



DECISION AID

Endometriosis:

What are your treatment options?

You have been diagnosed with endometriosis. This means that the type of tissue that lines your womb (endometrial tissue) is also growing inside the wall of your womb or outside of your womb. Endometriosis can cause particularly severe period pain, other cramp-like abdominal pain and fertility problems. These symptoms often go away after you have had your very last period (menopause), but they might persist after that.

There are various treatment options for endometriosis. Doctors usually recommend medication at first. Surgery might be considered for some women. Sometimes a combination of treatments is used. The aim of this decision aid is to help you choose a suitable treatment together with your doctors. You also have the right to seek a second medical opinion.

THESE ARE THE TREATMENT OPTIONS:

Medication

- Painkillers: NSAIDs such as ibuprofen or diclofenac
- Hormone therapy: Progestins, birth control pill, GnRH agonists or GnRH antagonists

Surgery

- Surgery to remove the endometriosis tissue
- Partial or total removal of the womb (hysterectomy)

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

There are also various ways to manage the symptoms. These include pain management, psychological support, as well as sports and exercise.

MAKING AN INFORMED DECISION

This decision aid probably won't include all of the information that you need. You will still have to talk to a doctor, but the decision aid can help you. Your treatment decision will depend on other factors too, like:

- how distressing your symptoms are
- how effective non-surgical treatments are
- where the endometriosis tissue is
- how old you are
- whether you wish to have any (more) children
- whether you would like to keep your womb
- whether you have any other medical conditions



Even if you find your heavy periods very distressing: Take the time to find out what you want to know and don't let anyone pressure you into choosing a certain treatment.

PROS AND CONS OF THE MEDICATIONS

	Painkillers (NSAIDs)	Progestins	The birth control pill (contraceptive pill)	GnRH agonists	GnRH antagonists
What does the treatment involve?	Painkillers can be taken if needed. Not suitable for long-term daily use.	The mini-pill, containing the hormone progesterin, is taken every day. Hormonal coils (IUDs) are inserted into the womb and can stay there for three to eight years, depending on the coil.	The combination pill has both progesterin and estrogen in it. It is taken once a day – either with a break each month, or continuously without a break.	The hormone injections are given every 1 or 3 months. The nasal spray is used once a day. Only suitable for short-term treatment (3 to 6 months).	One tablet is taken each day.
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.	For women who don't currently wish to become pregnant.
How effective is treatment?	Painkillers can relieve severe period pain, but often have only a very limited effect on endometriosis symptoms.	Can reduce endometriosis symptoms. You might stop getting your period altogether.	The birth control pill can reduce endometriosis-related problems. When the pill is taken continuously, you may not get your period at all until you stop taking it.	Can reduce endometriosis symptoms. You might stop getting your period altogether.	Can reduce endometriosis symptoms. You might stop getting your period altogether.
What are the possible side effects?	Stomach problems, nausea	Headaches, nausea, dizziness, breast tenderness, mood swings, spotting between periods, acne Over the long term, your bone density may decrease.	Headaches, nausea, dizziness, breast tenderness, mood swings The pill increases the risk of thrombosis.	Hot flashes, sweating, vaginal infections GnRH agonists have stronger side effects than the other medications do.	Headaches, hot flashes, spotting between periods

PROS AND CONS OF THE SURGICAL PROCEDURES

	Surgery to remove endometriosis tissue	Hysterectomy (surgery to remove the womb)
What happens during the operation?	The areas of endometriosis tissue (endometrial implants) are removed during laparoscopy. This involves making small cuts in the abdominal wall. The womb is not removed.	The womb is removed – either partially or completely. If they are also affected, one or both ovaries may be removed too. The surgery can either be performed through the vagina or through a cut in the abdominal wall.
Who is it suitable for?	For most women with endometriosis, but usually only if medication hasn't helped enough. Sometimes surgery is recommended sooner – for example, if the endometriosis tissue affects the function of an organ (like the bladder) or reduces your fertility.	For women who don't wish to have any (more) children and who have endometriosis tissue in the wall of their womb. A hysterectomy is usually only considered if medication wasn't effective and surgery to remove just the endometriosis tissue doesn't help enough (or isn't possible).
How effective is it?	This procedure can relieve pain in mild to moderate endometriosis. It can also increase the likelihood of getting pregnant. But endometriosis tissue may grow again, causing the symptoms to return.	The pain often improves after the operation, or even goes away completely. But endometriosis tissue may appear again in other places.
What are the possible side effects?	In about 1 out of 100 women, the surgery leads to organ injuries or other complications such as infections or heavy bleeding.	In about 5 out of 100 women, the surgery leads to organ injuries or other complications such as infections or heavy bleeding. If both ovaries are removed, the menopause sets in immediately afterwards (with possible symptoms such as hot flashes, vaginal dryness and mood swings).
Can you still have children after the treatment?	Yes.	No.

YOUR DECISION

You can now weigh the pros and cons of the different treatments for yourself. Which of them are better suited to you and your life circumstances, and which of them aren't?

WHAT IS IMPORTANT TO YOU?

You can use this table to note the main issues for you when considering the options. Which of them will affect your decision? How important are they to you? Mark the statements that apply to you, and add any thoughts of your own. Ranking the statements could help: For instance, you could mark the statements that are especially important to you with a 1, those that are a little less important with a 2, and so on.

Which statements apply to you?		Your ranking (1, 2,)
My endometriosis symptoms are so distressing that I definitely want a treatment with a permanent effect.	<input type="radio"/>	
I've already tried medications but they didn't help enough.	<input type="radio"/>	
I've already had an operation but it didn't help enough.	<input type="radio"/>	
I'd still like to be able to get pregnant.	<input type="radio"/>	
I wonder whether hormone therapy could help.	<input type="radio"/>	
I'm worried about the side effects of hormones.	<input type="radio"/>	
I wonder whether surgery could help.	<input type="radio"/>	
I'm worried about the risks of surgery.	<input type="radio"/>	
	<input type="radio"/>	
	<input type="radio"/>	

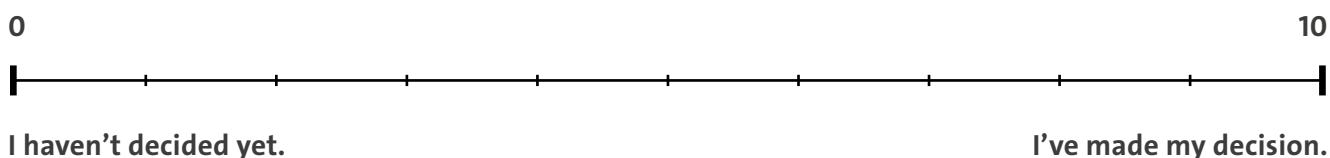
WHICH TREATMENT WOULD YOU CONSIDER?

You can use this table to assess the different treatments. Mark the ones you would consider and write down what you like and don't like about them.

Which treatment would you consider?		What do you like about it?	What don't you like about it?
Painkillers	<input type="radio"/>		
Progestins	<input type="radio"/>		
The birth control pill (contraceptive pill)	<input type="radio"/>		
GnRH agonists	<input type="radio"/>		
GnRH antagonists	<input type="radio"/>		
Surgery to remove endometriosis tissue	<input type="radio"/>		
Hysterectomy (surgery to remove the womb)	<input type="radio"/>		

HOW FAR HAVE YOU GOT WITH YOUR DECISION?

You can use this section to record how far along you are in your decision-making process. Mark where you are on a scale of 0 to 10.



If you still aren't sure and need more help, you can find some tips and more information on the following pages.


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.

Then the following might help:

Knowledge If you feel that you don't have enough information:	<input type="checkbox"/> Write down your questions. <input type="checkbox"/> Make notes on where you could get answers (for example, on the internet, at the library, or from healthcare professionals or counselors). <input type="checkbox"/> You have the right to seek a second medical opinion. You can find out more about that option on the next page. <input type="checkbox"/> There you will also find links to further information.
Importance to you If you aren't sure which pros and cons are most important to you:	<input type="checkbox"/> Talk with people who know about these pros and cons from their own experience. <input type="checkbox"/> Speak to others who have already made the same kind of decision. <input type="checkbox"/> Read about others who were in a similar situation and see what mattered most to them. <input type="checkbox"/> Discuss with other people what is most important to you.
Support If you feel you aren't getting the support you need:	<input type="checkbox"/> Discuss the various options with a trusted person (for instance, with your doctor, someone in your family, or a friend). <input type="checkbox"/> Take this decision aid with you to your next appointment and talk about it with your doctor. <input type="checkbox"/> Contact patient advice services or a support group. You will find more information about this on the next page. <input type="checkbox"/> Seek help to support your choice (like financial support, childcare, transport for appointments, or someone to go with you).
If you feel pressured by others to choose a certain option:	<input type="checkbox"/> Focus on those people's opinions that matter to you the most. <input type="checkbox"/> Discuss this decision aid with others. <input type="checkbox"/> Ask someone else to fill in this decision aid. Where do your answers match? If you disagree on the facts, get more information. If you disagree on what matters most, consider the other person's point of view. Take turns listening to what matters most to the other person. <input type="checkbox"/> Find a neutral person to help you and the other people who are involved.

**YOU WILL FIND IN-DEPTH INFORMATION ABOUT THE FOLLOWING TOPICS
ON THE INTERNET:**

	Endometriosis and the treatment options www.informedhealth.org/endometriosis
	At the hospital in Germany www.informedhealth.org/at-the-hospital.html
	Surgery www.informedhealth.org/surgery.html
	Second medical opinion www.informedhealth.org/second-opinion-before-surgery.html
	Patient advice services and support groups www.informedhealth.org/support-groups-and-information-centers

PREPARING FOR THE DOCTOR'S APPOINTMENT

Do you still have any questions or concerns? Write down your questions or your own thoughts to discuss with the doctor.

There's a list of possible questions here:

www.informedhealth.org/list-of-questions/

PUBLISHING DETAILS

Institute for Quality and Efficiency in
Health Care (IQWiG, Germany)

www.informedhealth.org/about-us

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The format of this decision aid is based on the following:

- Ottawa Personal Decision Guide. O'Connor, Stacey, Jacobsen 2012. Ottawa Hospital Research Institute and University of Ottawa, Canada.
- MAKING SDM A REALITY – Hospital-wide shared decision making – G-BA Innovation fund 2023.
- Institute for Quality and Efficiency in Health Care (IQWiG, Germany). Development of a decision aid for hysterectomy: Rapid Report; Commission P18-01. 2019.