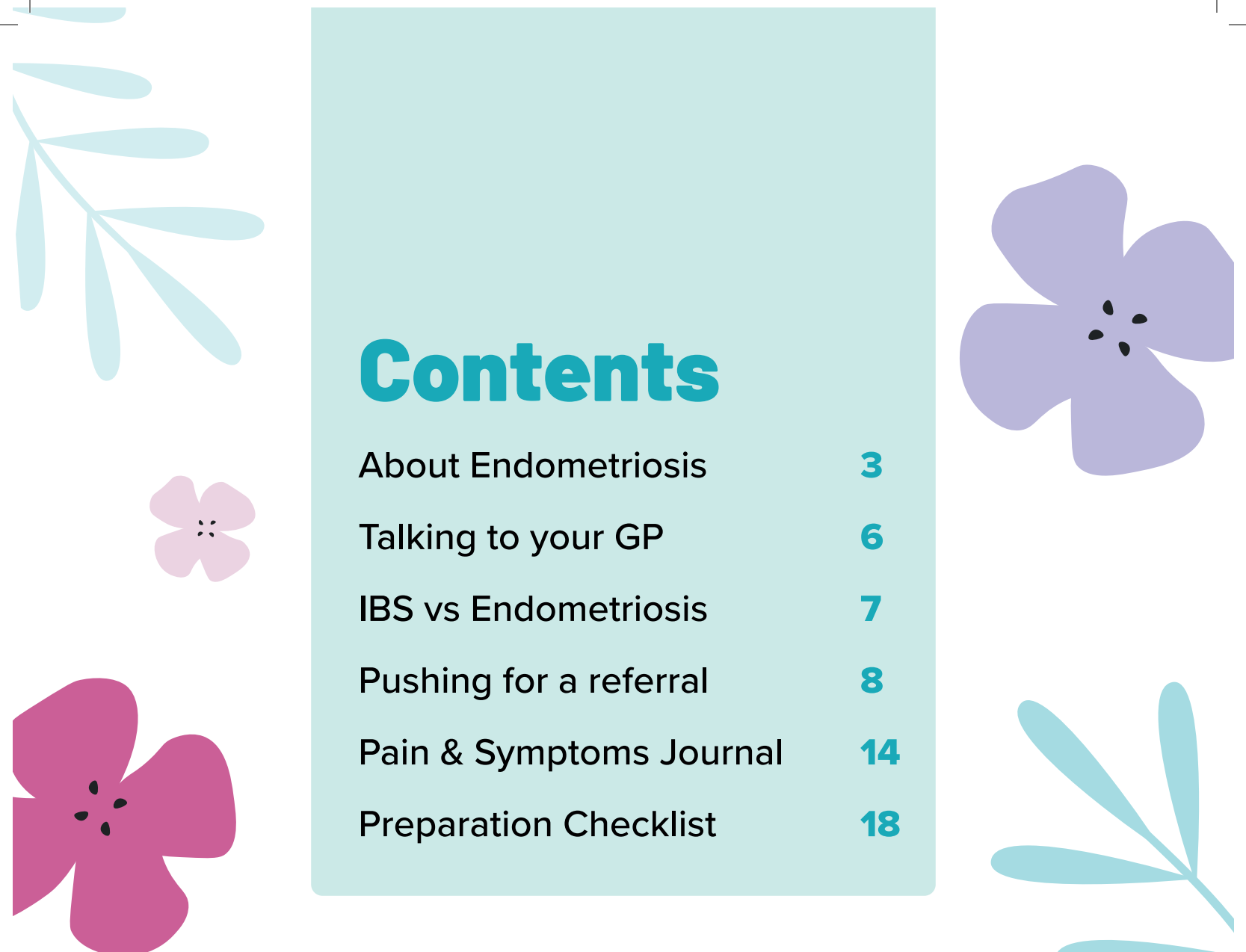




Endometriosis Diagnostic Toolkit



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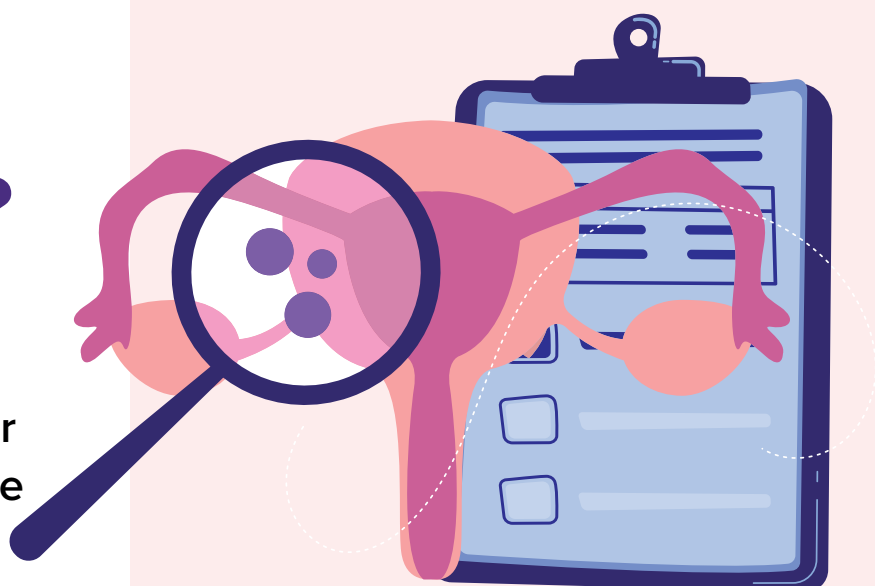
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What is Endometriosis?

Endometriosis is a systematic inflammatory condition where cells similar to the lining of the womb are found elsewhere in the body which can cause debilitating symptoms.



How do I know if my periods aren't normal?

Periods should not be painful.

It is not normal if your period is stopping you from doing your normal day to day tasks.

Symptoms of Endometriosis

- Ovulation pain
- Bloating
- Heavy, long, and/or erratic periods
- Chronic pain in the pelvis and lower back
- Pain during or after sex
- Painful & erratic bowel movements
- Rectal bleeding
- Pain when passing urine
- Lower back & thigh pain
- Chronic Fatigue
- Infertility
- Vomiting & Nausea

Who does endo affect?

Endometriosis affects women and those assigned female at birth from puberty to menopause.

Stigma surrounding Menstrual Health & Women's health

Never feel embarrassed about talking about your Menstrual Health.

It is just as important to talk about as other areas of our health. Women and those assigned female at birth do not have a choice whether we have periods therefore we should not feel ashamed.



The gender gap in medical research

At a cellular level, sex differences, due to hormones such as oestrogen, have a huge impact on drug efficacy and safety profiles. Historically, however, medicines have been tested on mostly male cells in the lab - with those developing the drugs often citing the unscientific reason that female hormone fluctuations make women too tricky to study!

All of this not only means that we are presented with medication that isn't always fit-for-purpose; it means a lack of understanding from some medical professionals. The unknowingly biased knowledge they have access to has far-reaching consequences too: women in Britain are 50% more likely to be misdiagnosed following a heart attack, while it takes seven years for someone to be diagnosed with endometriosis.

DID YOU KNOW?

There is 5x more research into erectile dysfunction, which affects 19% of men, than into PMS, which affects 90% of women!



Take caution when using hot water bottles

A great example of this is heat therapy, which can do more damage to your tissues and make chronic inflammatory conditions such as endometriosis worse!

While full-body heat immersion, such as a warm bath is the best version of heat therapy, it should only be done for 30 minutes.

The same goes for TENS machines which advise cycles of 30 minutes at a time. This means you're often left without support for large parts of the day and is a huge reason why many leading gynaecologists and endometriosis researchers at the forefront of the field recommend using BeYou patches as they do not rely on heat and they release over 12 hours for lasting comfort.

Talking to your GP

Your GP will ask questions you may consider personal but the more information you give them, the better understanding they will have of your situation.

Go armed with as much information as you can, including your medical history, menstrual cycle, symptoms, and any patterns you have noticed with your health.

When you speak to your GP, there are a few things you should remember:

- Many people tend to downplay their pain when talking about it with their GP, but you should never do that.
- Do not be afraid to prompt questions. Ask your GP about endometriosis and that you suspect you may have it
- Don't allow yourself to be medically gaslighted (fobbed off). Some medical professionals are still undereducated when it comes to endometriosis.



Describing the pain

People often find it difficult to effectively describe the pain they are in but it's important to think about because it can help communicate the severity of your pain with your doctor. Here are some common examples:

- Similar to hot pokers in your abdomen
- Sharp, stabbing, shooting like pains in your abdomen
- Twisting pain
- Similar to barbed wire wrapped around your stomach

It is important to note not just how the pain feels but how it IMPACTS your life day-to-day.

Tracking your Menstrual Cycle and Symptoms

This is imperative for you to be able to track and communicate with your doctor effectively. Use a period tracker app or even a manual diary and be sure to keep note of daily symptoms.

Endometriosis Journals

We've created a fantastic pain and symptom diary to help you keep track.

Our Preparation Checklist goes a bit further and has a list of questions to help you go to your GP with as much information about your symptoms as possible.

[Go to Pain & Symptoms Journal](#)



IBS vs Endometriosis

Many doctors misdiagnose endometriosis with IBS because the symptoms can be so similar. It's worth knowing some of the subtle differences between symptoms of endometriosis and IBS.

While each person is obviously different, research suggests that endometriosis patients are more likely to experience:

- Bleeding in between periods
- Elevated pain during the premenstrual phase of the menstrual cycle
- Tenderness within the vagina

Vs IBS patients who are more likely to report:

- Bowel habit changes, i.e. constipation, diarrhoea, etc.
- Abdominal distension
- Colicky pain
- Upper abdominal pain
- Pain aggravated by certain foods or stress
- Nausea

These symptoms are not to rule out the possibility of Bowel Endometriosis, which can be similar and feel a lot like Irritable bowel syndrome (IBS). Symptoms can include:

- Diarrhoea or constipation (Difficulty pooping or loose, watery stool)
- Severe intestinal cramps or pain
- Pelvic pain during sexual intercourse
- Painful bowel movements
- Rectal bleeding
- Abdominal pain or discomfort
- Bloating
- Nausea
- Symptoms may worsen before and during your period.

These symptoms are not just cyclical and can happen at any point through the month if you have bowel endometriosis present.

There is no one-size-fits-all approach to endometriosis, you should still speak to a gynaecologist if you're unsure.

How to ask for a referral

Refer to the NICE guidelines regards to a referral for women and those assigned female at birth who have suspected Endometriosis.

Ask for a referral to a gynaecologist with expertise in endometriosis.

- They should refer per the NICE guidelines if a patient has severe, persistent, or recurrent symptoms of endometriosis.
- They have pelvic signs of endometriosis.
- Initial management is not effective, not tolerated or is contraindicated.
- If they have suspected or confirmed deep endometriosis involving the bowel, bladder, ureters or outside the pelvic cavity they need referring to a **specialist endometriosis service (BSGE Centres)**.
- If aged 17 and under with suspected or confirmed endometriosis they should be referred to a paediatric and adolescent gynaecology service, gynaecology service or specialist endometriosis service (endometriosis centre), depending on local service provision.

If you feel your medical professional is not taking you seriously do not be afraid to request a second opinion.



Possible next steps after a referral

You may be referred for an ultrasound scan, transvaginal scan, and/or MRI Scan.

- Seeing a gynaecologist with a specialist interest in endometriosis – this is where you discuss your symptoms in detail. It's very important to be open and honest at this appointment so your consultant can get a better understanding as to how your symptoms impact your life.
- Your specialist may refer you for a Laparoscopy – this is keyhole surgery which is the only definitive way to diagnose endometriosis.

What is a Laparoscopy?

A laparoscopy is an operation in which a camera is inserted into the pelvis via a small cut near the belly button.

The trained endometriosis specialist will use the camera to see the pelvic organs and look for any signs of endometriosis. If endometriosis is found it may be excised on the day or in a separate surgery.

Treatment options

It is important to be aware that there is currently no cure for endometriosis.



- **Excision surgery** – to cut away the endometriosis deposits.
- **Hormone treatments:**
 - Combined pill** – works by suppressing ovulation.

Mirena coil – a plastic t-shaped intrauterine device (IUD) that releases a synthetic form of progesterone.

GnRH analogues – These are medications that can stop the production of oestrogen, essentially placing the body in a temporary menopausal state. It works by ‘starving’ the endometriosis of oestrogen essentially causing the endometriosis to become inactive. Often they advise taking hormone replacement therapy to counteract the side effects of the drug so please speak to your specialist if you encounter any side effects.

Progesterones – such as Norethisterone & Depo Provera. These suppress the growth of endometriosis and may also reduce inflammation. It’s important to note women will stop ovulating and menstruating whilst taking it.

• Medication & Pain Relief

- NSAID’s such as Voltarol, mefenamic acid, ibuprofen
- Simple analgesics such as paracetamol for mild pain
- Codeine based pain relief
- Opioids such as slow-release morphine
- Pain modifiers like amitriptyline help by trying to stop the pain messages travel through your nervous system.
- Cold therapy
- Heat therapy
- BeYou patches
- Physiotherapy

It is important to always consult your doctor regarding medication due to the possible side effects. For example, certain treatments which stop the production of oestrogen can negatively impact bone density so supplementation may be required.

Endometriosis and Fertility

It is important to note even in severe endometriosis natural conception is still possible.

- Infertility can affect between 30-50% of endometriosis sufferers
- Having a laparoscopy to excise superficial endometriosis can lead to better natural conception rates
- Endometriosis can increase your risk of miscarriage from 1 in 5 to 1 in 4
- Access to IVF and other fertility services are down to individual healthcare boards/trusts.
- You can access an earlier referral for a fertility consultation when there is a known clinical cause like endometriosis.
- Pregnancy does NOT cure Endometriosis. You may have a reduction in pain during pregnancy, but it may return once your menstrual cycle returns after birth.

Endometriosis Information for Teenagers

How do I know what is normal?

- Period pain should not be so bad that it stops you from doing your day-to-day tasks and carrying on with normal life
- A normal period lasts anywhere from a couple of days to a week. With a normal period, you should only be changing your tampon/towel every 3-4 hours and should be a light-moderate blood flow
- If your periods don't settle and combine with back/leg pain, heavy bleeding, pain when going to the toilet you should speak to your nurse or doctor.

Sometimes what you are going through is not normal. Trust your body. You know better than anybody. Do not be afraid or embarrassed to speak up. The sooner you can get the correct help and support the better.

Endometriosis and Menopause

Menopause doesn't cure endometriosis.

Menopause may alleviate the symptoms of endometriosis for most women, but some will continue to experience symptoms or even develop endometriosis after menopause.

- **Natural Menopause** – typically menopause naturally happens between your late 40s & 50s and occurs 12 months after your last menstrual cycle.
- **Chemically Induced Menopause** – GnRH analogue injections, such as Prostag and Zoladex, are medications that stop the production of oestrogen, essentially placing the body in a temporary menopausal state. You can be on these injections for up to 6 months sometimes longer, but this is decided with your specialist gynaecologist for the right treatment plan for you. When you stop the injections, it can take 6-10 weeks for periods to return. The longer you are on the course of treatment the longer it can take for periods to return. You can discuss hormone replacement therapy with your gynaecologist to help combat some of the side effects (please note its not suitable for everyone).

- **Surgically induced menopause** – this is when you have a total or radical hysterectomy that removes your ovaries. You will experience menopause immediately after your operation regardless of your age. HRT is usually prescribed to help combat menopausal symptoms such as hot flushes, depression, insomnia, vaginal dryness, fatigue and night sweats.



Endo Myths

A hysterectomy does **NOT** cure endometriosis

Pregnancy does **NOT** cure endometriosis

That endometriosis only grows in the womb – it is a **WHOLE** body disease

‘Endometriosis is just a period’ – it’s not and it can be a debilitating disease to live with

Other Menstrual Health Conditions & Concerns

Adenomyosis

Occurs when the tissue that normally lines the uterus grows into the muscular wall of the uterus. Common symptoms are heavy, painful or irregular periods, pre-menstrual pelvic pain, pain during intercourse, pain related to bowel movements.

PCOS

A common condition that affects how women and those assigned female at birth ovaries work. PCOS contain a large number of harmless follicles. These follicles are underdeveloped sacs where eggs develop. These sacs are sometimes unable to release an egg, which means ovulation does not take place. Symptoms are irregular periods or no periods, difficulty getting pregnant, excessive hair growth, weight gain, thinning hair or hair loss, oily skin or acne.

Fibroids

Non-cancerous growths that develop in or around the womb. Growths are made up of muscle and fibrous tissue that vary in size. Some women and those assigned female at birth have no symptoms although 1 in 3 women may experience heavy periods, tummy pain, lower back pain, frequent urination, constipation, pain or discomfort during sex.

PMS (Premenstrual Syndrome)

This is the name for the symptoms women and those assigned female at birth can experience in the weeks before their period.

The symptoms can be mood swings, feeling anxious, tiredness, trouble sleeping, bloating or tummy pain, breast tenderness, headaches, spotty skin, greasy hair, changes in appetite and sex drive. Most women will have PMS at some point.

PMDD (Premenstrual Dysphoric Disorder)

A small number of women and those assigned female at birth may experience more severe symptoms of PMS known as PMDD. Symptoms of PMDD are similar to PMS but are much more intense and can have a greater negative impact on your daily life.

Symptoms include physical symptoms such as cramps, headaches, joint and muscle pain, behavioural symptoms like binge eating and problems sleeping, and mental and emotional symptoms such as anxiety, anger, depression and in some cases suicidal thoughts.

It is very important that you contact your GP if you have any of the above symptoms.

Accessing Emotional Support



Support groups



Ask your GP



Social Media



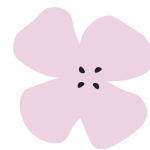
**Preparation
Checklist**

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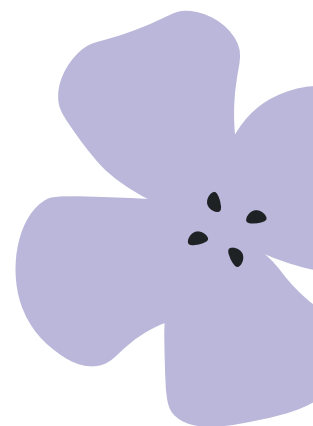
beyou.co.uk

**www.menstrualhealthproject.org.uk
hello@menstrualhealthproject.org.uk**



Pain & Symptoms Journal

Talking through your symptoms with your doctor becomes much easier if you keep a diary. It also helps you keep track of changes and can even help identify triggers that may be causing you to flare up. You might find your body likes certain things so journalling can be a key tool in helping you and your doctor navigate your journey together.



**There is no one-size-fits-all approach -
all experiences and bodies are different.**

First things first, print The Pain Scale off once so you can refer back to it, and print as many copies of the journal page as you need.

How to use

Step 1)

As soon as you wake up fill in the top section:

- Day and date
- If you're on your period, what day of your period is it?
- How did you sleep out of 10?

In the first row of the table, note any pain or symptoms you experienced overnight, using the Pain Scale to input your pain score.

Step 2)

Fill in the middle section when you can throughout the day to ensure you capture as much detail as you can. It is important to note your pain score throughout the day as this will help you identify patterns.

- Circle or shade the diagram wherever your pain is and describe it in the table
- Use The Pain Scale to record a number out of 10 (but feel free to leave notes - for example, if you're at level 4 but didn't take any medication write that down, as well as anything else you did to help)
- Be as specific and descriptive as possible when filling in the table. On The Pain Scale, we've included some common words Endometriosis sufferers use to describe their pain to help you get started
- If you need to circle or shade multiple areas of pain on the diagram, simply label each one with a (1), (2), (3), etc so you can refer to the number when you're describing it in the table.

Some examples are below:

- If you have pain in your lower back and right thigh at the same time you could circle them and put a (1) next to both. Or you could mark them with a (1) and a (2) and write about them separately
- If you had rib pain in the morning and then again in the evening you could either use one label (1) for both, or you could differentiate between the morning rib pain (1) and add a (2) to represent your evening rib pain

(These are just some examples. We've intentionally made the journal flexible so you can do what makes sense to you!)



Step 3)

Fill in the blue section at night before you go to sleep.

This is often the time you have some time to reflect and can add any other thoughts you may have missed.

This includes your mental wellbeing which is a crucial part of your journey. Score your mood, stress, and energy levels out of 10. We haven't provided a scale for this so use your best judgement.

For best results

- Incorporate it into your routine—morning and night. That way no matter how good or bad you feel, you have it all documented
- Our studies show that doing the first section as soon as you wake up keeps you mindful of your symptoms throughout the day

Lastly, we've all been there - you leave your doctor **and then** remember something you wish you had told them or answered differently!

That's why we've included the Preparation Checklist, which has additional questions for you to think about before speaking to your doctor so you have a better chance of communicating everything you want to. It will help you summarise your pain and symptoms - so we recommend using your journal regularly.

The Pain Scale

Pain can be incredibly difficult to explain as it is so subjective and it can be hard to find the right words. Use the pain scale below to help you fill in your pain journal.

It's loosely based on the Numerical Pain Rating Scale, which is used by the NHS and is a great tool to help describe your pain to doctors. While it may not be perfect for every scenario, it is a great starting point to help you with describing your pain using a single framework for consistency.

THE PAIN SCALE		
Mild	0	No pain
	1	Hardly notice pain
	2	Notice pain, does not interfere with activities
	3	Sometimes distracts me
Moderate	4	Distracts me, can do usual activities
	5	Interrupts some activities
	6	Hard to ignore, avoid usual activities
High	7	Focus of attention prevents doing daily activities
	8	Awful, hard to do anything
Severe	9	Can't bear the pain, unable to do anything
	10	As bad as it could be, nothing else matters

We've also included some **common words** Endometriosis sufferers use to describe their pain to help you get started. Feel free to add others so you have them all in one place!

aching agonising burning debilitating excruciating constant
 cramping crippling dragging nauseating numb piercing pressure
 radiating sharp shooting sore spasm stabbing tender
 throbbing relentless unbearable erratic

Day: _____

Date: ____ / ____ / ____

Period? No ☐ Yes ☐

Period Day: _____

Sleep Score: ____ / 10

Describe it i) If you have pain in multiple areas, put a number on the diagram and reference it ii) Be as specific and descriptive as you can	When did it start? i) What time? ii) After any activity?	How long did it last?	Did anything help or make it worse? E.g. food, activities, etc. If you used any medication, what and how much?	Related to any symptoms? E.g. bloating, bleeding	Did it stop you from doing anything? E.g. work, social activities
LAST NIGHT					
MORNING					
AFTERNOON					
EVENING					

Pain Score
(From the Pain Scale)

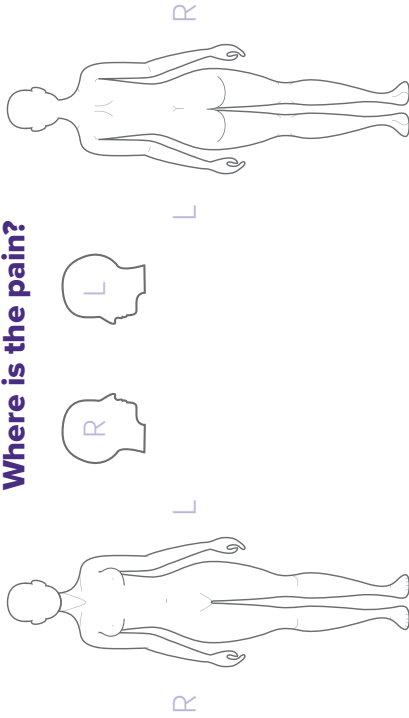
Last Night
/ 10

Morning
/ 10

Afternoon
/ 10

Evening
/ 10

Where is the pain?



Any other symptoms?

e.g. bleeding, bloating, exhaustion, nausea, vaginal tenderness

Anything else you want to track?

e.g. food/activities (e.g. walking or exercise) / anything which you think might be triggering pain

Mood / 10

Stress / 10

Energy Level / 10

Water Intake ____

**Today's
Pain Score**

/ 10

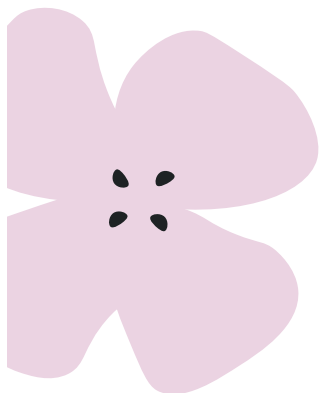


Preparation Checklist

Questions to help avoid those “I wish I had said...” situations!

These questions have been designed to help you make the most of the limited time you’ll have at an appointment with your doctor. Take your time to answer them carefully and give as much detail as you can. Upon completing it, you should be able to answer almost any question your doctor throws at you!

Sometimes a question might trigger something you want to make sure you talk about so we’ve included some blank spaces at the end. Using this checklist each time you have an appointment can help you and your doctor keep track of your journey.



Pro tip: Photocopy your answers and give them to your doctor each time!

You and your lifestyle

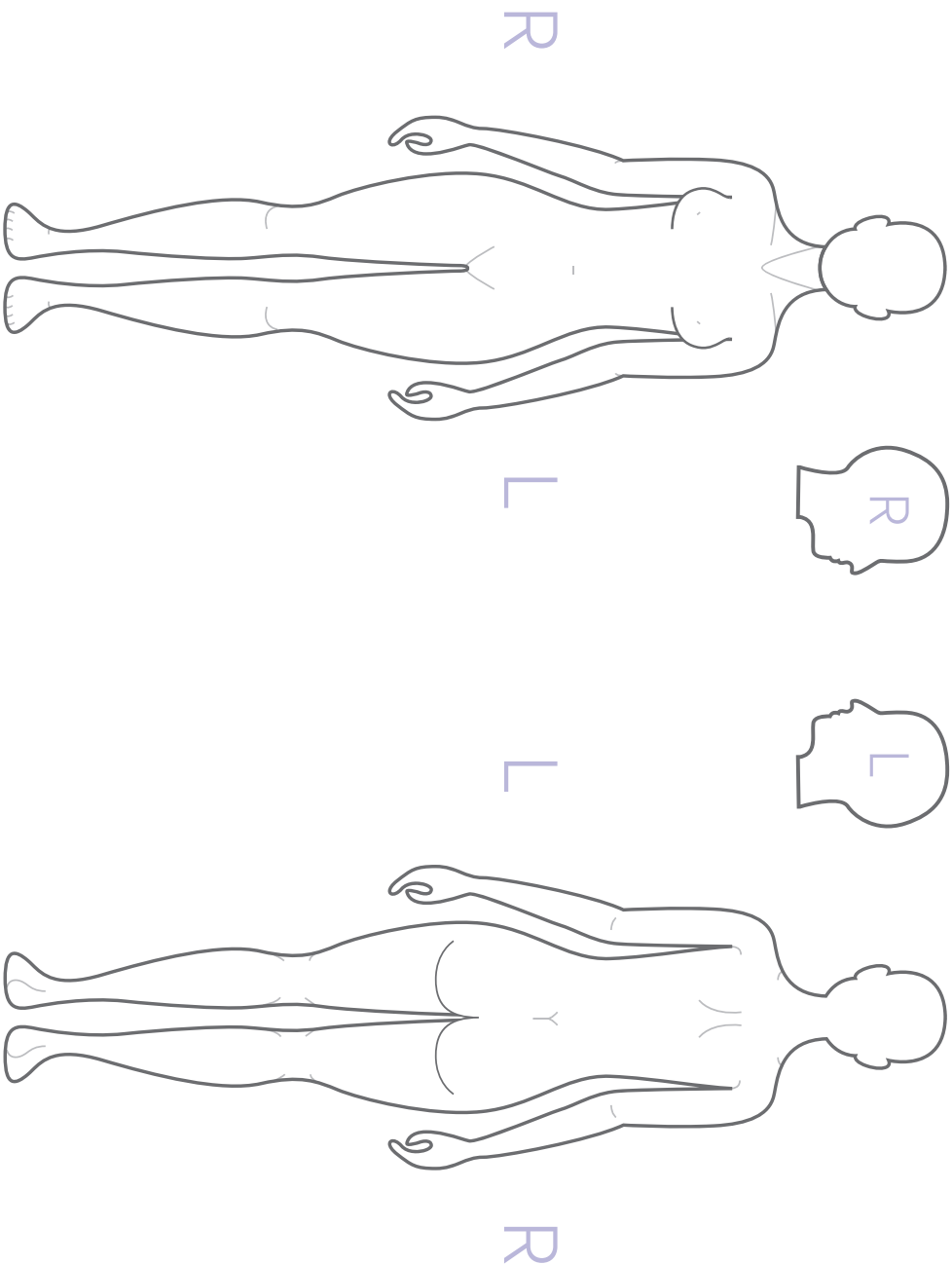
Name:	
Age:	
Does anyone in your family have any major illnesses or diseases?	
Have you had, or do you currently have any major illnesses, diseases or gynaecological conditions? If so, what?	
In relation to your answer above, what are the most common symptoms you experience?	
Have you had any major operations? If so, what, when and what was the outcome?	
Are you on any medications? If so, what medication, what for, what strength and how often do you take them? <i>Include any hormones, birth control and any herbal medicines too</i>	
When was your last smear test? <i>(If applicable)</i> What was the result?	
Do you have any allergies?	
How much water do you drink each day on average?	
Do you follow any particular diet?	
Do you take any supplements regularly? <i>If so, what are the key components/nutrients and how much?</i>	
What is your daily activity level?	☐ Sedentary <i>(little to no activity; deskbound)</i> ☐ Lightly active <i>(you spend some of the day standing and walking; light exercise 1-3 days / week)</i> ☐ Moderately Active <i>(on your feet most of the day; moderate exercise 3-5 days / week)</i> ☐ Very Active <i>(physical job; very strenuous exercise 5 days / week)</i>
Do you drink alcohol? <i>If so, how frequently and how much?</i>	
Do you smoke? <i>If so, how frequently and how much?</i>	
Do you or have you ever used illegal drugs? If so, how frequently and how much? <i>(some substances can have an adverse effect on endometriosis)</i>	

Your period

When was your last period?	
How old were you when you got your first period?	
Do you have your period every 28 - 30 days? If not, how regular or irregular are they?	
Have you noticed anything which may have caused your period to be more or less regular?	
How many days does your period usually last?	
Have you noticed anything which may have caused a period to last longer?	
Would you describe your flow as light, medium, heavy or very heavy?	
Have you noticed anything which may have caused a period to be lighter or heavier?	
Do you bleed between periods? <i>This includes any spotting</i>	
Have any of the above answers changed over time? If so, explain.	
When do you experience pain in relation to your period?	☐ During my period ☐ All the time ☐ It comes and goes
In relation to your answer above, how many days do you experience pain every month?	
When do you experience the worst pain?	☐ When my period is due ☐ When I'm ovulating ☐ During my period ☐ Not applicable ☐ Other days throughout the month
In relation to the three answers above, is this always the case or does it vary?	

Pain and symptoms

This is where your Pain & Symptoms Journal will come in handy! You should be able to answer these questions with confidence knowing that you've been keeping track of your journey. At any time, if you feel you need to make any notes just use the blank spaces - remember, this is about helping you keep everything top of mind for when you speak to your doctor.



Describe your pain

If you've been using your journal, use this to summarise the last 4 weeks. Take an average but feel free to write any additional notes in the space provided.

Step 1) On the diagram, circle or shade the areas where you most commonly experience pain.

Step 2) Next to each area, label how frequently you feel that pain in descending order. *For example, if you most frequently get pain in your back, label it with a (1), then the next most common pain area with a (2), and so on.*

Step 3) Next to each label, write the intensity of the pain you experience using the Pain Scale. *Take an average of the pain scores from your journal.*

Step 4) Next to each label describe the pain in that area. *Tip: see what words you've used the most in your journal to describe the pain in that area.*

Additional Notes

Common Questions

Two of the most sensitive topics your doctor will need to talk to you about is your pain in relation to sexual intercourse and bowel movements. For many people, this can be an extremely uncomfortable conversation but it will help your doctor gain a better understanding of what you are going through and the next steps.

Pain during	When is it worse?	In relation to your period	Any other notes
Sexual Activity	☐ During intercourse ☐ After intercourse ☐ Both	☐ Ovulation ☐ When due ☐ During period ☐ All the time	
Bowel movements	☐ Before bowel movement ☐ During bowel movement ☐ After bowel movement ☐ All of the above	☐ Ovulation ☐ When due ☐ During period ☐ All the time	

Other Symptoms

What other symptoms do you experience?

Tick all that apply. We've kept space for anything else you might want to add.

Symptom	When is it worse?	How long does it last?	Any other notes
Nausea	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Vomiting	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Vaginal bleeding	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Painful urination or blood in urine	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Bloating	☐ Ovulation ☐ When due ☐ During period ☐ All the time		

Symptom	When is it worse?	How long does it last?	Any other notes
Physical fatigue	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Constipation	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Diarrhoea	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Blood in stool	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Back Pain	☐ Ovulation ☐ When due ☐ During period ☐ All the time		
Pelvic/ Abdominal Pain	☐ Ovulation ☐ When due ☐ During period ☐ All the time		

Patterns

Have you noticed the severity of your pain or symptoms change with any of the following:
We've left some blanks for you to add in any other patterns you may have noticed.

Variable	When does it change?	For better or for worse?	Any other notes
Time of day	☐ Morning ☐ Afternoon ☐ Evening ☐ Overnight		
Exercise	☐ Light movement before period ☐ Light movement during period ☐ Light movement any time ☐ Moderate movement before period ☐ Moderate movement during period ☐ Moderate movement any time ☐ Strenuous exercise before period ☐ Strenuous exercise during period ☐ Strenuous exercise any time		

Variable	When does it change?	For better or for worse?	Any other notes
Diet			
Stress			
Water intake			

Diagnosis & Management

Summarise your pain journey.

This is a reflective exercise to help you keep your journey at the forefront of your mind.

Your period	
When did you start getting pain? Have there been any changes over time? Has anything got better or worse over time? Where is your pain level now compared to before?	
Have you had any previous appointments with a doctor to get help with your symptoms? <i>If so, what happened?</i>	
Have you been taking any medication to help with your symptoms? <i>If so, include what you took, dosage, and what effect it had (including any side effects).</i>	
Have you tried anything else to help with your symptoms? <i>If so, what, how much, and what effect did it have?</i>	
Describe how your symptoms have impacted your life. <i>This is vital. Are you having to miss work, education, social activities, exercise, etc? Is it impacting your relationships?</i>	

Anything else

This is a space for you to write down any other information you feel is important.



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