

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 Access Australia – a national patient advocacy 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 conception in order to help others experiencing a similar journey. Merck Healthcare 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.

Merck Healthcare acknowledges the contribution of Professor Luk Rombauts in the preparation of this booklet.

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. Your doctor will determine the best treatment options and course of action for you based on your requirements and circumstances.

Prescription medicines have benefits and risks. Use all prescribed medicines strictly as directed by your doctor and raise any questions or concerns with them before, during or after using them. If you experience side effects consult your doctor.

Medication availability and funding criteria may differ between Australia and New Zealand.



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INTRODUCTION

Endometriosis is a common and sometimes painful condition of the reproductive system, which affects up to one in ten 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 generally not life threatening.

There are many ways to help manage 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.

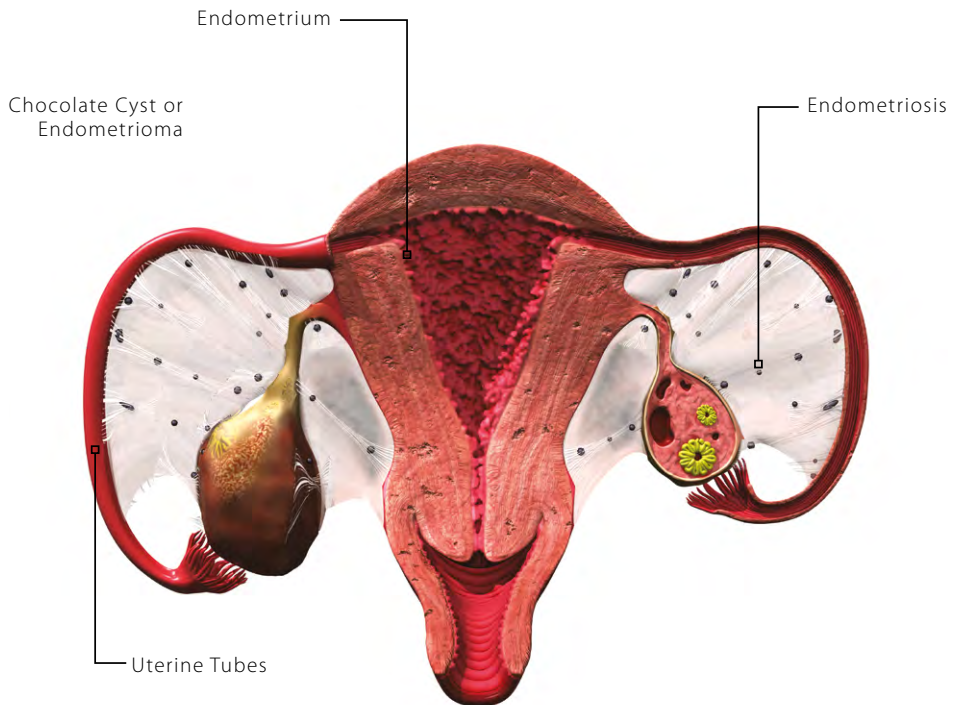
This booklet aims to give you information about endometriosis – what it is, some of the common symptoms, and how it is treated. In the back of the booklet, you will also find some contact details of support organisations, which offer further information and resources, access to self-help groups and online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

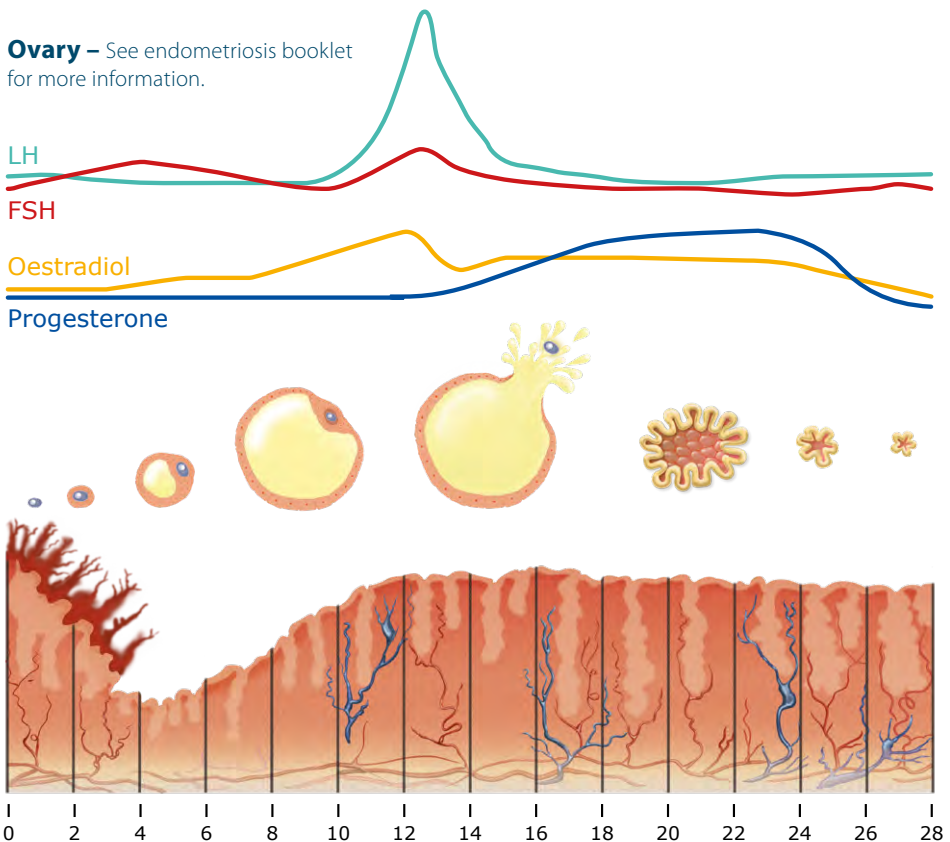
Endometriosis occurs when the tissue that normally lines the inside of the uterus (the endometrium) grows in other places of your body where it doesn't belong, such as on the ovaries, uterine tubes, outside surface of the uterus, bowel, bladder and rectum.² This stray endometrial tissue is often referred to as endometrial implants. Because this tissue still acts in a similar way to that found in your uterus and responds to changes in your hormones during your menstrual period (see explanation next page), the tissue can break down and 'bleed' into the surrounding area causing pain and inflammation before and after your period, potentially leading to scarring and adhesions (organs sticking together).



ENDOMETRIOSIS AND YOUR MENSTRUAL CYCLE

The menstrual cycle refers to the maturation and release of an egg each month, and to the preparation of the uterus (womb) to receive and nurture an embryo, once fertilised. A typical cycle takes approximately 28 to 32 days, but there is considerable variation from woman to woman. Your menstrual cycle is regulated by hormones. The pituitary gland at 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 uterus for pregnancy by thickening its endometrium (lining).

Ovary – See endometriosis booklet for more information.

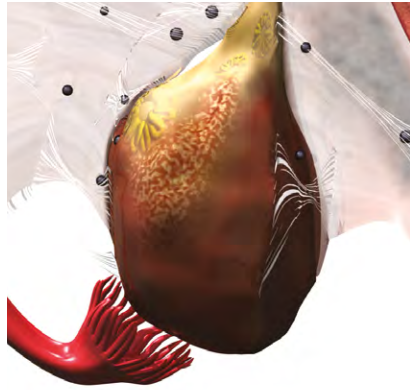


Endometrium – See endometriosis booklet for more information.

When you have endometriosis, the stray tissue in other parts of your body also responds to hormones in a similar way to the lining of the uterus, thickening as it prepares for pregnancy. When pregnancy does not occur, the uterus and the stray endometriosis tissue shed their fluids or 'bleed' causing your period. Because the fluids from the endometriosis are unable to pass out of the body in the usual way, they leak instead 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 retained blood within the ovary develops a sludgy-brown 'chocolatey' appearance. Refer to the image on page 5 for more information.



WHO GETS ENDOMETRIOSIS?²

Any woman, from teenagers through to those aged in their 40s, is 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.

WHAT CAUSES IT?⁵

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 uterine 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 onto other organs and start growing and multiplying.

However, this is only part of the picture. The majority of women have retrograde menstruation, but only 10% of women develop endometriosis.⁵ This is believed to be because most women have a natural defence against endometrial cells developing elsewhere in the body. The immune system identifies them as 'foreign' and kills them before they attach in the wrong location and become endometriosis.

SYMPTOMS^{2,6}

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 falling pregnant. Endometriosis is usually classified into four stages: minimal, mild, moderate and severe, depending upon the extent of the condition and the degree of associated scarring and adhesions.

Pain^{2,6}

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 endometrial tissue sheds its fluids into the abdominal cavity, resulting in irritation and inflammation of 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 endometriosis spreads by forming new lesions elsewhere.

Bleeding²

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

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

Other symptoms^{2,6}

Other symptoms might include:

- bleeding or discomfort in the bowel or bladder
- irregular bowel activity, including diarrhoea
- bloating
- tiredness
- infertility (see page 11)
- 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.



ENDOMETRIOSIS SEVERITY⁶

Mild forms of endometriosis can cause quite severe pelvic pain, whilst some women with very severe levels of endometriosis and extensive pelvic damage do not experience symptoms. It is important to note that the severity of endometriosis does not always correlate with the symptoms experienced. Speak with your doctor if you suspect you may have endometriosis, even if your symptoms are mild.

WILL I BE ABLE TO TELL IF I HAVE ENDOMETRIOSIS?²

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 methods (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
- a family history of endometriosis
- sharp pains when opening the bowels during your period
- bleeding on the stools at the time of your period
- significant pain/discomfort during sexual intercourse.

IF IT'S NOT ENDOMETRIOSIS, WHAT IS IT?⁷⁻⁹

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^{1,10,11}

Up to 50% of women with infertility problems have endometriosis.¹ 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 their infertility.

Like the condition itself, the reason endometriosis causes infertility is not well understood. In some cases, the uterine tubes are damaged or have scar tissue due to the formation of endometriosis, and this can impede the flow of the egg from the ovaries, through the uterine tubes to the uterus. It also makes it more difficult for the sperm to travel along the uterine tubes to the egg, making fertilisation more difficult.

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 15), while others may conceive naturally and go on to have a healthy and normal pregnancy.

PREGNANCY AND ENDOMETRIOSIS SYMPTOMS¹²

Pregnancy can relieve the symptoms of endometriosis – because you are no longer menstruating – but it is not a cure in itself, and some women experience a worsening of symptoms, particularly during the first trimester.¹²

For many women, the symptoms usually return after giving birth or within a few months to years after childbirth. Most women can delay the return of the symptoms by breastfeeding, as long as the feeding is frequent enough and to suppress the menstrual cycle.¹²

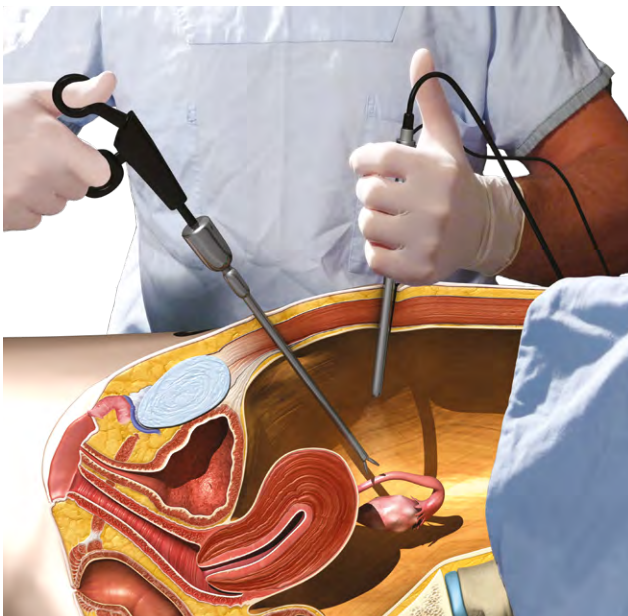
HOW IS IT DIAGNOSED?¹³

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.

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.

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. A gynaecologist with sub-specialist training in ultrasound imaging (look for the abbreviated qualification: COGU), can determine the severity of the endometriosis and where precisely it is located. 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 14 for more information).



TREATING ENDOMETRIOSIS

There are many treatments available for the varied symptoms of endometriosis. Below is a list of some available treatment options for endometriosis. Please ask your doctor for more information to find the most suitable treatment option for you.

‘Wait and see’ approach¹⁴

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 further treatment. If symptoms are left untreated, they might stay the same or even improve. For some women, the symptoms settle when they become pregnant or persist to menopause – the end of menstrual periods between the ages of about 45–55. However, if the symptoms become worse, there are other effective treatment options.

Natural therapies¹⁵

Some women report that alternative therapies, including acupressure, massage, meditation and breathing exercises, yoga, pilates and taichi/qigong, provide them with some level of relief from pain associated with endometriosis. Complementary treatments, such as herbal medications and vitamins may help to ease period pain, however always check with your doctor in case of any interference with your prescribed medication.

Lifestyle changes

Living with a chronic condition is not easy, but making a few lifestyle changes may help relieve some of the symptoms of endometriosis. In general, rest, relaxation, a healthy diet and exercise may improve your sense of well-being and help you maintain a positive attitude. Other remedies such as hot water bottles, exercise and relaxation techniques may give temporary relief from pain associated with endometriosis.



Drug treatment¹³

Medication used to treat endometriosis can alter hormone levels or simply provide pain relief.¹³ The medication chosen in consultation with your doctor will depend on your situation taking into account possible risks, benefits and side effects. These should be discussed with your doctor before commencing your treatment.

Surgery^{2,10,16}

Surgery is sometimes used to remove the endometriosis tissue, restoring the function of other organs and resulting in a reduction of symptoms and improved fertility. Surgery is considered the standard treatment for moderate to severe endometriosis. In the majority of cases, symptoms will improve or disappear after surgery.^{2,16} Surgery is also known to improve the likelihood of becoming pregnant.¹⁰ Surgery is considered a treatment, rather than a cure for endometriosis and there is a chance the disease may return after surgery. This is because the disease process causing your endometriosis may still be taking place in your body.¹⁰

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 may remove cysts of endometriosis in the ovaries, known as chocolate cysts or endometriomas. Most women will be able to go home the same day they have the operation but it will generally take between five to seven days to feel better.¹³ In complex cases a surgeon might need to remove parts of the bowel, bladder or other organs where endometriosis has formed, which may mean that patients need to stay in hospital for longer.

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, involving removal of the uterus, other endometriosis tissue, possibly one or both ovaries and uterine tubes. Because women of reproductive age naturally cycle each month, ovaries may need to be removed to stop the cycling of hormones that can exacerbate endometriosis. Removal of both ovaries results in early menopause.

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. ART 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 uterine tube but for those with damaged tubes due to endometriosis, IVF is able to place the fertilised egg directly into the uterus.

IVF AND ENDOMETRIOSIS¹⁷

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. While this also increases the oestrogen levels significantly and may stimulate the growth of endometriosis more than natural ovulation would, a resulting pregnancy will slow or stop the growth of endometriosis.

For more detailed information on female infertility and IVF, access *Pathways to Parenthood* booklets on these topics at www.fertilityportal.com.au/merck

COPING EMOTIONALLY

It is understandable that living with a chronic (ongoing) illness like endometriosis can take an emotional toll on you, 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
- anger
- frustration.

It's only natural that ongoing pain and symptoms can get you down from time to time. 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, you could try talking 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 that you're informed 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.

Refer to the book *Managing the Stress of Infertility* for more information.

SUPPORT ORGANISATIONS

AUSTRALIA

Access Australia

www.access.org.au

Ph: 1800 888 896;

Email: info@access.org.au

Access Australia is a national patient advocacy 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
- lobbying governments for equal access to affordable, quality assisted conception treatment.

Jean Hailes for Women's Health

www.jeanhailes.org.au

Jean Hailes for Women's Health is a national not-for-profit organisation dedicated to improving the knowledge of women's health throughout the various stages of their lives, and to provide a trusted world-class health service for women.

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.

Endometriosis Australia

www.endometriosisaustralia.org

Email: admin@endoaustralia.org

Provides information on state contacts.

Endometriosis Australia endeavours to increase recognition of endometriosis, provide endometriosis education programs, and help fund endometriosis research. They strive to build strong relationships with existing endometriosis support networks throughout the country.

SAFE

www.safe-endo.com.au

SAFE consists of a team of gynaecologists who specialise in ultrasound. The organisation aims to improve the diagnosis of deep infiltrating endometriosis by transvaginal ultrasonography (TVUS), through education and workshops. They also provide information on where expert ultrasound assessments for endometriosis are currently available.

European Society of Human Reproduction and Embryology (ESHRE)

www.eshre.eu/guidelines-and-legal/guidelines/endometriosis-guideline.aspx

A patient version of the ESHRE guideline on management of women with endometriosis. It is designed to help women with endometriosis learn more about the current standards of care, and make informed decisions about their health, supported by the best available evidence.

SUPPORT ORGANISATIONS

NEW ZEALAND

Fertility NZ

www.fertilitynz.org.nz

Ph: 0800 333 306;

Email: support@fertilitynz.org.nz

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

- regional support and contact groups
- general advice and contact service
- comprehensive information brochures
- a forum for confidential feedback on any issues or concerns
- a chatroom where you can seek online support from people in similar situations.

Endometriosis New Zealand

www.nzendo.org.nz

Ph: +64 3 379 7959 (phone support line);

Email: info@nzendo.org.nz

Endometriosis New Zealand promotes awareness of endometriosis, provides information, education and raises funds to support endometriosis related initiatives. It includes disease information specifically designed for teenagers, a support group network, regular seminars and workshops and a free phone support line.

SANDS New Zealand

www.sands.org.nz

Ph: 027 44 91 019;

Email: info@sands.org.nz

Sands New Zealand is a network of volunteer-run, non-profit groups providing awareness, understanding and support for families dealing with the loss of a baby during pregnancy, birth, or as a newborn, and due to medical termination and other forms of reproductive loss. Sands has over 25 groups throughout New Zealand and offers the opportunity to talk, listen and share experiences.

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Looking for more information?

Other booklets in the *Pathways to Parenthood* series are available at www.fertilityportal.com.au/merck:

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