

# Understanding Endometriosis

## information for women

### Understanding Endometriosis

#### 1. What is endometriosis?

Endometriosis occurs when endometrial tissue, which usually grows in the uterus (womb), is found in other parts of the body, for example the ovaries, fallopian tubes and pelvis. Cysts can form and grow with

each period. As a result of the endometriosis, scar tissue can also form. When this process occurs within the wall of the uterus it is called adenomyosis.

## **2. What is endometrial tissue?**

Endometrial tissue is the lining of the uterus, which is responsible for menstruation. This tissue grows and swells each month in response to cyclic changes to hormone levels. If pregnancy does not take place the tissue breaks down and is shed, along with some blood, during menstruation (your monthly period). In some women retrograde bleeding occurs. This is when the endometrial tissue and blood passes back through the fallopian tubes, past the ovaries and into the abdominal cavity.

## **3. So how is this a problem in endometriosis?**

If there are endometrial cells outside the uterus they are still influenced by the normal cyclic changes. In the growth phase they can irritate the surrounding tissue causing pain. At the time of menstruation these endometrial cells cannot escape through the vagina like the endometrial tissue within the uterus, so they break down and bleed into surrounding organs, such as the bowel, bladder and ovaries. This can cause inflammation and scar tissue.

When endometrial cells grow into the ovary, they may form cysts containing old blood and cells.. These are called chocolate cysts. These can also rupture, spilling their contents, causing more inflammation and scar tissue.

## **4. How serious is endometriosis?**

Some women with endometriosis do not suffer any symptoms. Others experience severe pain and discomfort, especially prior to and during menstruation. The condition is not life threatening, but it can make life miserable, and can also cause infertility.

## **5. Who gets endometriosis?**

Endometriosis is usually diagnosed in women between the ages of 20 and 50 however teenagers can present with endometriosis symptoms. It is found 10 –15% of menstruating women. It seldom occurs before menstruation starts, or after menopause.

## **6. What are the symptoms of endometriosis?**

The common symptoms of endometriosis include pain such as dysmenorrhoea (painful periods), dyspareunia (painful intercourse), lower abdominal pain, lower back pain, bowel and ovulation pain and pain passing bowel motions. The pain often occurs when you are having your period, but some women also have pain at other times, especially prior to menstruation. Heavy periods and bleeding from the bowel during a period may be associated with endometriosis.

## **7. How is it diagnosed and treated?**

The symptoms of endometriosis are similar to other conditions such as pelvic infection and ovarian cysts, often making it difficult to diagnosis endometriosis in the early stages. Only a gynaecologist can reliably diagnose endometriosis by performing an operation known as a laparoscopy. This operation is conducted under general anaesthetic. A tube with a telescope device known as a laproscope lets the gynaecologist see

which organs in the pelvis are affected by endometriosis. The endometrial implants are usually seen as either small black lumps or red flame like areas.

Although some women may find self-help or complementary therapies helpful, the two main treatment options used are surgical and medical.

## **8. What are the Surgical options available?**

The surgical treatment options can be divided up into two categories.

### ***8.1 Conservative Surgery***

This type of surgery is used to reduce symptoms and improve the chances of fertility. Endometrial implants, scar tissue, and adhesions can be removed or released by heat or laser at the time of the laparoscopy or during an abdominal operation. (laparotomy). This type of surgery can be proceeded with hormone therapy to shrink the endometrial tissue prior to surgery. You may also receive hormone therapy after surgery to help prevent the recurrence of endometriosis. Neither the uterus nor the ovaries are usually removed with this surgery.

### ***8.2 Radical Surgery***

In this operation a hysterectomy (removal of the uterus) may be performed particularly if fertility is no longer required. In addition removal of the ovaries may be recommended as the endometriosis may return after a hysterectomy alone. After removal of the ovaries, endometriosis usually subsides. This is because the cyclic hormonal changes no longer occur so the endometrial tissue usually becomes inactive.

Removing both ovaries also means you may experience menopause symptoms such as hot flushes. You may therefore be recommended to take oestrogen tablets. This is a decision to made in discussion with your specialist

## **9. What medical treatment is available?**

The aim of hormone therapies (apart from the oral contraceptive pill) is to prevent both ovulation and menstruation (periods). This means the endometriosis is no longer stimulated by oestrogen. Shrinkage and healing of the endometrial deposits should result. If there is no vaginal bleeding then it is unlikely that endometriosis is developing. There are a number of medical treatment options available, but all hormonal and may cause side effects. After discussion with your doctor you can decide which therapy suits you best.

### ***9.1 Combined Oral Contraception Pill***

In many women the pill is effective in reducing pain during periods. This treatment suppresses ovulation and results in lighter menstrual periods, consequently the growth of endometrial implants will be less. The dose is one tablet every day for three weeks, a break of seven days (monthly periods) then recommence the pill again, or every day for three months followed by a break of 7 days (3 monthly periods) before recommencing the pill again.

Side effects of the oral contraceptive pill include weight gain, irritability, headaches, sore breasts, loss of libido and nausea.

## **9.2 Progestogens**

Synthetic steroid progesterone is similar to naturally occurring progesterone. It can be given in a daily oral tablet or as an intramuscular injection (Medroxyprogesterone acetate or Depo Provera every two or three months) to stop periods. No contra-ception is necessary with the injection, but is recommended to prevent pregnancy when women take the progesterone tablets.

Side effects that can occur with progesterone include weight gain, bloating, and irregular bleeding. While on treatment your periods should stop. Prolonged use (more than 12 months) is associated with a small loss of bone mineral density.

## **9.3 Levonorgestrel intrauterine system (Mirena)**

This is a progesterone containing intrauterine device that can be inserted at the time of surgery and Has been shown to reduce recurrence of pain associated with endometriosis. It lasts for five years. It needs to be removed if you wish to become pregnant.

Side effects include, light bleeding and spotting for the first three months. Some women have no periods. It does not make you gain weight, develop acne or increase hair growth.

## **9.4 Gestrinone**

Gestrinone is a synthetic hormone, which prevents the cyclic hormonal changes in the body, thus preventing growth of the endometrial implants. Treatment eventually leads to atrophy (shrivelling up) of endometrial tissue. The usual dose is one capsule twice a week, the first dose on Day 1 of your period and the second.

capsule 3 days later. From then on you should take the capsule on the same two days. If you miss a dose, take the capsule as soon as you remember and carry on with your twice-weekly schedule. Should you miss two or more doses, stop treatment and inform your doctor as soon as possible. It is recommended that barrier contraception be used during this treatment.

With gestrinone therapy a small increase in male hormones occurs which sometimes results in acne, hirutism (increase in facial hair) and oily skin. Appetite changes, headaches and nervousness are also reported. Your period will cease in the first six weeks of therapy, although you may experience some spotting or light bleeding. This does not mean the medication is not working.

## **9.5 Danazol**

Danazol is a synthetic steroid, which causes atrophy of the endometrial tissue. It can also cause an increase in male hormones. Danazol tablets are usually taken three times recommended barrier contraception be used during therapy to prevent pregnancy.

## **9.6 GnRH Analogues**

GnRH is an abbreviation for ‘Gonadotrophin releasing Hormone’. There are currently a number of these preparations available in New Zealand. They work by switching off the release of hormones from the pituitary gland thereby preventing the production of oestrogen in the ovaries. As a result oestrogen levels

fall to similar to menopause. When endometrial tissue is no longer being supplied with the hormones it needs to assist growth, it shrivels up and atrophies.

The GnRH analogues cannot be taken by mouth, so are given by monthly injections or via a daily nasal spray for a maximum of six months. It is recommended barrier contraception be used to avoid pregnancy during therapy.

The side effects are similar to those experienced at the time of menopause – bone loss, hot flushes, vaginal dryness, reduced breast size, mood swings, and decreased libido.

Taking oestrogen and progesterone while on GnRH analogues can reverse these. While on treatment your periods will stop.

## **9.7 Staying Healthy**

Eating in a healthy manner is helpful. Sometimes an appointment with a dietician/nutritionist can also be helpful. Caffeine can cause insomnia (sleeplessness) nervousness, anxiety and irritability. Decreasing caffeine can also help breast tenderness. You can do this by limiting your intake of the following :

- Tea ( try herbal tea instead)
- Chocolate
- Other caffeinated drinks such as Coca-Cola
- Milo
- Coffee (try decaffeinated)

Keep your blood sugar levels even.

- Eat small frequent meals i.e. every 2-3 hrs
- Eat complex carbohydrates, i.e., pasta or spaghetti, rice, cereal, whole grain breads
- Minimise chocolate and sweets, as these cause uneven blood sugar levels.

You can also improve your health by:

- Reducing salt intake. Don't use salt in cooking and allow the rest of the family to add salt at the table.
- Decrease cigarettes/alcohol intake
- Increase fluid intake ( drinks other than alcohol)

### **9.7.2 Exercise**

Exercise, which does not cause added pain can improve your overall well being and help minimise weight gain. If you have not undertaken exercise for some time you may want to check with your doctor first.

Suitable exercise includes

- Gentle jogging
- Fitness walking
- Cycling
- Swimming for 30 minutes, four times a week

### **9.67.3 Stress management**

Learning to minimise the effects of stress in your life will help you cope with the symptoms of endometriosis. You could try:

- Massage
- Counselling
- Meditation
- Warm baths
- Support group meetings

If you follow these guidelines for a healthy lifestyle and take the treatment your doctor has prescribed you should notice a marked improvement in your condition with a few weeks. If you have any other questions your doctor will be happy to help.

## **10. Further Information**

For further information and support you can contact the:

**NZ Endometriosis Foundation.**

PO Box 1673, mail centre Christchurch Ph 03 379 7959

Email: [nzendo@xtra.co.nz](mailto:nzendo@xtra.co.nz)

Website [www.nzendo.co.nz](http://www.nzendo.co.nz)

### **Women's Health Information Unit**

A range of health information is available from the Women's Health Information Unit on level 9 National Women's at Auckland hospital Mon-Fri 9am-4pm (ph 307 4949 ext 25678 or [HIWS@adhb.govt.nz](mailto:HIWS@adhb.govt.nz)). In addition to written information the Unit provides access to electronic research databases and the internet.

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