ENDO *Queen*

SYMPTOM DIARY

My pain *diary*

Memories fade, notes stay. My record, my pain day by day, my cycles, and what I want to tell my doctor.



First name _____

HOW TO USE IT

How to *use it*

Memories fade, notes stay. A few seconds a day so you arrive at your appointment with facts, not just impressions.

1. **Once**, your record: medical history, tests, operations, treatments, the diagram of your lesions and your body map. Add to it over time.
2. **Every day**, one column of the “My month” page: your pain from 0 to 10, your period, what hurt, what helped.
3. **At the end of each cycle**, one row of “My cycles side by side”.
4. **Every 3 months**, your review at a glance.
5. **Whenever you like**, “My wins and good moments”: what did you good, even on a hard day.
6. **Before the appointment**, the “What I want to say” page. Take the whole diary with you, and let your clinician write their note.

Print the “My month” page as many times as you need. Three months of notes is already a lot.

MY RECORD

The essentials *about me*

Fill this in once, then add to it. It saves you repeating everything to each new doctor.

Me

Full name _____

Date of birth _____

GP, surgery _____

Gynaecologist, midwife _____

My periods

First period at age _____

My cycles: about _____ days

My periods last _____ days

- [ ] Heavy periods
- [ ] Clots
- [ ] Bleeding between periods
- [ ] Pain since my first periods

Contraception, hormone treatments

Current and past, with dates.

_____

_____

How I get on with it

- [ ] Mood
- [ ] Weight
- [ ] Sex drive
- [ ] Skin
- [ ] Unexpected bleeding
- [ ] Headaches

Details _____

My medical history

Illnesses, operations (including laparoscopy), hospital stays, with the year.

_____

_____

_____

Allergies _____

Pregnancies

Pregnancies _____ births _____

Miscarriages _____ terminations, ectopic _____

- [ ] Trying for a baby
- [ ] Having fertility treatment

In my family

- [ ] Endometriosis (mother, sister…)
- [ ] Adenomyosis
- [ ] Very painful periods
- [ ] Fertility problems

Who _____

Diagnosis

- [ ] No diagnosis yet
- [ ] Suspected
- [ ] Confirmed

- [ ] Endometriosis [ ] Adenomyosis [ ] Other

Suspected or confirmed on _____

By which professional, on which test _____

MY RECORD

My tests and *my operations*

Keep your reports with this diary. Here, just the essentials: the date, the test, what was described. What is seen on imaging, what is found during an operation and what is confirmed under the microscope are three different things: note them separately.

Tests I have had

Pelvic or transvaginal (internal) ultrasound, specialist scan, pelvic MRI, laparoscopy, blood tests, colonoscopy…

Date	Test	Where, by whom	What was described (lesions seen on imaging, result)

My operations

Laparoscopy, hysteroscopy, other. The operation note says what the surgeon saw; the lab analysis under the microscope (histology), when it is done, says what was confirmed. Not all lesions are analysed: that is common.

Date	Operation, where, by whom	What was seen during the operation	Lesions removed	Microscope result, if available	Recovery
			fully · partly · no	confirmed · not confirmed · not analysed · don't know	
			fully · partly · no	confirmed · not confirmed · not analysed · don't know	
			fully · partly · no	confirmed · not confirmed · not analysed · don't know	

MY RECORD

My treatments *and what helps me*

Note every treatment you have tried, even long ago. Colour in the stars: ★☆☆ a little, ★★☆ moderately, ★★★ a lot. Effect: does it ease the pain? Tolerance: do I get on well with it?

Medicines

Painkillers, hormone treatments (pill, hormonal coil, implant, other), others. The name is on the box.

Name, dose	From… to…	Effect	Tolerance	Side effects	Why I stopped
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		
		☆☆☆	☆☆☆		

Supportive care

Physiotherapist, midwife, osteopath, psychologist or counsellor, relaxation, adapted exercise, yoga, TENS, heat, other.

What, with whom	Since when, how often	What it does for me	NHS or cost	Downsides
		☆☆☆		
		☆☆☆		
		☆☆☆		
		☆☆☆		
		☆☆☆		

Tips for choosing

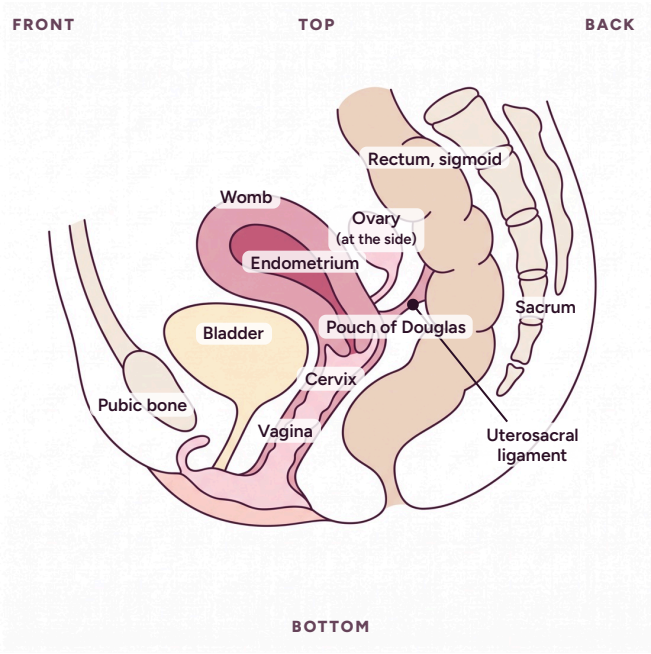
Complementary approaches can help ease some symptoms. How well they work, and how strong the evidence is, varies from one method to another. They add to your care and don't replace a suitable medical treatment. Be wary of anyone who asks you to stop your treatment, promises to cure endometriosis, criticises your doctors or asks you to pay for many sessions in advance. If in doubt, talk to your doctor or your midwife.

MY DIAGRAM

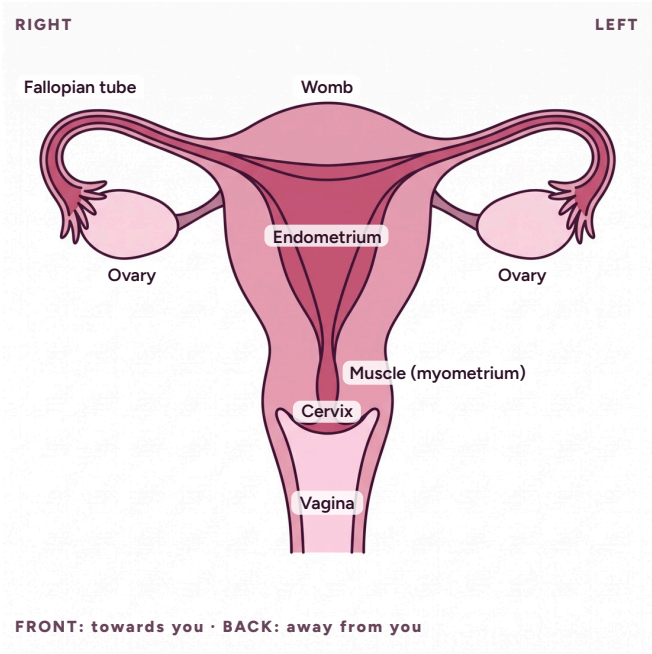
Where *my lesions* are

Using your ultrasound, MRI or laparoscopy report, or with your doctor, draw on these three diagrams. The same spot can appear on more than one diagram.

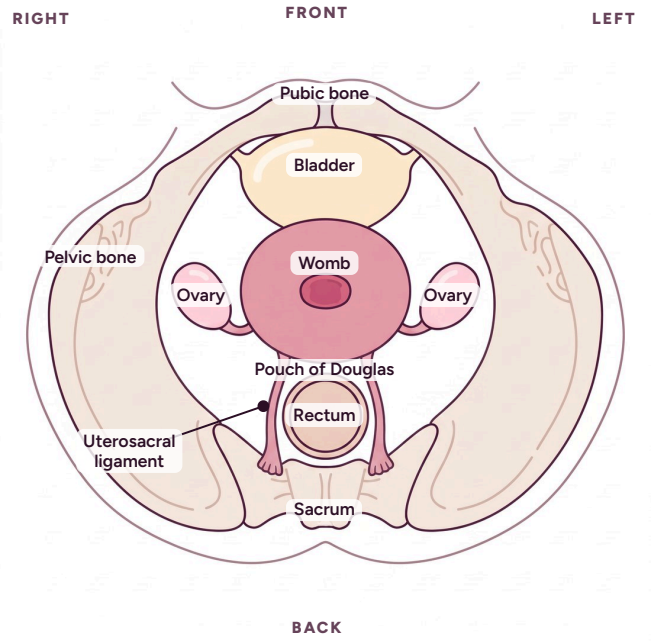
○ **Endometriosis** △ **Adenomyosis (in the muscle of the womb)** Size, if known, next to the symbol.



From the side · sagittal view, through the middle of the body; the ovary, which sits to the side, is drawn as see-through



From the front · orientation view



Cross-section · orientation view, seen from the feet

What my reports say

Test, date, and the places mentioned: ovaries, uterosacral ligaments, pouch of Douglas, bladder, rectum, rectovaginal septum…

Simplified diagrams and orientation views, to help you locate what you were told; they are not imaging slices and not for reading an MRI. Not to scale, EndoQueen illustrations. As on an MRI, the patient's right is on the left of the drawing.

WHERE IT HURTS

My body *map*

Draw straight onto the outlines with the symbols below. You can use one colour per period of time (during your period, the rest of the month) and write the date. Do it again when the pain changes.

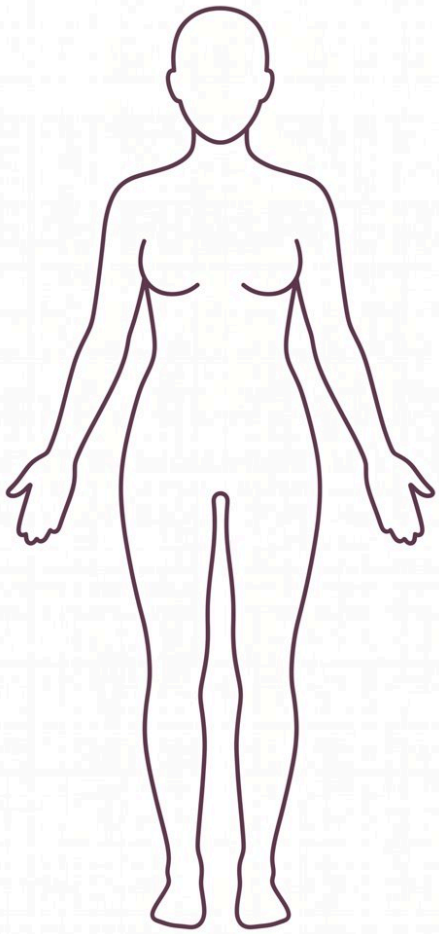
/// **Hatching** spread-out, widespread pain

Lightning burning, electric shocks, tingling

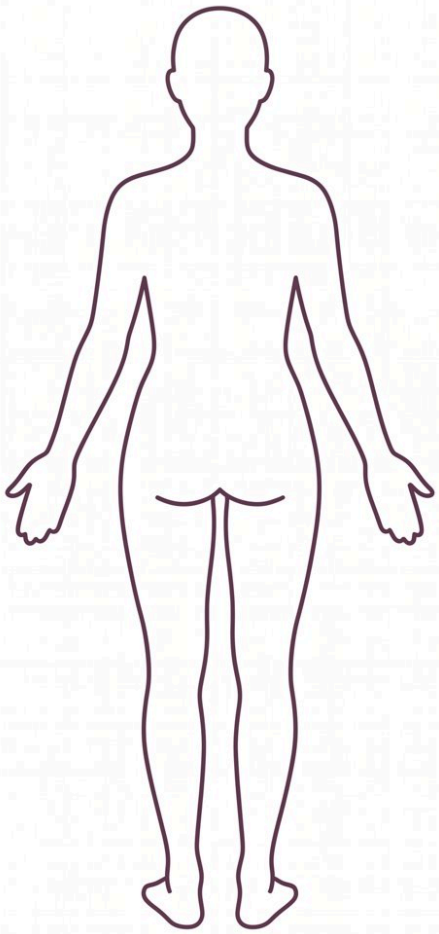
× **Cross** sharp pain at one precise spot

→ **Arrow** the pain starts here and travels or spreads

FRONT · your right is on the left of the drawing



BACK



Date _____

Colour 1 = _____

Colour 2 = _____

When

- ☐ During my period
- ☐ Around ovulation
- ☐ Almost all the time
- ☐ During or after sex
- ☐ When pooing
- ☐ When weeing

What triggers it or makes it worse

_____

_____

MY MONTH

Month of _____ 20___

One column per day. Note your worst pain of the day, from 0 (no pain) to 10 (the worst you can imagine). Tick whatever applies. An empty box is fine: note what you can.

Day of the month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Period none · + · ++ · +++																															
Pain 0 to 10																															
Lower tummy ✓																															
Back, legs ✓																															
When pooing ✓																															
When weeing ✓																															
During sex ✓																															
Bloating, bowels ✓																															
Tiredness 0 to 5																															
Mood good · OK · low																															
Sex drive usual · less · none																															
Sleep good · OK · poor																															
Pill, hormones taken ✓																															
Painkiller taken ✓																															
Effect none · a bit · good																															
Other relief heat, TENS…																															
Day disrupted work, school, going out																															
My day hard · OK · good · very good																															

Pain: 0 1 2 3 4 5 6 7 8 9 10 0 none · 1 to 3 mild · 4 to 6 moderate · 7 to 10 severe

Cycle starting _____ · *temperature, treatments, blood tests*

Day of cycle	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Date																															
Morning temperature (°C) · when you wake up, before you get up																															
37.5																															
37.4																															
37.3																															
37.2																															
37.1																															
37.0																															
36.9																															
36.8																															
36.7																															
36.6																															
36.5																															
36.4																															
36.3																															
36.2																															
36.1																															
36.0																															
Treatments · write the name, tick ✓ each day you took it																															
_____																															
_____																															
_____																															
_____																															
Bleeding · + ++																															
Pain 0 to 10																															

Blood tests, only if they were ordered for you · Most people don't need blood tests for their day-to-day follow-up: leave this box empty if that's you. Copy the unit written on the report (it can change from one lab to another).

Date	Test	Result	Unit

Date	Test	Result	Unit

Date	Test	Result	Unit

CYCLE AFTER CYCLE

My cycles *side by side*

Fill this in at the end of each cycle, looking back over your monthly pages. A cycle runs from the first day of your period to the day before the next one. It's often the table the doctor looks at first.

Period started	Cycle length	Period length	Worst pain	Days with pain 7 or more	Pain when pooing, weeing, during sex	Days disrupted	What helped

What you might notice

- Your cycles get longer, shorter, or stay regular.
- The pain starts before your period, or lasts after it.
- Painkillers help a lot, a little, or not at all.
- How many days the pain stopped you doing what you wanted.

These are facts you write down, not a diagnosis. Only a health professional can make a diagnosis.

When to get help

Keep an eye on · pain that changes or lasts longer, or painkillers that help less: note it and mention it at your next appointment.

See a doctor soon · blood in your wee or poo, weight loss for no reason, new and unusual pain: this needs a medical assessment. Your GP, or **111** (Scotland: NHS 24 on 111; Northern Ireland: GP out-of-hours).

Emergency, 999 · heavy bleeding, collapsing or feeling very faint, sudden severe pain, fever with strong pain or vomiting, or any other serious sign.

Dark thoughts: Samaritans **116 123**, free, 24 hours a day.

FOR ME

My wins *and good moments*

No pressure to be fine: hard days count too. This is where you keep what does you good, even on a day with pain.

Date	My small win or good moment

For example: going out despite the pain, a full night's sleep, an appointment where I felt listened to, a good laugh with a friend, a walk, a cuppa in the sun.

What does me good

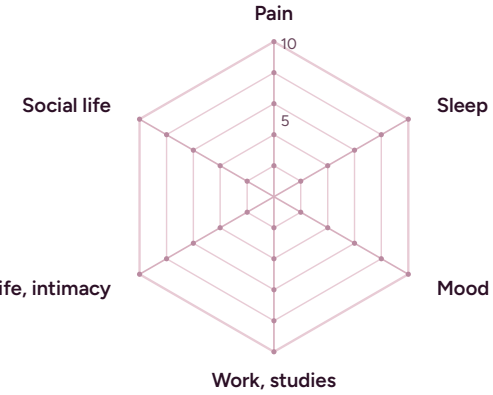
Something I'm proud of this month

EVERY 3 MONTHS

My review *at a glance*

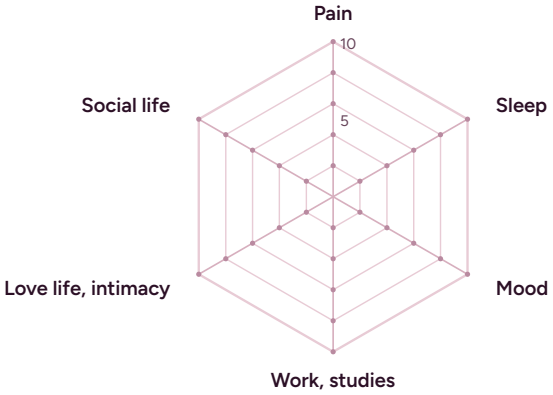
Every 3 months, or when a treatment changes. For each area, put a dot from 0 (not bothered at all) to 10 (hugely bothered) by endometriosis, then join the dots. The smaller the shape, the less the condition weighs on your life.

Review 1 · on _____



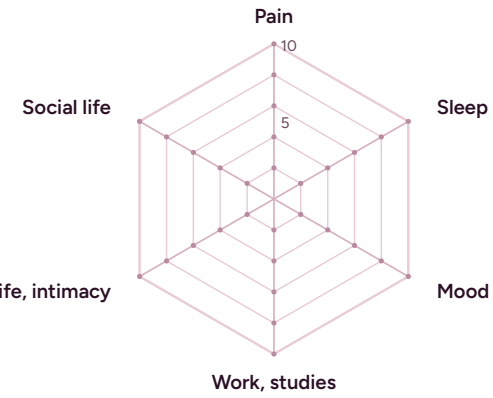
What is going well right now: _____

Review 2 · on _____



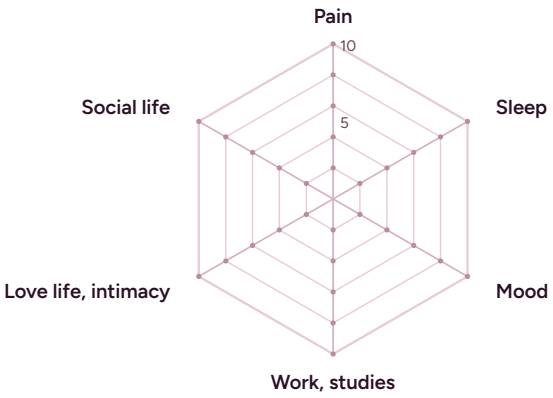
Since the last review, what has got better: _____

Review 3 · on _____



Since the last review, what has got better: _____

Review 4 · on _____



Since the last review, what has got better: _____

My lifestyle

	Review 1	Review 2	Review 3	Review 4
Sleep: hours a night, waking up				
Stress: rarely · sometimes · often				
Exercise: what, how much				
Smoking, alcohol: how much				
Food: what I notice				

These dots help you see how things change and talk about it; they are not a medical score.

MY TEAM

My care team *and practical steps*

Who	Name	Phone	Town, place
GP			
Gynaecologist			
Midwife			
Radiologist, sonographer			
Pain clinic			
Physiotherapist			
Psychologist, counsellor			
Other			

Practical steps

Note what you asked for (A), got (G) or were refused (R), with the date.

- [ ] Time off work, sick notes: ____
- [ ] Recognition of a disability: ____
- [ ] Adjustments at work, working from home: ____
- [ ] Adjustments at school, college, university: ____
- [ ] Financial help: ____
- [ ] Prescription costs: ____

These are granted according to medical and administrative criteria, not just because of the diagnosis. Prescription charges differ across the UK: ask your pharmacist. Advice about work: Acas helpline 0300 123 1100, Monday to Friday 8am–6pm (call charges may apply).

Near me

Specialist endometriosis centre near me _____

The British Society for Gynaecological Endoscopy (BSGE) lists accredited endometriosis centres on bsge.org.uk: check that list rather than a centre's own website. Ask your GP about a referral.

A note from my clinician

So that each professional can write down what to remember.

Date _____ · Name, role _____

_____

_____

Date _____ · Name, role _____

_____

_____

Date _____ · Name, role _____

_____

_____

BEFORE THE APPOINTMENT

What I want *to say*

Since when

My pain started around _____

How it has changed: _____

Where it hurts

- [ ] Lower tummy
- [ ] Right side
- [ ] Left side
- [ ] Lower back
- [ ] Legs
- [ ] Bottom (rectum, anus)
- [ ] Bladder
- [ ] Deep in the vagina
- [ ] Shoulder
- [ ] Elsewhere: _____

What I have already tried

_____

_____

_____

_____

_____

_____

How it affects my life

_____

_____

_____

My questions

1. Could my symptoms be endometriosis or adenomyosis?
2. Could I be referred to a gynaecologist, or to a specialist endometriosis service?
3. What are my options to ease my pain day to day?
4. Should we take this into account if I want to get pregnant?
5. _____
6. _____

EASIER ON YOUR PHONE

With the EndoQueen app, you note all this in a minute a day, and arrive at your appointment with a clear PDF summary. No account, no ads: your data stays on your phone.

endoqueen.fr · 3 free days, then a 14-day trial.

The things to note follow the symptoms described in NHS information on endometriosis and in the NICE guideline on endometriosis (NG73). This diary helps you describe what you are going through; it does not replace an appointment. If your symptoms carry on, go back to your GP.