brain work called **neuropathic pain** or **central sensitisation**. Pain from nerves is yet another pain you can't see at a laparoscopy, and part of what doctors call the "*Chronic Pain Condition*"

How did it happen?

When something painful happens to us, the nerves in that area send pain signals to the spinal cord and then up to our brain. It is when the brain notices the pain that we feel it.

Sometimes, after bad pain, or if there has been pain for a long time, the pain pathways from the pelvis to the brain change. The structure of the nerves change and they start sending pain impulses to the brain at any time, not just when something painful is happening. The brain changes too, and starts to feel pain even with normal sensations like touch or normal bowel function.

Central sensitisation is very common in women with pelvic pain, but it is also common after back injuries, or shingles. The pain that is felt long after a badly injured leg is amputated (Phantom Limb Pain) is another type of neuropathic pain.

Do I have the *Chronic Pain Condition (neuropathic pain)*?

There are no scans or blood tests that show neuropathic pain, but once you understand it, neuropathic pain is quite easy to pick:

- It can come on at any time, and is usually present on most days
- The pain may be burning, sharp, or aching
- It is common to feel bloated, even if you look normal
- It is common to sleep badly
- Things that would not normally be painful, *are* painful. Some women feel pain just with touching their abdomen. This is called '*Allodynia*'
- Things that are painful become *more* painful. For example, periods may have always been painful, but are now *very* painful. This is called '*Hyperalgesia*'
- When the pain is really bad, you may feel it over a bigger area. This is called '*Wind-up pain*'

The Chronic Pain Condition is a medical condition, just as asthma, diabetes, and endometriosis are medical conditions. We just don't know as much about it.



The Chronic Pain Condition

What can I do to help the pain?

Things have just become too much for me

Neuropathic pain affects our mood too. Women who have managed their pain well for years, may start to feel 'worn down' by their pain or anxious about things they don't need to be anxious about.

We know that some of the same chemicals involved in neuropathic pain are also involved in anxiety and depression, so once again, you are certainly not imagining it. These problems often improve once the pain is treated.

What is the 'Chronic Pain Condition'?

Chronic pain is a medical condition, just as asthma, diabetes and endometriosis are medical conditions, but it involves the way nerves work.

Around 20% of people (men and women) seem to be at risk of developing a long term pain condition. Often there are a mix of different pains. For example, a woman with pelvic pain might also have tender points in the muscles around her shoulders, headaches on most days, long term pain after an injury or an irritable bowel.

Brain scans show that in someone with neuropathic pain, even small things are seen by the brain as pain.

What will help me get better?

Once chronic pain becomes established, a cure may not be possible, but the good news is that you can expect a *big* improvement with management of your pain. All of the treatments aim to help your nerves work normally again.

Lifestyle issues: You may have worked out already that your pain is worse if you are stressed or over-tired. More than ever, you need to be kind to yourself. This doesn't mean lying on a couch all day. It means regular gentle exercise, a good diet, a positive attitude, regular sleep, and resolving stressful issues. Chronic pain is not dangerous, but it is painful. Even so, there are still lots of things in

life you can enjoy and a positive attitude really helps.

Medications every day to help the nerves work normally. These medications are not painkillers, but often help pain when taken regularly.

It is true that no one wants to take a regular medication, but we recommend you see your doctor and try them at least for a couple of months. Then think about the problems you had before and decide if they have been helpful:

- *amitriptyline* is an old-fashioned medication that used to be used in big doses to treat depression. Small doses won't treat depression but often help nerve pain, sleep, headaches, a bloated feeling, an overactive bladder and muscle pains. It suits around half the women who try it. Start with just 5mg (half a blue tablet) 3 hours before bed. If you are not too sleepy the next day, go up to 10mg, then slowly to between 10 and 25mg if all goes well. If you are sleepy, stay on 5mg and wait for this to pass.
- *pregabalin* or *gabapentin*. These are different medications you can discuss with your doctor. Start on a small dose and work up. There is no hurry.
- other medications for this type of pain

Preparing for an operation

If you have this type of pain and need an operation, it is a good idea to talk to your doctor about using a neuropathic medication before and after your surgery. This hasn't been commonly used for pelvic pain surgery in the past, but we believe it helps recovery.

If you are already on amitriptyline then this should be continued until you are fully recovered.

Alternatively, you can ask your anaesthetist whether a treatment for neuropathic pain before or after your operation might help with pain management.

About Us

Dr Susan Evans, MBBS, FRANZCOG, FFPMANZCA is a gynaecologist, laparoscopic surgeon and specialist pain medicine physician who lives in Adelaide, Australia. She specialises in the management of endometriosis and pelvic pain. Dr Evans has written a wide range of books and articles on pelvic pain for health professionals, women and girls. She has presented at meetings, on TV and radio, in Australia and internationally.

Ms Deborah Bush, QSM, Dip Tchg, LSB is Chief Executive Officer of Endometriosis New Zealand and lives in Christchurch, New Zealand. She developed the 'me' (menstrual education) schools program for teenagers, provides expert advisory consulting for women with pelvic pain in conjunction with their gynaecologist, and has been instrumental in raising awareness of endometriosis and pelvic pain in New Zealand and beyond.

There's much more you can do

It's always good to have friends. You can get in touch with other women just like you using the links in the pink box or attending an event run by Pelvic Pain Foundation of Australia or Endometriosis New Zealand.

Keep up with news and opportunities to be involved in research when you 'Like Us' on Facebook.

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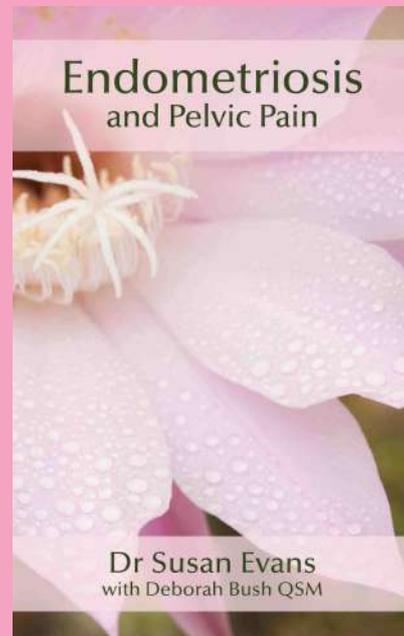
This ebook provides general information only and is not intended to take the place of medical advice. We will not be responsible for the results of decisions made resulting from the use of this information, and recommend that you discuss your personal situation with your doctor.

Read our book

If you've liked the e-booklet, you will love the book!

'Endometriosis and Pelvic Pain' has much more about all the different types of pain and lots on fertility. There are stories about real women just like you and it's really easy-to-read.

\$25 in English or Mandarin from www.pelvicpainsa.com.au and www.nzendo.co.nz



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New Zealand'**



**Our Pain
Website!**

We often update the information at www.pelvicpain.org.au