



Endometriosis and COVID-19

Information for patients

This leaflet will give you information, guidance and, hopefully, reassurance regarding your endometriosis during the COVID-19 pandemic. We will describe how and why our services are temporarily changing for the coming weeks and months to allow the NHS to manage unprecedented demand on its capacity.

How is the endometriosis service changing?

The unprecedented COVID-19 pandemic has put the NHS under strain and so we have had to suspend our normal endometriosis service. All surgical procedures, including surgery for endometriosis, have been put on hold to enable key staff to assist colleagues caring for patients with COVID-19 in intensive care. This means there is minimal theatre capacity, even for acute emergencies.

Face-to-face outpatient clinics are also suspended and we will be conducting only very limited consultations and investigations. We do not know when normal services will resume but anticipate this to be some weeks or months away. These measures have released staff and facilities to allow the hospital to care for our most unwell patients.

Once surgical procedures resume, there will be a considerable waiting list which will be closely scrutinised, and patients will be prioritised according to clinical risk. Please be patient with us—we will resume operating as soon as we can.

What management can I try while I wait?

We are well aware that any delay in investigation and treatment may cause significant stress and perhaps leave you in distressing pain. Please accept our sincere apologies. All of us in the endometriosis team deeply regret any delay as we understand what a long and difficult journey endometriosis can be. There are, however, treatment options that can be initiated, re-established, or continued depending on your individual circumstances. Treatment can vary a little depending on what you have tried before and what you have found works best, but the mainstay of medical endometriosis treatment is hormonal.

If you are currently on a hormonal treatment that works for you, we advise that you continue this for the duration of the COVID-19 postponement. Pain relief medication is usually helpful and we recommend taking regular paracetamol and drugs such as ibuprofen (non-steroidal anti-inflammatory drugs, NSAIDs) as required. There has been some press highlighting concern with the use of ibuprofen type drugs while actively infected by COVID-19 itself, but we believe NSAIDs are entirely appropriate to treat your pain symptoms if you are well. You must use caution with all NSAID medication if you have asthma, stomach ulcers, or kidney disease. Please do not take these if you have previously been advised not to by your GP.

Stronger pain relief such as codeine or dihydrocodeine (opiates) can be used sparingly, when required, but are sometimes the only thing that may help your symptoms. We recommend you use these drugs in combination with paracetamol and NSAIDs to reduce the amount of opiate medication you require. Opiates can have side effects such as constipation, nausea or drowsiness, even in small doses. Indoor living and reduced exercise can also make you constipated so, if you are taking opiates, we strongly recommend a mild laxative and plenty of fluids even before you become seriously affected.

What hormonal treatments can I try?

The mainstays of hormonal treatment are:

- progesterone-only preparations (oral, implant, injection or coil)
- combined hormonal preparations (combined oestrogen and progesterone pills)
- GnRH agonists (injection)

Each of these work in different ways but all can be effective in controlling the symptoms of endometriosis including pain and heavy bleeding.

If you are already taking a hormonal treatment that is working for you, however poorly, we strongly recommend continuing this throughout the pandemic. It is almost universally safe to do so, as you will have undergone a risk assessment before the first prescription was written. If you have not yet commenced hormonal treatment or you are awaiting investigations to formally diagnose possible endometriosis, it can still be appropriate to commence hormonal treatment.

Many of you will have previously used either a progesterone-only or combined preparation as a hormonal contraceptive—these can be used to manage the symptoms of endometriosis. It may be best for you to recommence a medication that you have used previously, unless you have developed new conditions since your GP last gave you a prescription for it*. These are prescription-only medications so you will need to at least speak to a doctor before you can start on them.

*If considering recommencing the combined pill, we recommend having a discussion with your GP if you have any other medical conditions, high blood pressure, a personal or family history of blood clots, suffer migraines, have a BMI >30, or if you are a smoker over age 35.

Progesterone-only treatment, safe to start?

Progesterone-only preparations, progestogens, are a very effective treatment for endometriosis and are almost universally appropriate and safe. These come in pills, injections, implants or intrauterine devices (IUSs). Progesterone-only pills are taken every day throughout your cycle and, over time, you should expect to have little or no bleeding.

When you first commence a progesterone you may experience some irregular spotting or bleeding which can go on for a number of months, though the blood loss will usually settle given time.

If a progesterone-only pill does not control your symptoms, there is usually an option to increase the dose.

Progesterone does sometimes have side effects which are not usually medically serious, but can interfere with your life. These include ache, nausea, bloating, fluid retention and mood changes. Some women are more sensitive to progesterone than others—some get no side effects, though if you do, they tend to settle in time.

The progesterone coil (we commonly use the Mirena IUS) is placed inside the womb, thus avoiding many of the side effects by delivering the hormone just where it is needed. This is very effective for endometriosis symptoms. Again, some irregular bleeding is expected for the first few months, but we would expect the vast majority of people's periods to become light or stop thereafter and vastly improve pain symptoms.

Can I change the way I take my medication?

Due to a delay in surgery, you may wish to change how you take your medication. This can include increasing the dose, changing preparation or taking a pill continuously where you would have previously had a break.

If you are already taking the combined pill (COCP) then feel free to run your packs together without taking a break. We would not expect you to have periods while doing this and it can help control symptoms. If you have bad period symptoms this is a very risk efficient way of managing them. We often recommend taking

the combined pill continuously as a trial of treatment. In some circumstances, usually to avoid surgery, patients opt to take the combined OCP for many months, or even years, without major consequences.

When taking the pill continuously, you may experience some unscheduled bleeding, though this is to be expected in the first 3–4 packets (9–12 weeks). If this becomes persistent and troublesome, we recommend taking a 5–7-day break and then restart again. During the pill-free days you will have a “period” but, once you start the pills again, the bleeding will stop. This strategy will hopefully provide some respite from your symptoms while awaiting consultations, investigations or surgical treatment.

Your response to different pills will vary and we recommend you use one you have previously tried that suits you. You can access prescriptions for the medication you need through your GP or some sexual health clinics. There may be limited access to appointments during the COVID-19 lockdown, and this could change, so consider asking for a repeat prescription early, especially if you are taking it with no gaps.

Can I try GnRH analogues or stay on them longer during COVID-19?

GnRH analogues (such as Zoladex or Decapeptyl) are usually a very effective choice at treating symptoms of endometriosis, and one which many of you will have previously tried or are currently using. If you have not previously used it and would like to consider it, we recommend discussing this with your GP, as we have given them guidance on who it is appropriate for and how to manage side effects.

These medications come in injection form which is usually monthly, but a 3-monthly preparation could be more useful in the lockdown if that is available at your pharmacy. The medication acts to reduce your ovary’s production of oestrogen, thus causing endometriosis to gradually become less active, then inactive over about 6 months. The effect of this is to put your body into a state like the menopause. It is, however, entirely reversible and when you stop the injections your periods will slowly return—hopefully less heavy and less painful. While using GnRH analogues, some women find they have menopausal symptoms (hot flushes, sweats, sleeplessness) and oestrogen add-back therapy (oestradiol or tibolone) can be used to control this if symptoms become distressing.

If you are using GnRH analogues for longer than 6 months, taking add-back therapy becomes more essential to reduce the risk of thinning bones. Usual treatment is for 6 months, although studies have shown that it is safe and effective to take for longer periods and, in the current circumstances, we support this. The longer the medication is used, the greater the risk, but these changes are largely reversible when treatment is over.

If, however, you have any additional risk factors for osteoporosis (family history or long-term steroid use, for example) then add-back is mandatory. We recommend that, if you are currently on a GnRH analogues and have been due to stop at the time of your surgery, you continue the treatment, provided you have oestrogen add-back. The alternative would be to take a high dose progesterone such as medroxyprogesterone acetate (Provera) 30–40mg daily. Your GP may wish to discuss this with us on an individual basis if they have any concerns.

What non-medical treatments can I try?

Many people find that alternative, non-medical or surgical treatments help control symptoms. This is very individual and different people will find what works for them through prior experience or trial-and-error. The regrettable delay of surgery or further investigation could be a good opportunity to find out if any of these therapies work for you.

- A **hot water bottle or warm bath** can considerably help symptoms when they are at their worst—you could try this with or without other pain relief. Direct application of heat for prolonged periods can cause a rash (erythema ab igne). If the area is only mildly affected with slight redness, the condition will resolve by itself over several months. If the condition is severe and the skin becomes pigmented, resolution is unlikely, although hopefully delays will not be too long.

- Some find **altering what they eat** can have an impact. This is often the case when endometriosis symptoms are combined with irritable bowel. Increasing dietary fibre, cutting down on gluten and/or dairy and eating plenty of fruits and vegetables can have a very positive effect. Be aware that some over-the-counter and herbal remedies can interact with hormonal treatments and we encourage you to seek advice from your pharmacist or GP when starting something new.
- **Maintaining good nutrition and taking multivitamins** is certainly advisable. Getting out to **exercise** is incredibly important, as is sunshine and air for both physical and mental health. This is, of course, affected by the current lockdown, but we recommend you use your allowed outside time wisely and continue to exercise as best you can. There are many web-based resources that can be used to help with home exercise, and we encourage their use even if it can be difficult to self-motivate.
- **Yoga and meditation** are techniques used by many to help control pain symptoms and improve their mental health. This could be especially useful in the current circumstances—try to find some time in the day away from other household members to relax and reflect.
- **Practicing mindfulness** can help us all become more aware of our own bodies and thoughts, which can be particularly useful for helping control pain symptoms and something you could choose to invest time in during this period of lockdown. There are few positives to the concept of social distancing at home, but taking a little time for yourself away from the pressures of modern life could help you understand your symptoms, thought processes, and what works for you a little better.

There is a significant mental health burden from endometriosis and chronic pain syndrome, which can add to the mental health strain associated with this period of confinement and delays in treatment due to the pandemic. We understand this and encourage you to seek support that you have previously found useful, whether that is a discussion with your GP regarding medication, or non-medical treatments that may be beneficial.

Social media is a wonderful tool for connecting people and has become invaluable to most during the COVID-19 outbreak. Exercising caution with trends and fads online is the best approach, as is taking time to self-reflect rather than worrying how you appear to others. We all find social distancing isolating and staying in touch with family and loved ones by voice or video is important. Do talk about your symptoms, stresses, and strains with those you feel able—it is not always easy but can be very helpful.

A useful website is Endometriosis UK (www.endometriosis-uk.org). Explore it and perhaps complete their pain diary—it may well help you understand your symptoms more and be able to explain them to us when we get to see you.

Contact us

Our email contact at Chelsea and Westminster remains endometriosis@chelwest.nhs.uk. This address is monitored by our specialist nurse who can pass queries on to the doctors as required. Please be aware that our specialist nurse is working primarily in intensive care to treat those most in need with COVID-19. As doctors, we have roles outside the endometriosis service covering obstetrics, acute gynaecology and helping areas of the hospital where there are additional pressures. We will try our best to answer any individual queries and certainly give advice to GPs, who have also received information from us. We ask for your patience if we do not respond as quickly as you would like—we understand the stress you are under and hugely regret any delays in getting your treatment underway.

Endometriosis Service

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Our team

- Amer Raza (Consultant Gynaecologist)
- Robert Richardson (Consultant Gynaecologist)
- Dimitra Georgiou (Consultant Gynaecologist Locum)
- Thomas Bainton (Endometriosis Fellow)
- James Phillips (Advanced Trainee Endometriosis_)
- Rebecca Payne/Kathryn Main (Endometriosis Specialist Nurses)

Patient Advice & Liaison Service (PALS)

If wish to give feedback about services, your care or treatment, you can contact the PALS office on our website www.chelwest.nhs.uk/pals. We value your opinion and invite you to provide us with feedback.

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