



DECISION AID

Endometriosis:

What are my treatment options?

If you are reading this, you have probably been diagnosed with endometriosis. This means that the type of tissue that lines your womb (uterus) is also growing inside the wall of your womb or elsewhere in your body. Endometriosis can cause particularly painful menstrual periods, other cramp-like abdominal pain and fertility problems. These symptoms usually go away after you have had your very last period (menopause).

There are various treatment options for endometriosis. Your doctor may also have advised you to have surgery to remove your womb and nearby endometriosis tissue (endometrial implants). But it often isn't necessary to remove the womb.

The aim of this decision aid is to help you choose a suitable treatment together with your doctors.

THESE ARE THE TREATMENT OPTIONS:

- Medication** [Painkillers: NSAIDs such as ibuprofen or diclofenac
Hormones: birth control pill, GnRH analogues or progestins
- Surgery** [Surgery to remove the endometriosis tissue
Surgery to remove the womb (hysterectomy)

You can read about the pros and cons of these treatments on the next pages.

Other treatment options are available, but they haven't been scientifically proven to help. These include herbal medicines, acupuncture and relaxation techniques.

Personal decision

This brief decision aid probably won't include all of the information that you need. You will still need to talk to a doctor, but the decision aid can help you. Your treatment decision will depend on various things, including

- how distressing your symptoms are,
- how effective the non-surgical treatments are,
- where the endometrial implants are,
- how old you are,
- whether you wish to have any (more) children,
- whether you would like to keep your womb, and
- whether you have any other medical conditions.

IMPORTANT:

Don't let anyone pressure you into choosing a certain treatment! Even if you find the symptoms very distressing, take the time to gather information and make the right decision for you.

PROS AND CONS OF MEDICATION

	Painkillers (NSAIDs)	Birth control pill	GnRH analogues	Progestins
What does the treatment involve?	Painkillers can be taken if needed. Not suitable for long-term use.	Birth control pills are taken once a day. Either with a monthly break or continuously (without a break).	Hormone injections, given every 1 or 3 months. Only suitable for short-term treatment (up to 6 months).	Longer-term treatment with tablets or a hormonal coil (IUD). The tablets are taken every day. The hormonal coil is placed inside the womb, and can be left there for 3 to 5 years.
Does it help?	Can relieve severe period pain, but often have only a very limited effect on endometriosis symptoms.	Can relieve endometriosis symptoms. When taken continuously, the pill may prevent you from getting your periods altogether until you stop taking it.	May reduce endometriosis symptoms.	May reduce endometriosis symptoms.
What are the possible side effects?	Stomach problems, nausea.	Fluid retention (edema), headaches, breast tenderness. Increases the risk of thrombosis.	Hot flashes, sweating or vaginal infections. More likely to have side effects than other medications are.	<u>Tablets</u> : Spotting (vaginal bleeding between periods), weight gain, mood swings. <u>Hormonal coil</u> : Acne, spotting, mood swings and breast tenderness.
Who is the treatment suitable for?	For most women.	For women who don't currently wish to become pregnant.	For women who don't currently wish to become pregnant.	For women who don't currently wish to become pregnant.

PROS AND CONS OF SURGICAL PROCEDURES

	Surgery to remove endometriosis tissue	Surgery to remove the womb (hysterectomy)
What does the operation involve?	The areas of endometriosis tissue (implants) are removed during laparoscopy. This involves making small cuts in the abdominal wall. The womb is not removed.	The womb is completely removed. Sometimes the ovaries (one or both) are removed too if they are affected. This can be done either through the vagina or through a cut in the abdominal wall.
Does it help?	This procedure can relieve pain in mild to moderate endometriosis. It can also increase the likelihood of getting pregnant. In about 20 out of 100 women, new endometriosis tissue grows again within 5 years.	The pain often becomes milder or goes away completely. But endometriosis tissue can grow again.
What are the possible side effects?	Organ damage or other complications (in about 1 out of 100 women). General risks associated with surgery, such as infections or wound-healing problems.	Organ damage or other complications, such as infections and heavy bleeding (in about 5 out of 100 women). General risks associated with surgery, such as infections or wound-healing problems. Removing both ovaries will result in the immediate onset of menopause.
Could I still have children after the treatment?	Yes.	No.
Who is the treatment suitable for?	For most women who have endometriosis.	For women who don't wish to have any (more) children and who have endometriosis in the wall of their womb. Hysterectomies are usually only considered if surgery to remove the endometriosis tissue hasn't helped enough or isn't possible.

HELP WITH YOUR DECISION

You may still be unsure about which treatment you would prefer. You can write down your thoughts and questions on the following two pages.

Which treatment would I consider?		What do I like about it?	What don't I like about it?
Painkillers	<input type="radio"/>		
Birth control pill	<input type="radio"/>		
GnRH analogues	<input type="radio"/>		
Progestins	<input type="radio"/>		
Surgery to remove the endometriosis tissue	<input type="radio"/>		
Surgery to remove the womb (hysterectomy)	<input type="radio"/>		
No treatment	<input type="radio"/>		

If you still aren't sure, what else do you need in order to make a decision?

With all the different pros and cons to consider, it can be hard to choose a treatment. One advantage of medications is that they may make it possible to avoid surgery. If they don't help, surgery is still an option.

If you need more help:

- You will find links to further information on the next page.
- You can talk to your doctor again.
- You can also talk to a different doctor. You will find information about this option on the next page, too.
- You can talk about it with your friends and family.
- You can contact a patient information center or a support group.



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Publishing details

This decision aid was developed by the Institute for Quality and Efficiency in Health Care (IQWiG, Germany). You will find information about our work and the sources we use here:

- www.informedhealth.org/our-approach

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