

Patient Decision Aid for women considering treatment options for heavy menstrual bleeding

What this Patient Decision Aid is for

This Patient Decision Aid is intended to help patients and health professionals in discussions about treatment options for heavy menstrual bleeding, particularly when an operation is being considered.

This Patient Decision Aid is not suitable for use with women with underlying conditions such as endometriosis (in which cells like the ones lining the womb are found outside the womb) or significant uterine fibroids (benign, non-cancerous growths of muscle in the womb).

The Patient Decision Aid may be used in the consultation between GP and patient and can be taken away by the patient to be re-read and discussed with friends or family.

Links to further information on heavy menstrual bleeding and the options for treatment are given at the end of this leaflet.

What is heavy menstrual bleeding?

Heavy menstrual bleeding can be defined as *excessive menstrual blood loss which interferes with a woman's physical, social, emotional and/or material quality of life*. Heavy menstrual bleeding is sometimes called 'menorrhagia'.

Although heavy menstrual bleeding rarely causes severe problems with physical health, it can seriously affect a woman's quality of life and so it is a significant problem.

What are my treatment options?

There are several treatment options available to women with heavy menstrual bleeding. These include pharmaceutical treatments to reduce bleeding such as the Mirena® coil, tablets including oral contraceptives and injections, and operations such as hysterectomy.

The National Institute for Health and Clinical Excellence (NICE) has looked at the available scientific research and issued guidance on which options should be considered. NICE recommends that treatments are considered in the following order:

- Step 1 – Pharmaceutical treatments
- Step 2 – Further pharmaceutical treatments
- Step 3 – Surgical procedures

NHS Oxfordshire follows the NICE recommendations which are summarised below.

Pathway for treating heavy menstrual bleeding

- The information below is from the NICE Guidance on Heavy Menstrual Bleeding (CG44) unless stated otherwise
- NICE advises that the 'common' **unwanted effects** mentioned below may be experienced by **1 in 100** women

STEP 1 – Pharmaceutical treatments

It is recommended that women consider the following options in the following order:

- 1 – The Mirena coil
- 2 – Tablets to reduce bleeding
- 3 – Injected long-acting progestogen *or* oral progestogen.

These treatments are described below.

1 - The Mirena® coil

What is it?

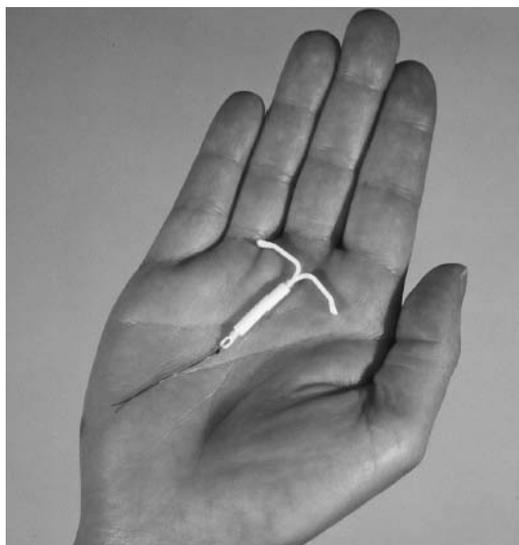
A small plastic device that is placed in the womb and slowly releases the hormone progestogen. It is inserted by a doctor or nurse at your GP surgery or clinic and lasts up to 5 years. This Mirena® coil is different to traditional copper coils (or IUDs) which are contraceptives but do not reduce bleeding.

Benefits

Women report up to 95% less bleeding and many women will have no periods at all after a few months. The Mirena® coil is also a contraceptive. In a summary of the available scientific research it was found that women are more satisfied with the Mirena® coil and far more likely to continue with treatment than with any other drug treatment.

Unwanted effects

Irregular bleeding can occur for up to six months (sometimes longer). Other common effects can include: breast tenderness, acne and minor headaches.



The Mirena® coil (picture from www.glowm.com)

2 - Tablets to reduce bleeding

- ***Tranexamic acid***

What is it?

Tablets taken from the start of your period for up to 4 days. They work by helping the blood in your womb to form clots, which reduces the amount of bleeding.

Benefits

Women report up to 60% less bleeding.

Unwanted effects

Side effects of these tablets are not common. Less common effects (experienced by 1 in 1000 women) include indigestion, diarrhoea and headache.

- ***Non-steroidal Anti Inflammatory Drugs (NSAIDs)***

What is it?

Tablets taken from the start of your period until heavy blood loss has stopped. They work by reducing the body's production of prostaglandin (a hormone-like substance linked to heavy periods).

Benefits

Women report up to 50% less bleeding. NSAIDs are also painkillers so reduce period pains.

Unwanted effects

Common side effects are indigestion and diarrhoea. Less common effects are stomach ulcers and bleeding in the stomach.

- ***Combined oral contraceptives ('the pill')***

What is it?

Tablets containing the hormones oestrogen and progestogen. You take one pill daily for 21 days, then stop for 7 days, then repeat this cycle. The pill stops the lining of the womb from growing quickly thus reduces blood loss during a period.

Benefits

Women report up to 40% less bleeding. It is also a contraceptive and regulates your menstrual cycle, reducing menstrual pain.

Unwanted effects

Common side effects are mood change, headache, fluid retention and breast tenderness.

3 - Injected long-acting progestogen or oral progestogen

What is it?

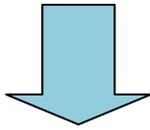
Injections given every 2-3 months or tablets taken from day 5 to day 26 of your menstrual cycle. They stop the lining of the womb from growing quickly, reducing blood loss during a period.

Benefits

Women report up to 80% less bleeding and most women will have no periods at all with the injections. They are also a contraceptive.

Unwanted effects

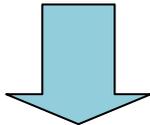
Common side effects are weight gain, irregular bleeding and premenstrual symptoms including bloating, fluid retention and breast tenderness. There can be a 6-12 month delay in being able to become pregnant after stopping the injection.



STEP 2 - Further pharmaceutical treatments

Because there are so many effective drug treatments available, experts recommend that at least 2 of the above options should be tried before other options are considered. If the first option doesn't work for you, consider the next option.

Combinations of treatments work well for some women. Also many of the treatments described above come in different versions, some may suit you more than others. These should be discussed with your GP.



STEP 3 – Surgical procedures

If you still have problems with heavy menstrual bleeding after following steps 1 & 2, having an operation may help.

There are 2 types of operation: *endometrial ablation/resection* and *hysterectomy*. These are described below.

After considering all the available scientific research, NICE advises that endometrial ablation/resection should generally be considered preferable to hysterectomy.

• **Endometrial ablation/resection**

What is it?

A procedure to remove or destroy the inner lining of the womb (the endometrium), and thus stop or reduce bleeding. In ablation, a device is inserted into the womb through the vagina and cervix (neck of the womb). The device is heated using different methods (for example, using microwave energy) and this heat destroys the lining of the womb. In resection, a cutting device is inserted into the womb and the lining is removed. Endometrial ablation and resection are performed under a general anaesthetic; most women go home the same day as the procedure.

Benefits

Bleeding is reduced and up to 4 in 10 women will have no bleeding at all.

Unwanted effects

Common side effects are vaginal discharge, increased period pain or cramping. In some women the lining grows back and the surgery may need to be repeated. A less common side effect is infection of the lining of the womb. A rare side effect, experienced by 1 in 10,000 women, is perforation of the womb (a hole made in the wall of the womb).

Pregnancy after endometrial ablation is unlikely but can occur and would be potentially dangerous because the lining of the womb has been removed. It is therefore important that women use contraception after this procedure.

• **Hysterectomy**

What is it?

Hysterectomy is an operation to remove the uterus (womb). There are several ways this can be done; commonly the womb is removed by laparoscopic ('keyhole') surgery, involving four small cuts on the abdomen.

Hysterectomy is considered a relatively safe but major operation. It is performed under a general anaesthetic. Women stay in hospital for up to 4 days after the operation, will require pain relief for the first few days, need extra help at home for 2 weeks and are advised not to drive for 6 weeks. Sex should be avoided for 6 weeks after the operation.

Am I eligible?

NICE have considered the research on the risks and benefits of different treatments for heavy menstrual bleeding. They found that the Mirena coil improves the quality of life of women with heavy menstrual bleeding as much as surgical procedures do. They also found that, although all treatments for heavy menstrual bleeding have potential unwanted effects, hysterectomy is more likely to cause serious complications.

Because of these findings, NHS Oxfordshire only supports hysterectomy for heavy menstrual bleeding when women have first tried other treatment options *AND* have had a full discussion with their GP about their wishes and expectations, the potential side effects of the operation and the other treatments available.

Benefits

You will no longer have periods after a hysterectomy.

You will no longer be able to become pregnant.

Unwanted effects

A common complication of hysterectomy is infection (1 in 6 women). This can be in the wound, bladder, lung or rarely inside the pelvis.

Other complications are:

- Excessive bleeding during or after the operation requiring a blood transfusion (1 in 30 women)
- Damage to other organs (1 in 60 women)
- Deep vein thrombosis (DVT): a clot in a leg vein that can move to the lungs (1 in 200 women).
- Urinary problems such as frequent passing of urine and incontinence.
- Menopause: if the ovaries are removed during the operation this will bring on the menopause which can cause problems such as hot flushes, mood swings and vaginal dryness. In some cases the menopause is brought on even if the ovaries are not removed.
- Adhesions (scar tissue) forming in the pelvis causing pain.

Other points to consider

The womb and fertility are often seen as part of a woman's identity and many women feel a sense of loss or sadness after hysterectomy.

Many women experience an initial loss of sexual desire (libido) after a hysterectomy, but this normally returns once they have fully recovered. Research shows that, although each woman's experience is different, orgasm, libido and sexual activity generally improve after a hysterectomy.

What Matters to You?

When it comes to treatment for heavy menstrual bleeding and hysterectomy, your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to have surgery

Reasons not to have surgery

<p>I tried several other treatments, but my periods are still heavy.</p>	<p>I can live with the symptoms while I give other treatments some more time to work.</p>
<input style="width: 100px; height: 20px;" type="text"/>	<input style="width: 100px; height: 20px;" type="text"/>
More important	More important

<p>I don't mind having surgery if it can get rid of my symptoms.</p>	<p>I just don't want to have surgery.</p>
<input style="width: 100px; height: 20px;" type="text"/>	<input style="width: 100px; height: 20px;" type="text"/>
More important	More important

<p>I'm not worried about the chance of problems from surgery.</p>	<p>I don't want to take even a small chance of something going wrong with surgery.</p>
<input style="width: 100px; height: 20px;" type="text"/>	<input style="width: 100px; height: 20px;" type="text"/>
More important	More important

<p>I want to keep the option of having another child in the future.</p>	<p>I do not need the option of having another child in the future.</p>
<input style="width: 100px; height: 20px;" type="text"/>	<input style="width: 100px; height: 20px;" type="text"/>
More important	More important

My other important reasons:

My other important reasons:

<input style="width: 100px; height: 20px;" type="text"/>	<input style="width: 100px; height: 20px;" type="text"/>
More important	More important

How do you feel now?

Now that you've thought about the facts and your feelings, you may have a general idea of where you stand on this decision. Show how you feel about the options right now:

1. I feel I understand my options

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Strongly agree Strongly disagree

2. I would like some more information on my options

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Strongly agree Strongly disagree

3. I am ready to make a decision about the treatment that is best for me

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Strongly agree Strongly disagree

Further information

If you would like further information on heavy menstrual bleeding and your choices for treatment:

1. See the NICE patient leaflet at:
<http://guidance.nice.org.uk/CG44/PublicInfo/pdf/English>
2. Search under 'heavy periods' on the following websites:
NHS Choices website: <http://www.nhs.uk/Pages/HomePage.aspx>
NHS Clinical Knowledge Summary website: <http://www.cks.nhs.uk/home>
Patient UK website: <http://www.patient.co.uk/>
3. To hear about other women's experiences search under 'heavy periods' on Oxford's DIPEX website: <http://www.healthtalkonline.org>.