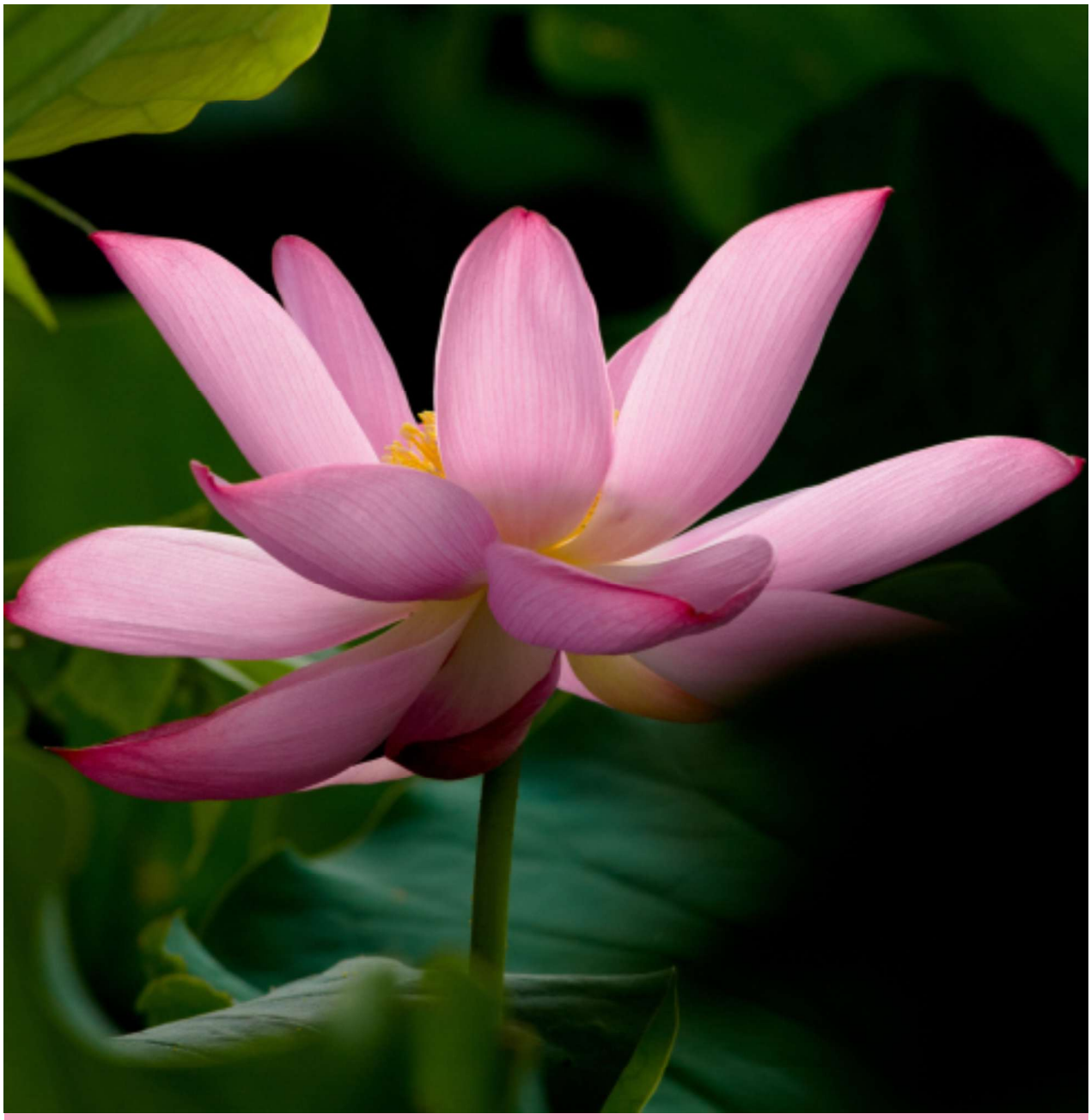
an introduction to pelvic pain for girls women men and families

PELVIC PAIN



Introduction to Pelvic Pain

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Pelvic Pain Foundation
OF AUSTRALIA

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Introduction

How to use this booklet

If you are someone with period pain, endometriosis or pelvic pain, you'll know that the pain can seem quite complicated. Don't worry. It doesn't need to be so. By learning more about your pain, you'll be much better able to make good decisions about treatment, and get better pain management. There are many girls, women, gender diverse people and even some men with pain just like yours.

You are certainly not alone.

I'm ready to learn more. Where do I start?

To work out what you need, a good start is to first think about how many days a month you have pain:

- Some people 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 people have a mix of different pains with pain of some kind almost every day. 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.

There may be more pains in this booklet than you expected. You may not have all of these pains. If you have Chronic Pelvic Pain, it's common to have several different pains at once. You can look through the list and read the sections that are most important to you.

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

Unfortunately, not yet.

It is true that for some people, the ones who have endometriosis, 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, even in people with endometriosis, surgery isn't the whole picture. 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. Even in a person with endometriosis, it may be one of the pains you can't see, such as pelvic muscle spasm, that turns out to be the worst pain.

If you find this introduction to pelvic pain useful, your friends and family are welcome to download their own copy from our website at www.pelvicpain.org.au

This booklet has been a good start, but I'd like to learn more about pain.

The Pelvic Pain Foundation of Australia at www.pelvicpain.org.au has much more information for girls, women, and men with pelvic pain. There are videos, information sheets and exercise programs, all free of charge.

Page 19 of this booklet explains where you can find further information. This includes, information about the book *'Endometriosis and Pelvic Pain'* which has been especially written for individuals like you.

Period Pain
Dysmenorrhoea

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

None of us know what another person'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 people 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.

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

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

Am I too young to have endometriosis?

Endometriosis used to be thought of as an uncommon problem of people 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 people it is often a dark brown colour. In young people it may look like tiny clear bubbles that can be hard to see.

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

Similar results have been found throughout the world.

It's really important that teens 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

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.

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 3-4 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 3-5 years, when used for pain. It slowly releases a progestogen medication to the uterus that makes periods lighter and less painful. It is also a useful 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. They 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 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, and some people have pain but no endometriosis. So, you may have a little bit of endometriosis and a lot of pain, or a lot of endometriosis and very little pain.

Things to remember about laparoscopy

After surgery, avoiding periods will reduce your pain even further, and reduce the chance that new areas of endometriosis will develop.

You will recover from surgery quicker by keeping moving and going for a gentle walk every day.

Some people have too many laparoscopies. They, or their doctor, think that surgery should be able to treat all types of pain. This isn't correct. Even if you have endometriosis, it is common for pain from the bladder, bowel, pelvic muscles or nerve pathways to be present too. They might even be your worst pain, but can't be seen at a laparoscopy. This booklet has lots of ideas on how to manage pain without surgery, and how to use a range of different treatments, as well as surgery, to get the best outcomes for your pain.

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. The bowel looks normal at a laparoscopy or ultrasound, but certainly doesn't feel normal.

People 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 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 uncomfortable. It also makes any other pelvic pain worse. Luckily, there is lots you can do to help.

Before you do anything about bloating, you should see your doctor. Sometimes people 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. People often feel like this near period time, but it is also aggravated by certain foods. These foods are described further below.

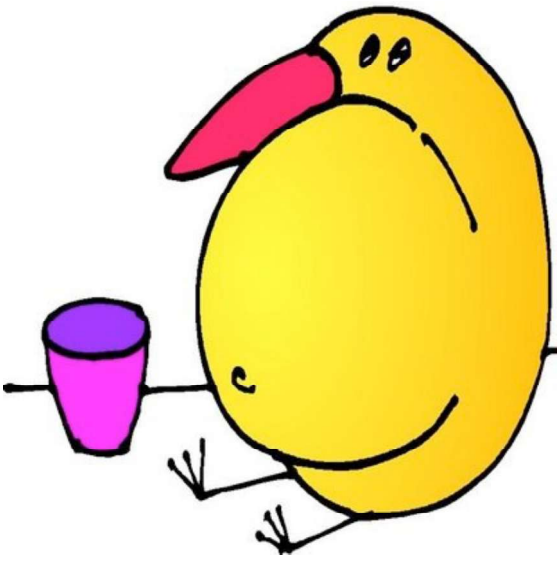
Cutting down on these foods often makes a big difference to pain.

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 people 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 people 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 go 'gluten-free'?

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

People 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 most people, 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 opioid medications such as codeine
- A herbal treatment such as slippery elm

But my constipation is severe

Some people 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 people feel when they are unable to enjoy sex with their partner. This experience can put pressure on relationships.

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

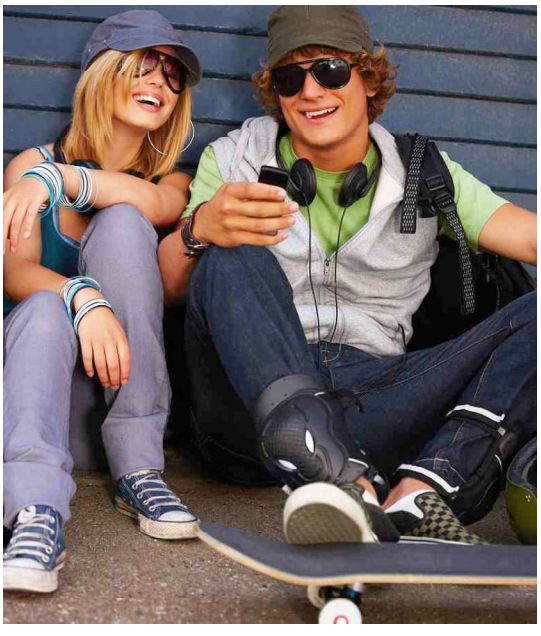
The pelvic floor muscles are the ones you tighten when you want to stop passing urine quickly. They can become too tight and painful.

Often there is an ache in the pelvis much of the time, sometimes with sudden crampy spasms. Penetrative sex, pelvic examinations, or inserting tampons becomes 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 core strength exercises 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 penetrative sex? Useful treatments:

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

Even if penetrative 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?

- Take a small dose (5-25mg) of amitriptyline early each evening, or duloxetine (15-60mg) in the morning. Your doctor can arrange this for you. There are instructions on how to take these at www.pelvicpain.org.au
- Continue regular gentle exercise, such as walking, or yoga
- 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
- For severe pain episodes, a 5mg diazepam suppository from your doctor in the vagina or bowel can help.

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.

If you do have penetrative sex then:

- Use a vaginal lubricant. An organic lubricant suitable for sensitive vulval skin is available at www.pelvicpain.org.au
- Ask your partner to go slowly and wait until you are ready. Using the relaxation audio 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. Surgery to remove this is difficult, and you will need a gynaecologist highly skilled in laparoscopic surgery. A laparoscopy will not fix pelvic muscle pain.

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 in this area is sore, then you may find these ideas helpful:

- 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 200mg 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’ (vulval 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 people 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.

People 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 people 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 if a sexual infection is possible.

Make sure you are drinking enough (but not too much) fluid each day. For most people, 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 the worst pain

Dietary changes.

There are many foods that can make bladder pain worse, but most people only have problems with some of these foods. 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 in particular can cause problems 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

There are several different medications for a painful bladder, but you may need to try a few different ones 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 improve 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 people who try it. Sleepiness in the mornings usually wears off in a week or so, but start with a small dose.
- **Mirabegron (betmiga®)** 25 or 50mg taken once a day is particularly useful for those with a painful bladder who find amitriptyline causes side effects. It won't help other pains or headaches.
- **Tolterodine** 1-2mg daily, or **oxybutinin** 5-15mg daily - or as a skin patch.

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
    - 1 teaspoon of bicarbonate of soda, or
    - a sachet of Ural ® or Citravescent ®.
- Then drinking 250ml water every 20 min for the next few hours
- If 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.

It is common for people with painful bladder syndrome to also have painful pelvic muscles.



Feeling Bad: Fatigue, Poor Sleep
Nausea, Sweaty, Anxious, Low Mood

Pelvic pain can be more than pain in the pelvis. It can also make you feel really unwell. This is especially true when pain changes from pain with periods to pain on most days.

This is when symptoms like fatigue, poor sleep, nausea, anxiety, low mood, sweating or dizziness really get started. These symptoms are common in any pain condition - male or female - where pain has been present on most days for more than three to six months. They can also be present just at period time.

So, what's happening?

When pain is severe, this can lead to changes in the way pain is processed in the spinal cord and brain. This is called central sensitisation of pain, and it's often associated with Feel Bad symptoms. Central sensitisation is aggravated by reduced activity and the regular use of opioid medications. These feelings can also be the result of a life that has been made difficult due to pain. Usually both these factors are present.

The changes in the brain and ways to treat them are discussed in the section on chronic pain, but the good news is that these changes can be managed.

Simple things first

If you feel unwell, it is important to first discuss this with your doctor. This ensures that no other causes of these feelings are present. There are then many ways to improve how you feel.

Fill your life with purposeful activity

Purposeful activities are the things that matter to you. The sorts of things you'll still do, even when you don't feel well, because you really want to.

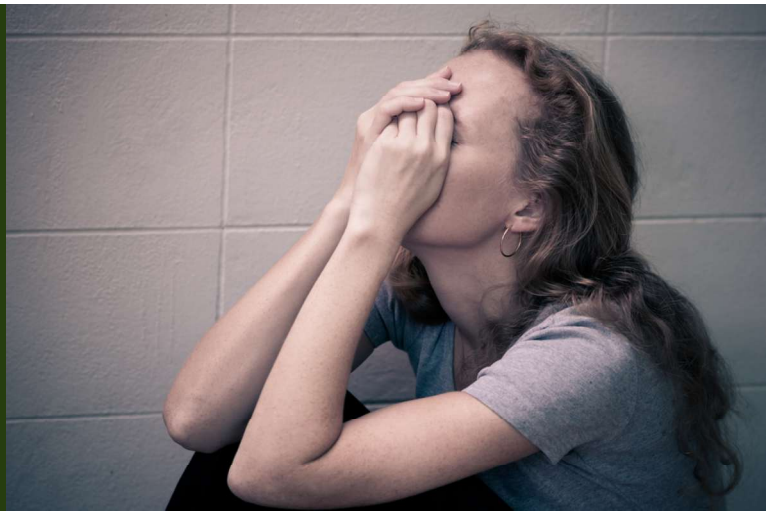
Maybe you like learning new skills, or keeping active with craft, or volunteering at a school or getting outside.

'Your brain has better things to do than think about pain'

Persistent Pain

Persistent pain is any pain that has been present on most days for more than 3-6 months.

Nowadays we know that severe period pain that happens every month, even if you feel well between periods, is also a persistent pain condition.



Feeling Bad: Fatigue, Poor Sleep
Nausea, Sweaty, Anxious, Low Mood

A good night's sleep is important

When we have a good night's sleep, our brain works better and is less irritable the next day. A good start to better sleep involves:
- getting up at a regular time each morning.
- having some time outdoors in sunlight each day
- doing regular exercise
- avoiding the use of 'screens' before bed
- a cool bedroom

For many more recommendations on how to improve your sleep, look for the sleep fact sheets by typing in 'Sleep Assessment Insomnia Management Kit' at: www.sahealth.sa.gov.au

Listening to the Pelvic Muscle Relaxation Audio Download available at www.pelvicpain.org.au will help reduce your pelvic muscle pain and prepare you for a better night's sleep. If you are woken at night by pain that makes you want to move, this is often pelvic muscle pain.

Keep Active

While you may not be able to do strenuous exercise, it is important to keep moving. When we move, our muscles are healthier and our brain releases feel good chemicals that reduce pain. Remember to build up slowly and do gentle exercise 'away from the core'. This might include walking. According to your health, this may range from a 5 minute walk on flat ground twice daily to regular more strenuous exercise.

When simple things don't work

If your mood continues to be low, or anxiety is severe, it is important to see your doctor. They have many options for you to consider, from the simple to the complex. You do not need to feel alone or unsupported.

Consider seeing a psychologist

A psychologist specialises in helping you lead the best life you can. Most psychologists are experienced in the management of anxiety and low mood, but a Pain Psychologist has extra training in how to manage chronic pain conditions.

Online Pain Education Courses

Even if you are at home, or live far away from health services, or are busy with children or work, you can still access education and assistance with recovering from pain.
If you have an internet connection, then one of the following pain courses may help you. These courses have been fully evaluated. Those people who complete the course find that while the severity of the pain may be only mildly reduced, the impact of the pain on their life is substantially reduced. They live better despite still having some pain.

- The *free* online 'Pain Course' at www.ecentreclinic.org provided through Macquarie University, which can teach you to manage your pain, anxiety or depression.

- The *low cost* 'Chronic Pain Reboot' online course, developed at St Vincent's Hospital. It costs $59 for 4 months course access and can be found at www.thiswayup.org.au

The Protectometer Workbook

This book explains modern neuroscience concepts in pain and how to reduce the impact of pain on your life. It has been written by world famous educators, Lorimer Moseley and David Butler and is available from www.pelvicpain.org.au

Stabbing pains and ache
Often the problem is muscle spasm

Everyone knows that muscle cramp is painful, but imagine what a muscle cramp in the pelvis might feel like.

Many people with pelvic pain describe a sudden pain that comes 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.

People with this type of pain often find getting the help they need frustrating. Nothing shows on an ultrasound scan, or a laparoscopy, but they have severe pain. Often they have been told that no cause for their pain can be found.

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. Botox injections in the muscle can be useful for short term use, when this pain is severe.

A diazepam suppository inserted in the vagina or bowel is useful for severe flares of pain, when you are at home and not driving. You will need a script from your doctor and to have it made up by a compounding pharmacist. Information on this is available at www.pelvicpain.org.au

What else could cause sudden pain on one side?

Other possible causes include:

- Appendicitis (right side. Not usually a long term pain)
- Ovulation pain (2 weeks before a period, 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'. The best exercises if you have this pain are gentle exercises 'away from the core' e.g. Yoga or a walk.

Salsa or Zumba dancing can also help loosen the pelvis



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:

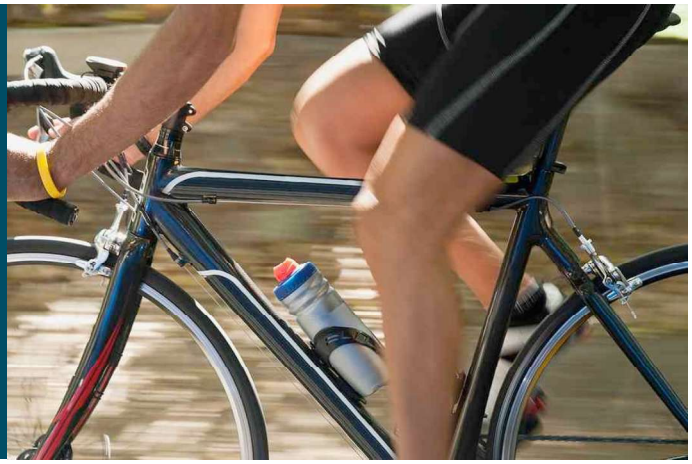
- Pain in the area of the pudendal nerve anywhere from the clitoris or penis back to the anal area. It may be on one side or both sides, near the front, or further back. This pain is usually a burning or sharp 'electric' feeling
- Sexual problems with less feeling in the penis or clitoris
- Difficulty opening your bowels

What can I do to recover?

To help the nerve recover, you should:

- Avoid activities like sitting or cycling that put pressure on the nerve
- When you 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
- See a pelvic physiotherapist, and use the pelvic muscle relaxation audio download from www.pelvicpain.org.au to learn how to relax 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 for this

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 booklet. Headaches are very common in people with pelvic pain, especially at period time.

It's always best to talk about your headaches with your doctor first, but once they are sure 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. Life is better without headaches.

Headaches with periods

A headache that comes each month with your period, often feels like a migraine headache. Even if it just feels like a bad headache, it often improves with a migraine treatment:

- A diclofenac 100mg suppository
- A 'triptan' nasal spray available from your doctor, or, both these treatments together

A headache for several days each month

If headaches (even mild ones) are common for you, it is definitely worthwhile trying a preventer medication taken every day. Helpful medications in young people include:

- Amitriptyline 5-25mg 3 hours before bed each day
- Topiramate tablets. start with a small dose and build up slowly
- 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' medication such as sumatriptan.

There is more information on diet, headache triggers and non-drug treatment for 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.

When pain is present on most days for more than 3-6 months, the nerve pathways in the spinal cord and brain change. They become 'sensitised'.

The structure of the nerves changes 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 in other pain conditions, including back pain, or shingles.

What would I notice?

You may notice that even light touch on your lower abdomen, or wearing tight clothes feels unpleasant. Other problems including fatigue, poor sleep, nausea, a bloated feeling, dizziness, sweating, anxiety and low mood are common.

Things that would not normally be painful, become painful. Things that have always been painful become *more* painful. For example, period pain may worsen. When the pain is really bad, you may feel it over a wider area.

Doctors may use words like **neuropathic pain, central sensitisation, or chronic pain condition**. There are no scans or blood tests that show neuropathic pain, and it can't be seen at a laparoscopy.

Do I have *Chronic Pain*?

Whether you are a man or a woman, if you have had pain on most days for more than 3-6 months, then it is likely that you have this condition. Your pain may have started with period pain, endometriosis, or a sporting injury, but is now more complicated.

For example, a person who started with period pain, might now also have tender points in the muscles around their shoulders, headaches on most days, painful pelvic muscle spasms, and an irritable bowel. Their pain condition affects her whole body.

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



What can I do about Chronic Pain?
This is where you can take control

Simple things first

If you have chronic pain, then it is even more important to take care of your health and wellbeing than ever before. Healthy exercise, sleep and most importantly a positive attitude allows the brain to release healthy chemicals that reduce pain.

Exercise

If you wish to be well, it is essential to exercise. Start slowly with regular gentle exercise such as walking or yoga - and gradually increase how much exercise you do. Avoid core exercises until your pain improves, as core exercise can worsen pelvic pain. Although your body may feel as if you need to rest, you will have less pain if you keep moving.

Lifestyle issues

You may have worked out already that your pain is worse if you are stressed or over-tired. Being kind to yourself means a positive attitude, regular sleep, and resolving stressful issues. Chronic pain is not dangerous, but it is painful. Even if you can't do everything you once did, look for the things in life you *can* enjoy and stay active. A positive attitude really helps.

Avoid regular opioid medications

Opioid medications such as codeine, fentanyl, oxycodone, morphine and others should be avoided. While they may be necessary for 2-3 days after an operation, they actually make chronic pain worse when taken regularly.

When simple things aren't enough

Although taking opioid medications regularly should be avoided, there *are* special medications you can take for chronic pain. These medications work slowly and are taken every day. They help the nerves in the spinal cord and brain work normally again. There are several different types of special medications for long term pain.None of these suit everyone, so you may need to try a few to find the one that helps you most:

- *Amitriptyline* is an old-fashioned medication that used to be used in large doses to treat depression. It isn't used for depression any more, but small doses (5-25mg at night) are used to treat nerve pain, difficulty sleeping, headaches, a bloated feeling, an overactive bladder and muscle pains. It suits around half the women who try it. If it makes you too sleepy, you can change to nortriptyline.
- *Duloxetine* is useful for women with pain, anxiety or low mood. Most anxiety medications (called SSRI's) don't help pain, but *duloxetine* is an SSRI *and* SNRI medication so can also help pain.
- *Pregabalin* or *gabapentin*. These are medications to discuss with your doctor.

There are information sheets on how to take these medications at www.pelvicpain.org.au

Before you have an operation

If you have this type of pain and need an operation, ask your doctor about using amitriptyline 10mg each night after your surgery until you are fully recovered, or maybe for longer if you have headaches, bladder problems or long term pain. This hasn't been commonly used after surgery in the past, but we believe it helps recovery.

Remember to go for a walk every day after your operation. Start with a short walk and do a little more each day. You will have less pain if you keep moving.

Surgery can worsen chronic pain in some people, so avoid having more laparoscopies than necessary. Sometimes people have a laparoscopy when the main cause of their pain was something that can't be seen at an operation - such as pelvic muscle spasms, bladder or bowel pain. Their pain might improve for 2-3 months, then return.

Where can I find out more?
This booklet is just the start

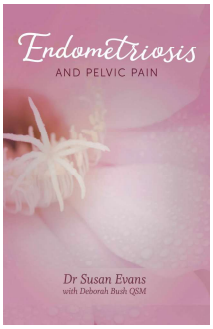
Our Website

The Pelvic Pain Foundation of Australia website has information for girls, women, men, parents, health professionals and families. We are a registered, not-for-profit charity.

www.pelvicpain.org.au

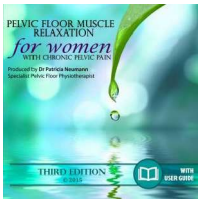
Our Book

This booklet is an intro to pelvic pain, but girls and women with endometriosis will find much more information in our full-size book ***'Endometriosis and Pelvic Pain'.*** It is easy-to-read and includes sections about improving your fertility (for women and men), understanding what happens at a laparoscopy, how to manage each type of pain in more detail, how to take medications, and stories of women just like you. Order the book for $AUS27.50 plus postage, or download the Ebook for $AUS22 from the website.



Pelvic Muscle Relaxation Download (for men and women)

The Relaxation download and other pelvic pain products are available from the website, and can be downloaded for $22 (Australian Dollars)



Our Facebook Page

For the latest pelvic pain news, LIKE us at the Pelvic Pain Foundation of Australia

Events for Health Professionals

Each year the Pelvic Pain Foundation holds practical pelvic pain training seminars for Health Practitioners. Find out about our next seminar by contacting PPFA at contact@pelvicpain.org.au



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Pelvic Pain Foundation of Australia

Pelvic Pain Foundation of Australia

The Pelvic Pain Foundation of Australia is a registered, not-for-profit charity that promotes education and research into pelvic pain in girls, women and men.

Health professionals registered with AHPRA in Australia or the relevant health boards of New Zealand are eligible to become subscribers to the Pelvic Pain Foundation of Australia. Being a subscriber provides access to training videos in pelvic pain and use of a range of patient resources.

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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.