ENDO *Queen*

FOR THE PERSON WHO SHARES HER LIFE

The partner's *booklet*

Understand what she is going through, know what to do on bad days, and look after yourself too.



First name _____

HOW TO USE IT

How to *use it*

To understand what she is going through, know what to do on bad days, and look after yourself too.

1. **Read the first pages**: what she feels, why she is in pain, the possible effects of her treatments.
2. **Fill in the flare-up plan together**. She is the one who knows what helps her.
3. **Every day**, one column of “Day by day”: her day, what you did, how you are.
4. **Whenever you like**, “Our good moments”: your memories, what makes you laugh, what you’d love to do.
5. **Keep a page for yourself**: what you notice, how you feel, your questions for the doctor.

Boyfriend, girlfriend, husband, wife: in this booklet we say “partner”. It is for the person who shares her life.

What she *feels*

The pain is real

Endometriosis affects around one woman in ten. Tissue similar to the lining of the womb grows elsewhere: on the ovaries, the bladder, the bowel, the ligaments. It reacts to the hormones of the cycle and can lead to inflammation and pain. The pain is real: it is not "in her head".

Not only during periods

Over time, the nerves in the pelvis can become more sensitive. The pain can then carry on outside her period, spread to the back or legs, come when she goes to the toilet or during sex. It changes from one day to the next, sometimes from one hour to the next.

The size of the lesions doesn't tell you the pain

Small lesions can hurt a lot, large ones hardly at all. What she feels matters more than a scan report.

Tiredness, the other half

Being in pain often, sleeping badly, inflammation: all of this can contribute to tiredness that is frequent and deep. A nap isn't always enough. Cancelling plans is not a whim.

Her mood is affected too

Years of hearing "period pain is normal", a diagnosis that can take a long time, plans that depend on the day: sadness, irritability or anxiety are common. It's not weakness, and it's not against you.

What often helps

- Believing her, without playing it down.
- Asking "what do you need?" rather than guessing.
- Taking over at home without waiting to be asked.
- Going to appointments with her, if she wants you to.

Avoid: "you're exaggerating", "it's all in your head", "you should have a baby".

The possible effects *of her treatments*

Putting the cycle to rest

The most common hormone treatments (the pill taken continuously, a progestogen, a hormonal coil, sometimes medicines that put the ovaries to rest) aim to stop or reduce periods. This can help reduce inflammation and pain, for many patients but not all. They don't cure endometriosis: their effect usually lasts while they are taken.

Possible effects

Changing hormones can affect, in some women and not in others:

- mood: sadness, irritability, mood swings;
- sex drive, vaginal dryness;
- unexpected bleeding, weight, skin;
- hot flushes with some treatments.

Some changes may be linked to the treatment, the condition, sleep or other things. If these effects are hard to live with, it's important she talks to the professional who looks after her.

What you can do

- Note with her when her mood changed, and since which treatment.
- Encourage her to talk to her doctor: another treatment may suit her better.
- Don't ask her to stop her treatment on her own: that is decided with her doctor.
- Talk about desire and intimacy without blame. Touch and affection are not only about sex.

If her mood collapses

If she talks about not wanting to live, wanting to disappear, or if you are frightened for her: don't keep it to yourself.

Samaritans 116 123: free, 24 hours a day, for her and for you.
111: urgent help; in England, select the mental health option. In Scotland, NHS 24 on 111.
999: emergency, immediate danger.

TO FILL IN TOGETHER

Our plan for *flare-up days*

She is the one who knows what helps her. Fill in this page on a calm day, and keep it to hand.

How I know it's a hard day

What eases it

- [ ] Hot-water bottle, heat
- [ ] Hot bath or shower
- [ ] Lying down somewhere quiet
- [ ] TENS
- [ ] Breathing
- [ ] A back massage

Her treatment for a flare-up

Written by her, from what her doctor prescribed.

What she would like me to do

What she'd rather I didn't do

What she agrees I can do or share with family and friends

Who to tell, with her agreement

GP: _____

Family, friend: _____

Work, school: _____

See a doctor soon · unusual pain, a fever, blood in her wee or poo: her GP, or **111** (Scotland: NHS 24 on 111; Northern Ireland: GP out-of-hours).

Emergency, 999 · sudden severe pain, collapsing, heavy bleeding, she goes pale or faints.

Deaf or unable to speak on the phone: register in advance for emergencySMS (text "register" to **999**), or use 999 BSL.

Month of _____ 20___

One column a day, a few seconds. At the top, her; in the middle, what you did; at the bottom, you. It's not a competition: an empty box is fine.

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
Her what she told me or what I saw																															
Her day calm · OK · hard																															
Flare-up ✓																															
I believed her, listened ✓																															
Meals, shopping ✓ taken care of																															
Children, home ✓ taken care of																															
Hot-water bottle, care ✓																															
Appointment, pharmacy ✓																															
A good moment together closeness, affection ✓																															
My mood good · OK · low																															
My tiredness 0 to 5																															
My sleep good · OK · poor																															
Time for me sport, going out, a break																															
I talked to someone ✓																															

If you often tick "My mood: low" or "My sleep: poor", talk to your GP. Having dark thoughts: Samaritans **116 123**, free, 24 hours a day.

FOR ME

What I *notice*

This booklet is personal. Anything about your partner should be written down and shared with respect for her privacy. One row a week. This is not a report on her: it's what you saw, what you did, and how you are doing. Show it to her if you want to.

Week of	What I noticed	What I did to help	How I am

My questions for the appointment I go to with her

1. How can I help her day to day, and during flare-ups?
2. Which side effects of the treatment should we report?
3. What does it change if we want to have a baby?
4. _____

TOGETHER

Our good *moments*

No pressure to be fine: hard days count too. This is where you keep what does you good. Fill it in separately or together, whenever you feel like it.

Our memories together

Date	What we shared, what we want to keep

What I admire about her

Our plans and wishes, big and small

What makes us laugh

AND YOU?

Look after *yourself too*

Living alongside someone who is often in pain is tiring too. Feeling helpless, cancelled plans, changes in intimacy, worry about the future: what you feel is legitimate.

A few pointers

- Keep some time for yourself, without feeling guilty.
- Talk to someone you trust: a friend, your GP, a counsellor.
- In England, you can refer yourself to NHS Talking Therapies without seeing your GP.
- If anger or sadness take up too much room, get help: it's not a failure.

For information: Endometriosis UK, endometriosis-uk.org, helpline 0808 808 2227 (opening times on the website).

What does me good

Helplines

116 123 · Samaritans, for you or for her. Free, 24 hours a day. In Welsh: 0808 164 0123.

Text SHOUT to 85258 · crisis text line, free, 24/7.

999 · medical emergency, immediate danger.

111 · urgent advice (England, Wales; NHS 24 in Scotland). Northern Ireland: GP out-of-hours; Lifeline **0808 808 8000**, 24/7.

Domestic abuse · England **0808 2000 247** (free, 24/7) · Scotland **0800 027 1234** (24/7) · Wales **0808 80 10 800** (free, 24/7) · Northern Ireland **0808 802 1414** (free, 24/7) · Men's Advice Line **0808 801 0327** (Mon–Fri, 10am–5pm).

THE PARTNER SPACE

In the EndoQueen app, she can share what she chooses with you, and let you know on flare-up days. The partner space is free, with no account or email.

endoqueen.fr

This booklet informs and helps you organise; it does not replace advice from a health professional.