NICE National Institute for Health and Care Excellence

Patient decision aid

Hormone treatment for endometriosis symptoms – what are my options?

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About this decision aid

This decision aid can help you decide about hormone treatment to try to control your endometriosis symptoms. Your decision depends on several things that this information will help to explain. Different women will feel that some of these things are more important to them than others, so it is important that you make a decision that is right for you. **This decision aid is designed for you to work through with your healthcare professional**. You might also find it helpful if you want to talk things over with your family or friends.

Why hormone treatment and what does it involve?

The lining of the womb contains cells that respond to the hormones of the menstrual cycle and produce regular bleeding, resulting in a period. In women with endometriosis, similar cells exist inside the abdomen (and rarely in other parts of the body), and these also bleed during a period. This bleeding creates inflammation, scarring and may cause organs and tissues to stick together – these effects cause pain. The aim of hormone treatment is to reduce or stop this bleeding so that these effects are reduced or do not happen.

Most women with endometriosis are asked to think about hormonal contraceptives as the first kind of hormone treatment to try. These control the menstrual cycle so, although they are

commonly used for contraception, they are also used to treat endometriosis. The combined pill (which contains the female hormones oestrogen and progestogen), the progestogen-only pill (also known as the POP or mini-pill) and long-acting reversible contraception (LARC) are all used[a]. There are several different types of LARC including:

- An intrauterine system (IUS): a small plastic device that is fitted inside your womb and releases progestogen. It lasts up to 5 years.
- Progestogen injections, which are given into the muscle of your bottom every 12 weeks.
- A progestogen implant placed under the skin of your arm. It lasts up to 3 years.

Other kinds of hormonal contraceptive are sometimes used.

What is my choice?

This decision aid covers hormonal contraceptives because they are the first kind of treatment for endometriosis symptoms most women are asked to think about trying, in addition to pain-killers. You do not have to try hormone treatment. If treatment with hormonal contraceptives doesn't work or they are not suitable (for example, because of side-effects), you can be offered other types of hormone treatment, with or without surgery.

You can continue to take painkillers while having hormone treatment. It is important to discuss your painkillers with your healthcare professional to make sure you are making the best possible use of these.

There are differences between hormonal contraceptives, and some might suit you better than others. There are pros and cons, and the key points to think about are as follows:

- Most women find their endometriosis symptoms improve with hormonal contraceptives, and many women get considerable relief of symptoms. However, it is not possible to say what will happen to any individual woman or which kind of hormonal contraceptive is likely to work best for you.

[a]Hormone treatment with hormonal contraceptives is recommended by NICE as an option to try to control endometriosis symptoms, based on NICE's assessment of the scientific evidence. However, the manufacturers have not applied for licences to cover their use for this purpose, so this would be an 'off-label' use. There is more information about licensing of medicines on NHS Choices.

- If you decide to try hormonal contraceptive treatment, you will need to give the kind you choose time to work (usually 3–6 months), but if it doesn't suit you or you don't feel it is helping you can try a different kind if you wish. You can stop treatment at any time.
- If you decide to try hormonal contraceptive treatment, you need to think about whether you would prefer a tablet, IUS, injection or implant.
- Hormonal contraceptive treatment might give you side effects, although not every woman gets these. Hormonal contraceptives are widely used (as contraceptives) by many women.
- Although you would be using the treatment to try to control your endometriosis symptoms, it will also work as a contraceptive. You need to think about your plans regarding having children.

Using this decision aid to help you make your choice

There is a lot of information that you will need to think about before you decide what to do. **You do not have to make a decision immediately.** Once you have made a choice, you can change your mind later if you wish or if your situation changes.

The information in the table below and on the following pages covers many of the questions that women want to think about and discuss with healthcare professionals when making this decision. It is based on the scientific evidence that NICE assessed when it produced its guideline on endometriosis. Where it has been possible, the table gives information about the number of women affected per 10,000. As a guide, 10,000 people is about the size of a small town. These numbers are also explained in diagrams on pages 9–12.

You can use the table on page 8 to make a note about how important the different issues are to you. You might also find information from the charity Endometriosis UK helpful in deciding what is the best option for you.

A user guide, written for healthcare professionals, is also available. It explains how this decision aid was produced and where the information came from.

	Combined pill	Progestogen-only pill	Progestogen injection	Progestogen IUS	Progestogen implant
1. What does this option involve?	You can take 1 tablet every day for 3 weeks, then a week's break. For better endometriosis control, you may be advised to have week's break only every 3 months, or to have no breaks at all.	You take a tablet every day without a break.	An injection is given into the muscle of your bottom, every 12 weeks.	A small plastic device that releases progestogen is inserted into your womb through your vagina by a doctor or nurse. It must be removed or replaced after 3 to 5 years	A small implant is injected under your skin on the inner side of your upper arm. It must be removed or replaced after 3 years.
2. How likely am I to get relief of endometriosis pain?	Most women find their endometriosis symptoms improve with hormone treatment and many get considerable relief of symptoms. However, it is not possible to say for certain what will happen to any individual woman. There is no good evidence to say which of the options is likely to work best for you. It is important to give the one you choose time to work (usually 3–6 months), but if it doesn't suit you or you don't feel it is helping you could try a different option if you wish. Treatments are usually reviewed every year to see if they are still suitable for you.				
3. How will it affect periods?	Your periods will be regular and only occur when you have a week's break from taking the tablets. They will usually be lighter and shorter. A few women have irregular bleeding or spotting, especially during the first few months.	You may get irregular bleeding or spotting, especially during the first few months, but bleeding will usually be lighter. You might find that you have no bleeding at all.	After the first injection you may have irregular, possibly lengthy bleeding or spotting. After 4 injections most women find that their periods have stopped completely.	During the first few months you may have lighter, heavier or painful periods or some spotting and irregular bleeding You should have lighter periods after 3 to 6 months and you may eventually have no periods at all.	You may have lighter or heavier periods or some spotting and irregular bleeding, or you may have no periods at all. The bleeding pattern you have in the first 3 months usually stays the same while you have the implant.

	Combined pill	Progestogen-only pill	Progestogen injection	Progestogen IUS	Progestogen implant
4. What if I want to stop using it?	You can stop taking the combined pill at any time.	You can stop taking the progestogen-only pill at any time.	The injection can't be reversed but its effects start to wear off after 12 weeks. However, it may take longer (sometimes up to a year) to wear off completely.	The IUS must be removed by a doctor or nurse.	The implant must be removed by a doctor or nurse. This requires a small cut into the skin.
5. How well does it work as a contraceptive?	Each year, about 30 women in 10,000 who take the combined pill as recommended will become pregnant (so about 9,970 women in 10,000 will not)[a, b].	Each year, about 30 women in 10,000 who take the progestogen-only pill as recommended will become pregnant (so about 9,970 women in 10,000 will not)[a, b].	Each year, about 20 women in 10,000 who have the injection will become pregnant (so about 9,980 women in 10,000 will not)[a].	Each year, about 20 women in 10,000 who use the IUS will become pregnant (so about 9,980 women in 10,000 will not)[a].	Each year, about 5 women in 10,000 who have the implant will become pregnant (so about 9,995 women in 10,000 will not)[a].
6. What if I want to try for a baby?	Soon after stopping the combined pill your fertility will be the same as if you had never taken it. A very small proportion of women have a delay before their periods return and they can conceive.	Soon after stopping the progestogen-only pill your fertility will be the same as if you had never taken it.	Once the injection's effects wear off your fertility will be the same as if you had never used it. However, it can take a while (sometimes up to a year) for your periods to return and you can conceive.	Within a few days of the IUS being removed your fertility will be the same as if you had never used it.	Within a few days of the implant being removed your fertility will be the same as if you had never used it.

[a] This information comes from studies using this treatment as a contraceptive. The pregnancy rate may be lower in women with endometriosis.

[b] This information refers to taking the combined or progestogen-only pill exactly as recommended. Missing a dose or taking it late can make it less effective as a contraceptive.

	Combined pill	Progestogen-only pill	Progestogen injection	Progestogen IUS	Progestogen implant
7. What are the most common side effects? (Other side effects have been reported less often. See manufacturers' information for more details)	You may get some side-effects at first, but not every woman does. These include headaches, nausea, breast tenderness and mood changes. If they do not stop within a few months, changing the type of combined pill may help. The combined pill may increase your blood pressure.	You may get some side effects at first, but not every woman does. These include acne, breast tenderness, weight change and headaches. These may stop within a few months.	You may get some side effects, but not every woman does. These include acne, hair loss, lower sex drive, mood swings and headaches. Some women may put on weight.	You may get some side effects, but not every woman does. These include acne, headaches and breast tenderness. Some women develop small cysts on their ovaries, which may be painful. They usually disappear without treatment.	You may get some side effects, but not every woman does. These include headaches, breast tenderness and mood changes. These should stop within a few months. Some women may get acne or their acne may get worse.
8. What is the risk of blood clots such as deep vein thrombosis (DVT)? (See pages 9 and 10 for diagrams and more information)	Each year, about 2 women in 10,000 who do not take the combined pill will get a blood clot (and 9,998 will not). Each year, 5 to 12 women in every 10,000 who take the combined pill will get a blood clot (and 9,988 to 9,995 will not).	The progestogen-only pill is not thought to increase your risk of blood clots compared with women who do not use it.	The injection is not thought to increase your risk of blood clots compared with women who do not use it.	The IUS is not thought to increase your risk of blood clots compared with women who do not use it.	The implant is not thought to increase your risk of blood clots compared with women who do not use it.

	Combined pill	Progestogen-only pill	Progestogen injection	Progestogen IUS	Progestogen implant
9. What is the risk of other serious side effects? (See pages 11 and 12 for diagrams and more information)	About 100 women in every 10,000 who do not have hormone treatment will have breast cancer by the time they are 45 (and 9,900 will not). About 110 women in every 10,000 who take the combined pill for 5 years in their early 30s will have breast cancer by the time they are 45 (and 9,890 will not). More rarely, other types of serious side effects have been reported. See the manufacturers' information for more details.	It is thought that the progestogen-only pill increases your risk of breast cancer by about the same amount as the combined pill, but this is not known for certain. More rarely, other types of serious side effects have been reported. See the manufacturers' information for more details.	Using the injection increases your risk of breast cancer by about the same or less than the combined pill. Women who have the injection tend to have lower bone mineral density (BMD) than women who have never used it. BMD may increase after the injection is stopped. The effect on your risk of osteoporosis and fractures in later life is not yet known. More rarely, other types of serious side effects have been reported. See the manufacturers' information for more details.	It is thought that the IUS increases your risk of breast cancer by about the same amount as the combined pill, but this is not known for certain. More rarely, other types of serious side effects have been reported. See the manufacturers' information for more details.	It is thought that the implant increases your risk of breast cancer by about the same amount as the combined pill, but this is not known for certain. More rarely, other types of serious side effects have been reported. See the manufacturers' information for more details.

How you feel about the options

You can use the table to help you make a note about how important the issues are to you.

Issue	**How important is this to me?**			
	Very important	Important	Not important	Not at all important
Whether the treatment is a tablet, injection, IUS or implant				
Likely effect on my endometriosis pain				
Likely effect on my periods				
Issues if I want to stop using it				
Effectiveness as a contraceptive				
Issues if I want to try for a baby				
The risk of common side effects				
The risk of blood clots such as DVT				
The risk of other serious side effects				
Other concerns or questions I would like to discuss:				

Risk of blood clots while taking the combined pill

The combined pill increases your risk of blood clots such as deep vein thrombosis (DVT) or a blood clot in the lungs (pulmonary embolism). If blood clots block blood vessels they can cause very serious problems. The risk returns to normal soon after you stop taking the combined pill. The progestogen-only pill, progestogen injection, IUS and progestogen implant are not thought to increase your risk of blood clots compared with women who do not use it.

The graphics on the next pages show the effect of the combined pill on your risk, as the number of women affected per 10,000. As a guide, 10,000 people is about the size of a small town.

The actual number of women affected per 10,000 who take the combined pill depends on the chance of them having a blood clot anyway (known as their 'baseline risk' of blood clots), which will be different for different women. Your healthcare professional will explain if you are likely to be at higher or lower baseline risk than this, and what this means for your risk with treatment.

Remember that no-one can say what will happen to any individual woman

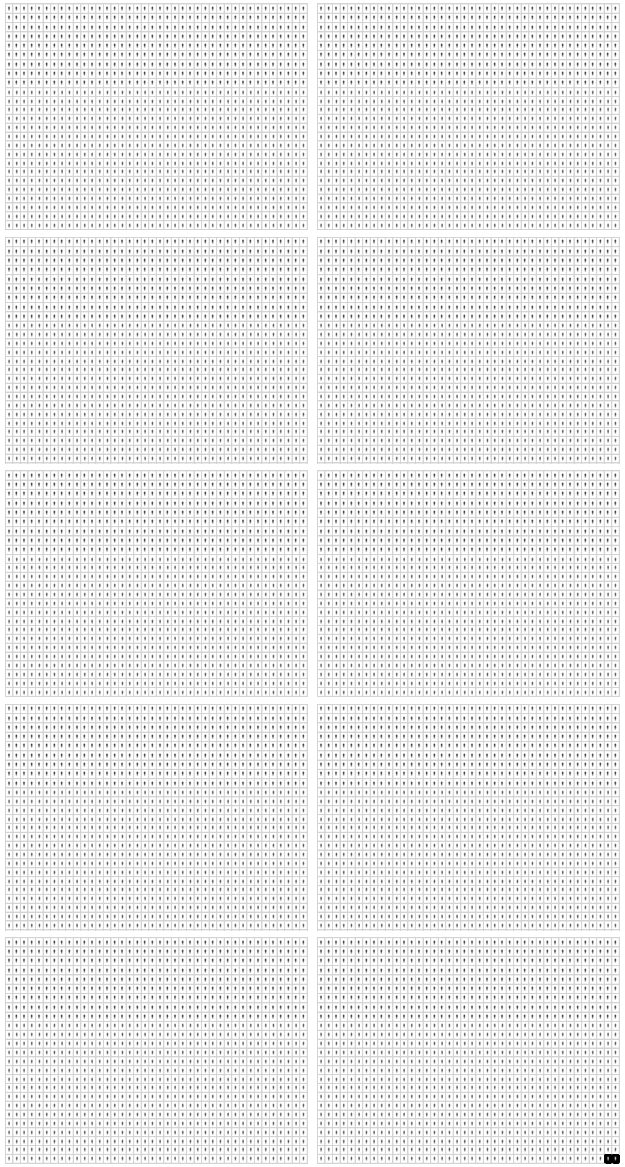
Some things make you more likely to get blood clots. Your risk is higher:

- If you are very overweight (BMI over 30 kg/m^2).
- If one of your immediate family has had a blood clot in the leg, lung or other organ at a young age (for example, below the age of about 50 years).
- If you need to have a major operation, or if you are off your feet for a long time because of an injury or illness, or you have your leg in a cast. You may need to stop the combined pill several weeks before and after major surgery or while you are less mobile (and use another method of contraception if necessary).
- As you get older (particularly above about 35 years).

The risk of developing a blood clot increases the more conditions you have. Air travel (more than 4 hours) may temporarily increase your risk of a blood clot, particularly if you have some of the other factors listed.

More information about blood clots is available on NHS Choices.

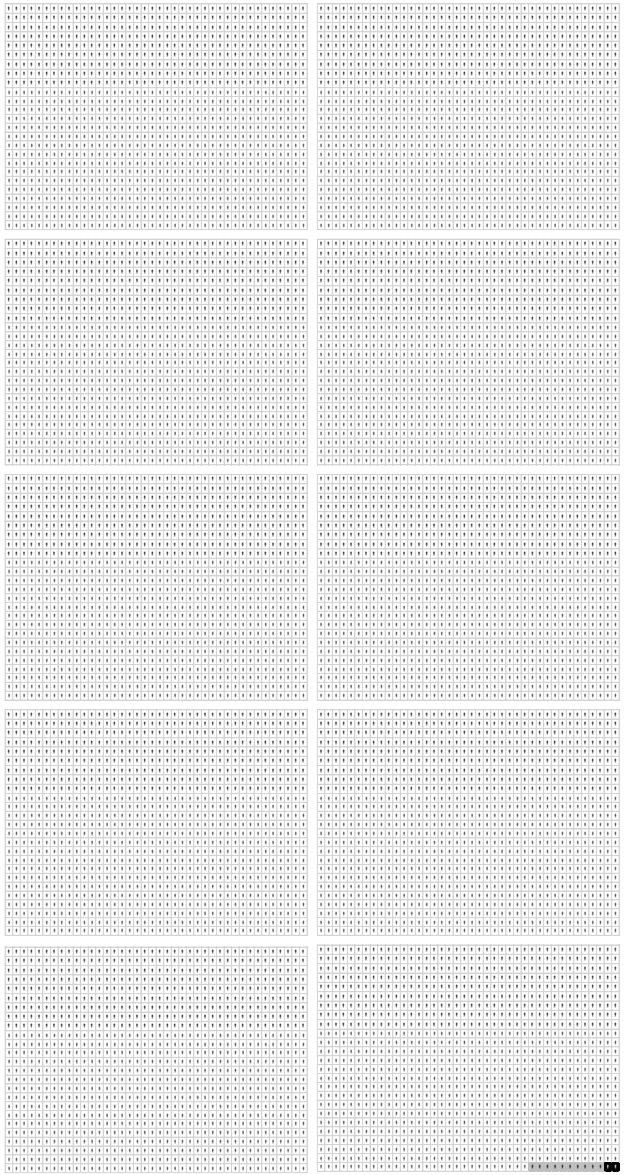
Risk of blood clots per year: no treatment



In 10,000 women who do not take the combined pill, on average each year:

- 9,998 women will not get blood clots
- 2 women will get blood clots

Risk of blood clots per year: combined pill



In 10,000 women who take the combined pill, on average each year:

- 9,998 women will not get blood clots
- 2 women will get blood clots, but would have done anyway
- Up to 10 extra women will get blood clots

Risk of breast cancer with the combined pill

The combined pill increases your risk of having breast cancer. Breast cancer is rare in women under the age of 40. This risk goes up the longer you're on the combined pill, but returns to normal within about 10 years of stopping it. It is thought that the progestogen-only pill, IUS and implant increase your risk of breast cancer by about the same amount as the combined pill, but this isn't known for certain. Using the injection increases your risk of breast cancer by about the same or less than the combined pill.

The graphics on the next pages show the effect of the combined pill on the risk of breast cancer in women who take it for 5 years in their early 30s. This information is shown as the number of women affected per 10,000 by the time they are 45 years old. As a guide, 10,000 people is about the size of a small town.

The actual number of women affected per 10,000 depends on the chance of them having breast cancer anyway (known as their 'baseline risk'), the length of time they take the combined pill and especially the age at which they stop taking it.

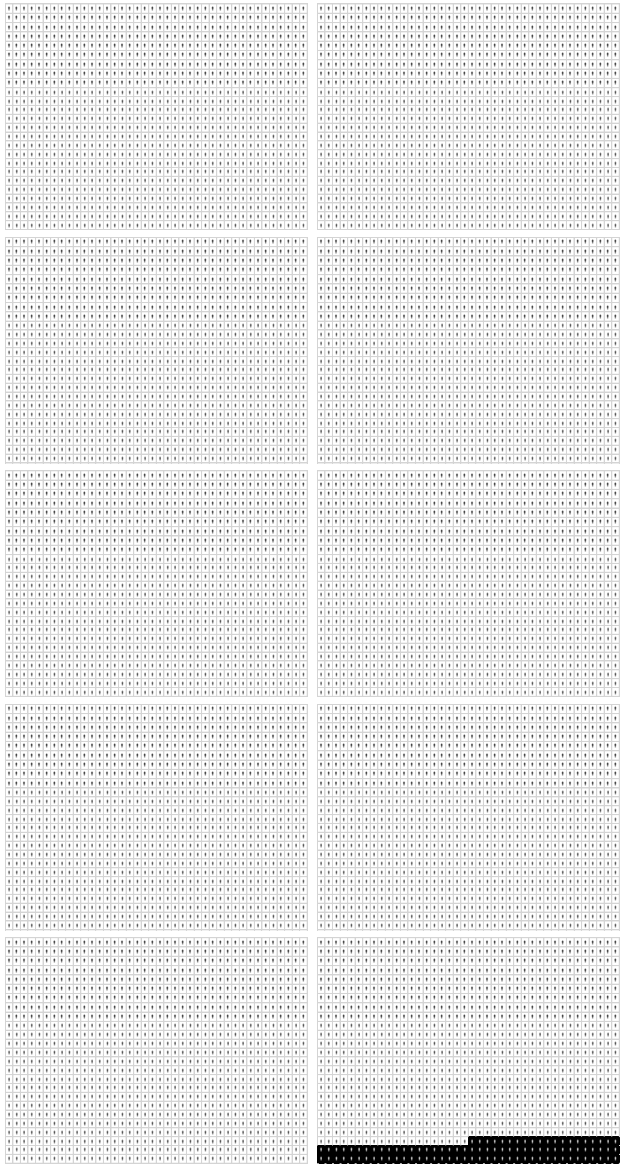
Remember that no-one can say what will happen to any individual woman

Your baseline risk of breast cancer is higher if you have a close relative (mother, sister or grandmother) who has had breast cancer or if you are very overweight (BMI over 30 kg/m^2).

Like all women, whether or not you take any hormone treatment, you should see a doctor as soon as possible if you notice any changes in your breasts, such as dimpling of the skin, changes in the nipple or any lumps that you can see or feel.

More information about breast cancer is available on NHS Choices.

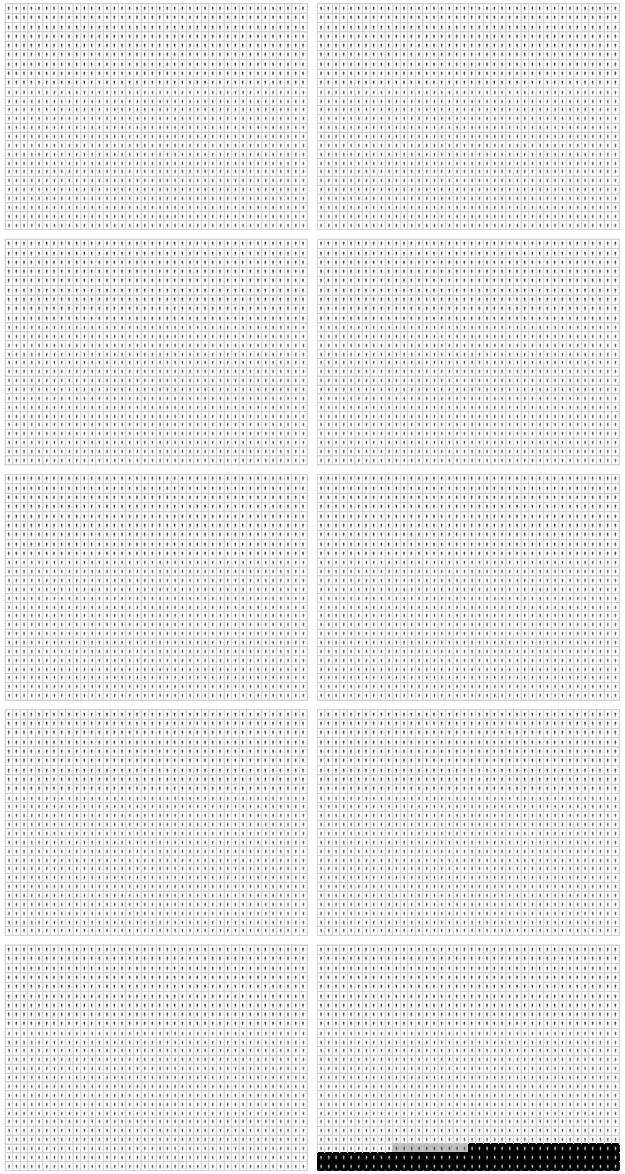
Risk of breast cancer by age 45: no treatment



In 10,000 women who do not have hormonal treatment, by the time they are 45 years old on average:

- 9,900 women will not have breast cancer
- 100 women will have breast cancer

Risk of breast cancer by age 45: combined pill



In 10,000 women who take the combined pill for 5 years in their early 30s, by the time they are 45 years old on average:

- 9,890 women will not have breast cancer
- 100 women will have breast cancer, but would have done anyway
- 10 extra women will have breast cancer