

ENDOMETRIOSIS

INSIDE:

- Causes and symptoms
- Can I still have a baby?
- Your treatment options explained



PART OF THE PATHWAYS TO PARENTHOOD BOOKLET SERIES

ABOUT THIS BOOKLET

This series of booklets has been developed and written with the support of leading fertility clinics across Australia, and AccessAustralia – a national organisation that provides numerous services for people having difficulty conceiving. We also acknowledge the many people who spoke openly about their own experiences with assisted reproductive technologies in order to help others experiencing a similar journey. Merck Serono thanks the many individuals, couples and Australian healthcare professionals, including fertility specialists, specialist nurses and psychologists who shared their knowledge and expertise during the production of these booklets.

Important notice: The information provided in this booklet does not replace any of the information or advice provided by a medical practitioner and other members of your healthcare team. If you have any further questions about endometriosis, please contact your doctor.

Please note that throughout this booklet, the generic name of a medication will be stated first followed by the brand name in brackets.

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INTRODUCTION

Endometriosis is a common and sometimes painful condition of the reproductive system, which affects up to one in 10 women.¹ Despite it being so common, it is often misdiagnosed because it has similar symptoms to many other conditions including irritable bowel syndrome, ovarian cysts and pelvic inflammatory disease.

For some women, endometriosis can cause a wide range of frustrating and debilitating symptoms such as pelvic, abdominal and back pain, heavy and painful periods and infertility. Sometimes it can be so severe that women are unable to go to work or school, or go about their daily routine. But while it might cause hardship, discomfort and inconvenience, it's not life threatening.

There are many ways to help with the symptoms you might have, and while endometriosis is a known cause of infertility, the medications and procedures available to assist you in becoming pregnant are well-established and effective.

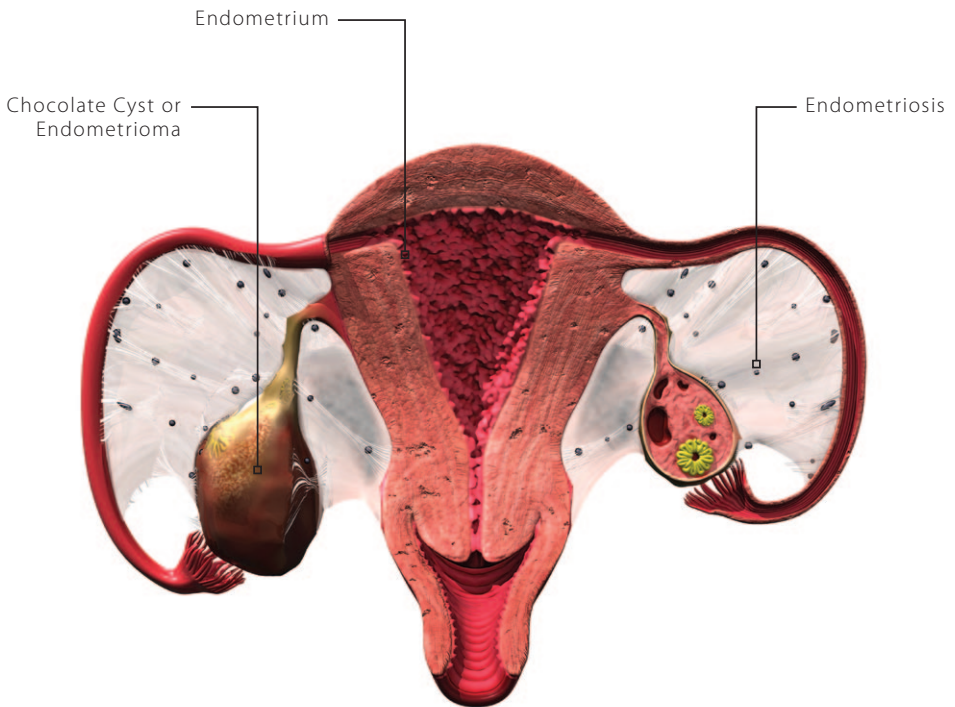
This booklet aims to give you information about endometriosis – what it is, why you have it, and how to treat the condition. In the back of the booklet, you will also find some contact details of support organisations, which offer further information and resources, access to self-help groups and online services.

Having endometriosis can be extremely challenging for you both emotionally and physically. It is important that you discuss how you feel with your partner, family members and friends and ask for support when you need it. With the help and the assistance of your healthcare team, endometriosis can be effectively treated and managed allowing you to live a full and healthy life.

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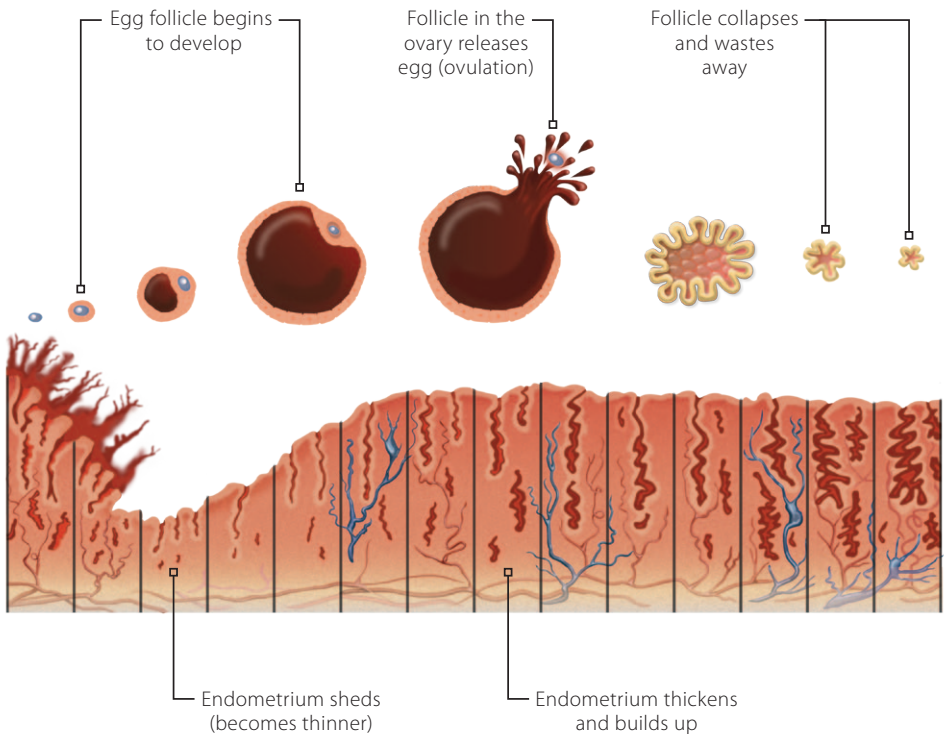
WHAT IS ENDOMETRIOSIS?

Endometriosis occurs when the tissue that normally lines the inside of the uterus grows in other places of your body where it doesn't belong, such as on the ovaries, fallopian tubes, outside surface of the uterus, bowel, bladder and rectum. This stray endometrial tissue is often referred to as **endometrial implants**. Because this tissue still acts the same as that found in your uterus and responds to changes in your hormones during your menstrual period (see explanation next page), the tissue breaks down and 'bleeds' into the surrounding area causing pain and inflammation before and after your period, scarring and adhesions (organs sticking together).



ENDOMETRIOSIS AND YOUR MENSTRUAL CYCLE

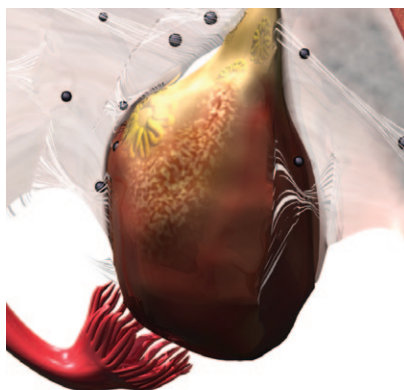
The menstrual cycle refers to the maturing and release of an egg and to the preparation of the uterus (womb) to receive and nurture an embryo. A typical cycle takes approximately 28 to 32 days. Your menstrual cycle is regulated by hormones. The pituitary gland in the base of the brain produces hormones to prepare an egg, and to release it once a month in a process known as **ovulation**. The ovaries produce other hormones to prepare the womb or uterus for pregnancy by thickening its endometrium (lining).



When you have endometriosis, the misplaced tissue in other parts of your body responds to hormones in a similar way to the lining in the uterus, thickening as it prepares for pregnancy. When pregnancy does not occur, the uterus and the misplaced endometriosis tissue shed their fluids or 'bleed' during your period. Because the fluids from the endometriosis are unable to pass out of the body in the usual way, they instead leak into the abdominal cavity and onto other organs, ligaments or muscle causing irritation and pain.

The fluids from the leaking endometriosis are thick and glue-like so they can also cause **adhesions** between one organ and another, sticking them together. Consequently, any movement such as that occurring in ovulation, sexual intercourse or emptying of the bowel can be painful. When the tissue 'heals' after bleeding it can lead to scarring.

Endometriosis found on the ovary can also grow larger and form cysts, known as **endometriomas**, or '**chocolate cysts**'. When the endometriosis cysts bleed during each period, most of the fluids cannot drain away, so this old sludgy-brown blood develops a 'chocolatey' appearance.



WHO GETS ENDOMETRIOSIS?

Any woman from teenagers through to those aged in their 40s are susceptible to endometriosis, however you are more likely to develop the condition if you have the following risk factors:

- have not had children
- are overweight
- have heavy or prolonged periods
- had your first period at an early age, i.e. before 12 years of age
- have a family history of endometriosis, e.g. mother, sister, aunt. Women in this group are twice as likely to develop the disease and are also likely to have a more severe form of the disease.²

WHAT CAUSES IT?

It is not known exactly what causes endometriosis, although it does tend to be hereditary, i.e. run in families.

One of the main causes of the endometrial implants is believed to be **retrograde menstruation**. This means that women menstruate 'backwards' through the fallopian tubes and into the pelvis, rather than through the vagina and out of the body. When this flowback occurs, endometrial cells from the uterus can leak out and onto other organs and start growing and multiplying.³

However, this is only part of the picture. The majority of women menstruate 'backwards' through their tubes, but only 10% of women develop endometriosis.³ This is believed to be because most women have a natural defence against those cells developing elsewhere in the body. Their immune system identifies them as 'foreign' and kills them off before they attach and become endometriosis.

SYMPTOMS

There are many symptoms of endometriosis and they vary widely from woman to woman. Some may experience severe pain and heavy bleeding, while another might not even be aware of the condition until she has difficulty becoming pregnant. Endometriosis is usually classified as four stages: minimal, mild, moderate and severe, depending upon the extent of the condition and the degree of associated scarring and adhesions.

Pain

Pain is the most common symptom and it can include:

- back or abdominal pain
- period pain
- ovulation pain including pain in the legs
- pain urinating or during bowel movements
- pain during sexual intercourse.



Period pain is thought to occur when the endometrium tissue sheds its fluids into the abdominal cavity where it irritates and inflames other tissue or organs. Additional pain can be felt going to the toilet or passing wind when endometriosis has spread onto the bladder or bowel. This pain can become worse over time as the body creates more of the unwanted tissue.

Bleeding

Menstruation in women with endometriosis can also vary greatly and include:

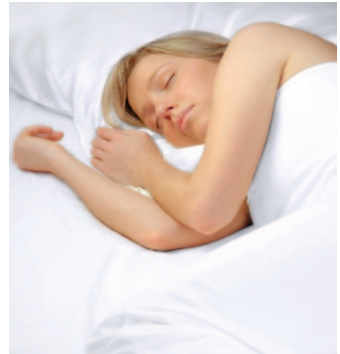
- heavy bleeding
- prolonged periods
- irregular bleeding
- light spotting

Other symptoms

Other symptoms might include:

- bowel or bladder symptoms, bleeding or discomfort
- irregular bowel activity, including diarrhoea
- bloating
- tiredness
- infertility (see page 9)
- emotional problems (e.g. depression, anxiety)
- premenstrual symptoms including mood swings and irritability.

Because of the confusing nature and range of symptoms, sometimes the condition can be misdiagnosed. For example, symptoms such as bowel pain might be confused with digestion-related illnesses such as irritable bowel syndrome.



SYMPTOMS AND ENDOMETRIOSIS SEVERITY

Mild forms of endometriosis can cause quite severe pelvic pain, whilst some women with very severe levels of endometriosis and extensive pelvic damage have had their endometriosis found by accident and have never previously complained of symptoms.⁴

WILL I BE ABLE TO TELL IF I HAVE ENDOMETRIOSIS?

In addition to the symptoms listed on the previous page, you should talk to your doctor if you have any of the following:

- period pain that is not relieved by pain killers (e.g. paracetamol) or other pain relief (e.g. hot water bottle)
- periods that last for more than seven days each month
- abnormal bleeding such as heavy or prolonged bleeding, spotting before the period
- symptoms which occur mid-cycle and/or at the time of your period
- a family history of endometriosis.³

IF IT'S NOT ENDOMETRIOSIS, WHAT IS IT?

Pelvic pain can be caused by a number of conditions including:

- adenomyosis (a condition in which the lining of the uterus burrows into the muscle of the uterus)
- pelvic infection such as chlamydia
- scar tissue (adhesions) caused by previous surgery
- infection or old pelvic inflammatory disease
- cysts on the ovary
- irritable bowel syndrome
- inflammatory bowel disease (e.g. Crohn's disease)
- a bladder problem such as chronic infection or inflammation.



ENDOMETRIOSIS AND INFERTILITY

About 30% of women with infertility problems have endometriosis.² Some women with mild endometriosis symptoms don't even know they have the condition until they have trouble becoming pregnant. For other couples, there may be additional or different factors contributing to the infertility.

Like the condition itself, the reason endometriosis causes infertility is not well understood. In some cases the fallopian tubes are damaged or have scar tissue due to the formation of endometriosis, and this can impede the flow of the egg down the tube. It also makes it more difficult for the sperm to travel along the tube to the egg, lowering the chance of conception.

Other possible reasons for infertility include chocolate cysts (see page 5) affecting ovulation, and eggs that don't develop properly and are less likely to be fertilised. It is also thought that the body produces toxins, which affect the sperm or that the endometriosis cells produce chemicals, which interfere with the developing embryo.^{5,6}

The good news is that it is possible to become pregnant when you have endometriosis. Some women may need some medical assistance to conceive (see page 14) while others may conceive naturally and go on to have a healthy and normal pregnancy.

PREGNANCY AND ENDOMETRIOSIS SYMPTOMS

Pregnancy can relieve the symptoms of endometriosis – because you are no longer menstruating – but it is not a cure in itself. For many women the symptoms usually return after birth or within a few years.^{5,7} Most women can delay the return of the symptoms by breastfeeding as long as the feeding is frequent enough and intense enough to suppress the menstrual cycle.^{5,7}

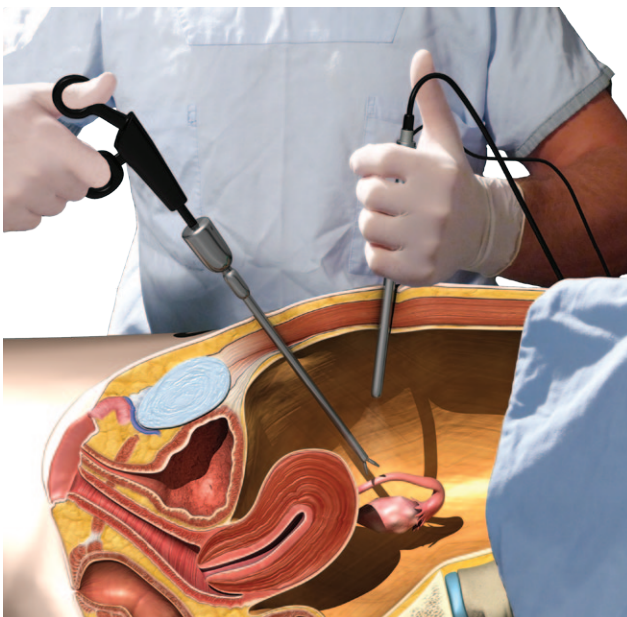
HOW IS IT DIAGNOSED?

As there is no simple test for endometriosis and symptoms may at first be attributed to other health problems, like pelvic inflammatory disease, fibroids, or irritable bowel syndrome, women can experience significant delays between the time they report symptoms and the time they receive a diagnosis of endometriosis.⁸

During a pelvic examination by a doctor, tenderness in the pelvic region, a uterus that appears fixed and immobile (due to adhesions) and enlarged ovaries (from chocolate cysts) may all indicate the presence of endometriosis.⁸

If enlarged ovaries or a mass in the pelvis is detected, a **vaginal** ultrasound (which uses a slim probe inserted into the vagina) may be used to identify endometriosis or to rule out other causes of pain. However, a **laparoscopy** is the most accurate way to diagnose the condition. Under anaesthetic, a gynaecologist inserts a telescope-like instrument through a small incision under the belly button to examine the pelvic organs. The presence of endometriosis can then be confirmed and assessed as mild (meaning a few spots scattered around the pelvis) through to severe (large cysts in the ovary and subsequent damage). Surgery to remove the endometrial implants and adhesions may be done during this initial investigative laparoscopy (see page 11 for more information).

Endometriosis can also be diagnosed through a **laparotomy**, which is a far more significant operation than laparoscopy as a full-sized incision is made in the abdominal wall.



TREATING ENDOMETRIOSIS

There are many treatments available for the varied symptoms of endometriosis. Please ask your doctor for more information on the following treatment options and their side effects.

‘Wait and see’ approach

If you have mild symptoms, one option is to monitor your condition through regular visits to your doctor. This may establish whether you can manage the condition without treatment. If symptoms are left untreated, they might stay the same or even improve.^{9,10} For some women, the symptoms settle when they become pregnant or go through menopause – the end of menstrual periods between the ages of 45 and 55. However, if the symptoms become worse, there are other effective treatment options.

Pain relief

Treating the pain is usually the first consideration, however it does not address the underlying symptoms. Over-the-counter painkillers such as paracetamol or anti-inflammatories are most commonly used. Other remedies such as hot water bottles, exercise and relaxation techniques may give temporary relief.

Surgery

Surgery is used to try to restore the function of any damaged organs resulting in a reduction of symptoms and improved fertility. Surgery has a high success rate.¹¹ In the majority of cases, symptoms will improve or disappear after surgery.¹² Surgery is also known to improve the likelihood of becoming pregnant.⁵ Unfortunately symptoms can reoccur after surgery because whatever process caused the endometriosis in the first place is probably still taking place in your body.

The surgical removal of endometrial implants (stray tissue) and adhesions (which stick organs together) can often be carried out at the time of the diagnostic laparoscopy. After identifying the affected areas, the surgeon might then cut away the endometriosis, or use a laser or diathermy (an electric current) to burn off as much of the endometriosis, scar tissue and adhesions as is possible. The surgeon removes cysts of endometriosis in the ovaries, known as chocolate cysts or endometriomas.

Surgery (cont.)

In complex cases a surgeon might need to remove parts of the bowel, bladder or other organs where endometriosis has formed. Most women will be able to go home the same day they have the operation but will generally take between five to seven days to feel better.

For some women a laparoscopy is not suitable, so a **laparotomy** might be recommended. This is an operation requiring a larger cut in the skin and a longer hospital stay is required.

In some cases, a **hysterectomy** might be recommended. This is a major operation removing the uterus and other endometriosis tissue and possibly one or both ovaries and fallopian tubes. Removal of the ovaries leads to early menopause. If they are not removed the continuing production of the hormones by the ovaries might stimulate the production of more endometriosis.

Hormonal therapy

Hormonal therapy might be recommended to treat symptoms and prevent the spread of endometrial cells. It may be used on its own or in conjunction with surgery.

Each month, the hormone **oestrogen** causes a woman's uterine lining to thicken in preparation for possible pregnancy. During menstruation, the hormone **progesterone** causes the plump uterine lining to shed. The misplaced endometrial cells in other areas of the body also respond to oestrogen and progesterone. Hormone therapy using medications that contain a combination of the hormones oestrogen and progesterone is generally used to suppress menstruation and stop the endometriosis cells spreading. If menstruation is stopped, the endometriosis cannot bleed and cause irritation, thereby reducing the symptoms. Also, without the normal cycle of hormones the unwanted tissue cannot grow and starts to shrink.

The contraceptive pill

The oral contraceptive pill is the most common long-term treatment and is used to suppress menstruation, stop mild endometriosis progressing and to address pain. The combined oral contraceptive pill contains a combination of the hormones oestrogen and progesterone. Oral contraceptives may be useful for women with milder symptoms, particularly adolescents and



women who do not wish to take the other medications available. In the treatment of endometriosis, oral contraceptives are sometimes given continuously for several months (skipping the sugar pills) to delay menstruation. Oral contraceptives are also frequently given following surgery to lower the risk of recurrence. This is an option only suitable for patients who do not want to conceive.

Progestins

Progestins (also known as **progestogens**) is the name given to the synthetically produced (in the lab) form of the naturally occurring hormone **progesterone**. They act as anti-oestrogens, inhibiting the growth of endometrial implants. Side effects may include weight gain, fluid retention, nausea, breakthrough bleeding, depression and fatigue.

It is not known exactly how these progesterone-like hormones work to relieve the symptoms. However they are thought to suppress the growth of the unwanted tissue, causing it to gradually shrink and disappear. There are generally fewer side effects with this treatment compared with others.

Danazol

Danazol (Azol®) is a synthetic hormone which is derived from the male hormone testosterone. It works to reduce oestrogen production, halt ovulation and stop bleeding from the endometriosis cells. This leads to a change in the tissue, causing it to reduce in size. However, as it is a mild male hormone, it can cause masculine side-effects such as increased muscle bulk, deepening of the voice, unwanted hair growth and enlarging of the clitoris. Because of the potential for side effects it is not commonly used.

Gestrinone

Gestrinone (Dimetriose®) is another hormonal steroidal tablet used to treat endometriosis. Gestrinone only needs to be taken two or three times weekly.

Gonadotrophin-releasing hormone agonists (GnRH)

These work to suppress ovulation and production of oestrogen by the ovaries. Low levels of the female hormones mean that the endometriosis tissue doesn't grow, so it breaks down. These include Zoladex® 3.6 mg Implant (placed under the skin of your stomach), and Synarel® (nasal spray). The possible side-effects with this treatment are similar to menopausal symptoms, e.g. hot flushes, loss of libido, dry vagina.

Natural therapies

Alternative therapies, such as acupuncture, yoga, massage, chiropractic and relaxation exercises (e.g. deep breathing, meditation, visual imagery, progressive relaxation) may be of assistance in easing your stress or some of your symptoms such as period pain.

Complementary (herbal) medications and vitamins, e.g. vitex agnus castus (chasteberry), vitamin E, zinc and magnesium tablets, may help to ease period pain, however always check with your doctor before taking these as they may interfere with the action of your prescribed medication.



Lifestyle changes

Living with a chronic condition is not easy, but by making a few lifestyle changes you can help relieve some of the symptoms of endometriosis. Studies have shown that aerobic exercise five hours a week can reduce reoccurrence of symptoms.⁴ Rest, relaxation, a healthy diet and exercise in general can improve your sense of well-being and help you maintain a positive attitude.

IMPROVING FERTILITY

As endometriosis can affect the function of the reproductive system due to adhesions, cysts and scarring, assisted reproductive technologies (ART) may help those having trouble becoming pregnant. Assisted reproductive technology is a general term referring to methods used to unite sperm and eggs by artificial or partially artificial means. The most common ART procedure for those with endometriosis is **in vitro fertilisation (IVF)**.

In a natural pregnancy, fertilisation takes place in the fallopian tube but for those with damaged tubes due to endometriosis, IVF is able to place the fertilised egg directly into the uterus.

IVF is generally used following surgery, with the optimal period for falling pregnant being between six months to one year after surgery. As the symptoms may return, there is unfortunately a limited window in which to conceive or to consider more surgery. Depending on the severity of the disease and a woman's age, some choose to bypass surgery altogether and immediately opt for IVF.

Women who have lost one or part of both ovaries, or with significant endometriosis in both ovaries which has destroyed ovarian tissue, have a lower chance of success on IVF.²



IVF AND ENDOMETRIOSIS

As part of the IVF procedure, medications are used to promote the growth of eggs. Having a greater number of mature eggs available for fertilisation increases the chances of pregnancy. However, please be aware that this also increases the oestrogen levels significantly and may stimulate the growth of endometriosis more than natural ovulation would. However a resulting pregnancy will slow or stop the growth of endometriosis.

For more detailed information on female infertility and IVF, ask your doctor for a copy of the *Pathways to Parenthood* booklet specifically on those topics.

COPING EMOTIONALLY

It is understandable that living with a chronic (ongoing) illness like endometriosis can take an emotional toll on you and your friends and family members. You may feel less 'in control' of your life as endometriosis can disrupt your days in many ways such as forcing you to take time off work, miss social activities or interfering with your ability to care for your children and partner.

As well as the physical discomfort you might be experiencing some of the following:

- fatigue
- stress
- anxiety
- depression
- a lack of self esteem
- a poor body image
- loss of libido
- inadequacy over infertility
- anger and frustration.

It's only natural that ongoing pain and symptoms can get you down from time to time. But it is important to keep a positive frame of mind to manage the condition, particularly if you are trying to become pregnant.

If at any stage you feel you are not coping, talk to a close relative, friend or your doctor and seek help from a counsellor or psychologist. There are also support groups and online support available through the organisations listed in the back of this booklet.

The following coping methods may also be helpful:

- Find out as much information about endometriosis as you can so you are in a better position to make decisions on your management and treatment options.
- When you are feeling well, take time out for you and do some of the things you enjoy doing.
- Simplify your life. Prioritise the tasks you need to do and set aside time when you are feeling well enough to do these. Think about what tasks or responsibilities may not be necessary or ask someone else to give you a hand.

SUPPORT ORGANISATIONS

AUSTRALIA

AccessAustralia

www.access.org.au

Ph: (02) 9737 0158; Email: info@access.org.au

AccessAustralia is a national organisation, which provides numerous services and resources for people having difficulty conceiving. Its services include:

- fact sheets, newsletters and personal stories
- putting you in contact by phone or email with others sharing a similar infertility experience
- a register of infertility self-help groups
- listing of infertility clinics accredited by the Reproductive Technology Accreditation Committee (RTAC)
- listing of professional infertility counsellors across Australia.

Endometriosis Association (Qld)

www.qendo.org.au

Ph: (07) 3321 4408; Email: info@qendo.org.au

This association provides information and news relating to the latest research and treatments for endometriosis.

Endometriosis Care Centre of Australia

www.ecca.com.au

Formed by a group of health specialists, this organisation provides patient information and a state by state 'find a specialist' search engine on its website.

The Jean Hailes Foundation of Women's Health

www.endometriosis.org.au

Ph: 1800 151 441;

Email: education@jeanhailes.org.au

The Jean Hailes Foundation for Women's Health provides a wealth of information on all aspects of endometriosis, latest research information and also has a section dedicated to the personal stories of those with the condition.

NEW ZEALAND

Endometriosis New Zealand

www.nzendo.co.nz/

Ph: 0800 733 277 (free phone support line);

Email: nzendo@xtra.co.nz

Endometriosis New Zealand provides disease information specifically designed for teenagers, a support group network, regular seminars and workshops and a free phone support line.

FertilityNZ

www.fertilitynz.org.nz

Ph: 0800 333 306;

Email: support@fertilitynz.org.nz

FertilityNZ is New Zealand's national network for those seeking support, information and news on fertility problems. It provides various services including:

- comprehensive information brochures
- a forum for confidential feedback on any issues or concerns
- a chatroom where you can seek on-line support from people in similar situations.

References

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Looking for more information?

Ask your doctor for a copy of the other booklets in the *Pathways to Parenthood* informational series.

- Overcoming male infertility
- Female infertility & assisted reproductive technology (ART)
- Your step by step guide to treating infertility
- Polycystic ovary syndrome (PCOS)
- Ovulation induction (OI)
- Intrauterine insemination (IUI)
- *In vitro* fertilisation (IVF) & intra-cytoplasmic sperm injection (ICSI)
- Managing the stress of infertility