



Medical and self-care advice for women with endometriosis during the COVID-19 pandemic

The COVID-19 pandemic is a source of significant worry and uncertainty for everyone. However, we understand that if your medical care has been affected then this time may feel even more challenging for you. We have therefore put together this information resource, to both guide you with regards to some of the current recommendations on medical treatments and to offer some strategies for the management of some of the associated symptoms. Please let us know if there is anything you feel is not covered adequately and we can update the resource.

Changes to your treatment plan

Medical

We are hearing lots of stories of women being unable to obtain the drugs they were taking or being asked to change to different drugs. This is obviously upsetting for a variety of reasons.

These are our recommendations for how hormonal treatments could be managed during the COVID-19 pandemic, including advice from the relevant bodies as appropriate*. Please remember that although your GP will not want to see you face to face to discuss these treatments, most are able to offer telephone appointments and electronic prescription services. Therefore if you have concerns we would suggest you contact them. It is also important to be aware that prescription services are taking longer than normal and therefore you should ask for a repeat prescription earlier than you would normally. Unplanned gaps in hormonal treatments could lead to breakthrough bleeding and a flare in pain.

If you are currently using...

1. Combined oral contraceptive pill (COCP):

These are pills containing estrogen and progestogen (*e.g.* Rigevidon, Microgynon, Femodene *etc.*). Normally you would need regular checks of your blood pressure and weight before being given a repeat prescription. However, current advice is that as long as these were OK at the last check, repeat prescriptions can be provided for the next 6-12 months without you being seen in person.

When these pills are used to treat heavy bleeding or painful periods/endometriosis-associated pain we find they work best if you aim to stop your periods altogether.

Therefore, if you are currently taking them in a traditional way (e.g. 21 pills followed by a 7 day break) you may want to switch to what is known as the “tailored regime”. To do this, you simply run the packs one after another without a break until you get bleeding for 2 days in a row. If this happens then don’t take the pill for 4 days and then restart, again running the pill packets back to back. This strategy allows you to have as few bleeds as possible per year and keeps them short when they do happen. Some women will be lucky and be able to run the packs together continuously without getting any bleeding, unfortunately we can’t predict who will get bleeding or how many packets can be run together before this happens. As long as the break between pill packets is 4-7 days and doesn’t happen more than every 21 days then the pill will still work as a contraceptive. There is no harm associated with using the pill this way and it is a recommended way of taking the pill even if only using it for contraception.

Important: the tailored regime is only suitable for pills that are exactly the same for the whole 21-day packet. These include most of the commonly prescribed pills (Rigevidon, Gedarel, Loestrin, Microgynon, Cilest). If you need to check whether your brand is one of these types there is a table [here](#). Any pill listed as “*Combined Oral Contraceptives Monophasic 21-day preparations*” is suitable.

There are also pills that come in packets of 28, however, 7 of the tablets are “dummies” i.e. they don’t contain any hormones and are just used to remind you to take a tablet every day. These brands are Femodene ED, Microgynon 30 ED and Zoely. You can do the tailored regime with these if you just throw away the dummy pills, but it is probably best to contact your GP and ask to change to one of the standard 21-day preparations.

Any pills listed as multiphasic (e.g. Logynon/Logynon ED, TriRegol, Synphase and Qlaira) are designed to mimic the hormonal changes of the natural menstrual cycle and so the doses of hormones in the pills varies. These pills are therefore not suitable for the tailored regime. Again if you would rather try a regime that reduces the number of periods you have during this time, we would suggest contacting your GP to change to a monophasic brand.

2. **Progestogen only pill (POP):**

These are pills that do not contain estrogen (e.g. Cerazette, Cerelle, Norgeston, Noriday). There are very few women who can’t take these pills, this means that they can be given to women who can’t take the COCP because of heart disease, migraines with aura or a history of blood clots for example. Current guidance recommends that during the pandemic a further 12 month supply of these pills can be given without a review.

Some women find they get irregular bleeding when using these pills and as well as being annoying, this bleeding can flare their pain. Remember that irregular pill-taking

is a common cause for this, so try to take your pill at roughly the same time everyday. If this still occurs, our recommendation is to double the dose of the pills. To do this, just take two pills once a day rather than one. There is most experience doing this with the pills containing desogestrel, but it is safe with any of the POPs and the dose of progestagen is still relatively low compared to other treatments. Please discuss this with your GP to ensure you get sufficient repeat prescriptions.

Important: remember that unlike the COCP you should not stop the POP if you get some bleeding. Stopping and starting the POP is likely to result in irregular bleeding and it won't work as a contraceptive if you miss tablets.

3. Depo-Provera (contraceptive injection):

This is the injection that lasts for 12 weeks. We know that this has been worrying many women, as they have been advised to change to the progestogen only pill to avoid the need for a face-to-face appointment. This recommendation is reasonable if the injection is only for contraceptive purposes, however, if it is to control symptoms associated with endometriosis this might not be the best solution. It is therefore worth discussing this with your GP and reminding them of the reason why you use this treatment. Some GP clinics may be offering "drive thru" services, where you could be given the injection. If you do need to switch to a tablet treatment during the pandemic we would suggest two alternatives:

- a) Provera tablets – these need to be taken three times a day (10mg dose)
- b) Desogestrel POP (e.g. cerazette) – consider starting on a double dose (150 mg, once a day)

Provera tablets are not licensed as a contraceptive and therefore if you do need contraception too we would suggest you use a condom or opt for the POP.

There is also a different version of the injection called Sayana Press, which is an injection you can give yourself. This has been unavailable for a number of months but that may be changing. Therefore, if you would be happy to give yourself an injection, it might be worth discussing this with your GP to see if it is available locally. Current recommendations are that up to 12 months of this preparation can be given without needing a face-to-face review or blood pressure check.

4. Provera tablets:

If you are taking Provera tablets already, there is no reason why you cannot continue on this treatment without a face-to-face review for the duration of the pandemic. If you are only taking 5mg three times a day and find you are getting some irregular bleeding then it might be worth considering increasing this to 10mg three times a day. Please discuss

this with your GP to ensure that you can get sufficient repeat prescriptions, as stopping it abruptly is very likely to cause bleeding.

5. Contraceptive Implant:

There is no need to get your implant removed currently, even if it is beyond 3 years since it was inserted. It is thought that the risks of pregnancy in the 4th year are very low, however its effectiveness as a contraceptive although likely is not guaranteed. If you find that you start getting breakthrough bleeding and/or flares in your pain, we would recommend adding in the desogestrel containing POP even if the implant is not yet out of date.

Obviously if you wish to start trying to get pregnant you will need to have the implant removed, but please see the information in the fertility section below.

6. Progestogen-secreting coils (Mirena, Levosert, Jaydess, Kyleena):

There is no need to get your coil removed currently unless you wish to start trying to get pregnant. If this is the case, then please see the information in the fertility section below.

It is thought that the risks of pregnancy in the 6th year of Mirena/Levosert use are likely to be very low. However, we do often find that bleeding and/or pain start to recur before the end of 5 years of use. If this is the case, then we would recommend adding in the desogestrel containing POP or Provera tablets. It is fine to use a double dose of the POP as described above even in combination with the coil.

Important: if you are using your coil as part of your HRT in combination with a menopause injection such as Zoladex, Prostag *etc.*, then it can not be used beyond 5 years. This doesn't mean that the coil needs removing, but your HRT preparation will need to change. Please let your GP know if this is the case.

The other coils, Jaydess and Kyleena, are not often used to control symptoms, however, if you do have one of these and are due to have it changed, current recommendations are that you use condoms or the desogestrel containing POP as well for contraception as there is not evidence that they will work beyond their change date. Again, there is no need to have it removed however.

7. Menopause injections (Zoladex, Prostag):

These are the injections that make you temporarily, but reversibly, menopausal. We have heard from a variety of sources that women are having trouble accessing these injections or being told that they are not an essential treatment. We feel very strongly

that these injections should continue as they allow women to have some control over their symptoms and to continue to work and care for their families. The drugs are only licensed for 6 months to treat endometriosis, however, there are many women who use them “off-license” for a number of years in combination with a low dose of Hormone Replacement Therapy (HRT) to protect their bones and heart/blood vessels and to reduce the associated menopausal symptoms. We suggest you contact your GP to discuss how you are going to access your injection well in advance of the date it is due.

These are our recommendations for how this treatment might be able to be accessed during the pandemic:

- a)** If you usually receive Zoladex, discuss with your GP changing this to Prostag. Although the drug works in the same way and so should be just as effective, it is given through a different type of needle. GPs may be able to provide this as a “drive thru” service similar to Depo-Provera.
- b)** If you usually have monthly (every 28 days) injections of Zoladex or Prostag, discuss with your GP changing to the 3-monthly preparation. You might find it wears off a bit earlier than it is supposed to, but there is no reason why you can’t have it a couple of weeks early if that is the case (we often give the 28 day injection on day 25 for women who get a flare in symptoms just before the next injection is due).
- c)** If you have been using one of these injections successfully with the plan to stop it after 6 months or when you have your surgery, then we would recommend that you continue it throughout the pandemic. Although this is not a licensed use, as mentioned above, many women do this and it will hopefully allow your symptoms to be controlled. If you are going to use it beyond 6 months, however, then this does need to be in combination with some HRT to prevent irreversible side effects – you are also likely to feel much better with a bit of estrogen on board! This HRT should be a low-dose continuous combined preparation (i.e. it contains a low dose of both estrogen and progestogen and the same dose is taken every day), however, it doesn’t matter whether this is a tablet or a patch. Some preparations that are commonly used include Kliovance, Tibolone [Livial] and Evorel Conti. If you have a Mirena coil (that was inserted less than 5 years ago) then you can use this as the progestogen part of the HRT and therefore only need an estrogen. Estrogen-only preparations commonly used include Elleste Solo (1mg), Evorel and Sandrena. Your GP will be able to discuss these options over the phone as they are very familiar with prescribing low dose HRT to post-menopausal women. Please note that the risks of HRT you may have heard about in the media, apply to women of menopausal age. If you are using these drugs to replace hormones taken away by the menopause injections but would not otherwise be menopausal the benefits far outweigh the risks.

Important: if you will have been using the menopause injections for two years or more (even with HRT) by the end of the pandemic it is important that you have a bone scan to make sure that your bones are strong. These scans will not be available during the pandemic however. You can maintain bone strength by ensuring your diet contains plenty of calcium-rich foods and that you get regular weight-bearing exercise. We know this may be difficult during times of social-distancing/isolation but it is worth trying to do this where possible, for example by walking, gentle running or following one of the many online exercise programs that are freely available currently. Please listen to your body when doing these though and stop if you find it worsens your pain.

If you are not using any hormonal treatment currently but would like to start something new, either because you are struggling with symptoms or because your surgery has been cancelled/postponed:

1) Progestogen only pill (POP):

The desogestrel containing POP (*e.g.* Cerazette, Cerelle, Feanolla) is currently recommended for women who want to start an hormonal contraceptive during the pandemic. This is because it is safe for the majority of women and does not require any checks of blood pressure or weight before starting it. If you would like to start this to control your endometriosis symptoms we would recommend starting at a double dose (two tablets once a day) as this is more likely to control your bleeding and any associated flares in pain.

Important: remember that you should not stop the POP if you get some bleeding, it is designed to be taken every day. Stopping and starting the POP is likely to result in irregular bleeding and it won't work as a contraceptive. It can often take a number of months for bleeding to settle down, so its worth persevering for 3 months at least.

2) Provera tablets:

If you have tried a double dose of a desogestrel POP previously and it didn't work for you or even a single dose gave you unacceptable side-effects (it suits most women very well, so please don't expect side-effects...) then our next recommendation would be Provera tablets. These need to be taken three times a day and we would suggest starting at a dose of 10mg, though this can be reduced to 5mg if it is working for your symptoms but you don't like the side effects (although again it is usually very well tolerated).

Important: Provera is not a licensed contraceptive and therefore you should use condoms as well if contraception is required. If the tablets work for you and you need contraception, you could consider asking your GP whether they are giving Depo-Provera

injections currently, however, we are aware that many are not. We usually recommend at least a month's trial before switching to ensure you don't have side-effects as the injectable form can't be taken out after it is given.

3) Menopause injections:

If you are really struggling with symptoms, it might be worth discussing with your GP whether you could start on a menopause injection such as Prostag. Although these drugs are only licensed for 6 months to treat endometriosis, there are many women who use them "off-license" for a number of years in combination with a low dose of Hormone Replacement Therapy (HRT) to protect their bones and heart/blood vessels and to reduce the associated menopausal symptoms. They can be very effective at controlling symptoms and may also allow you to see how much of your pain is driven by factors other than endometriosis/adenomyosis/your hormones (see below). If you are going to start this treatment we would suggest having three months of treatment without HRT and then adding HRT in, in our experience this achieves better pain relief than starting them at the same time.

It is worth noting that the way the drug works means that you will often get a flare in your symptoms (both pain and bleeding) in the first couple of weeks of treatment, however beyond that you are likely to notice menopausal side effects (hot flushes, mood changes and sometimes joint pain) but your pain should begin to decrease and your bleeding stop. If after 3 months there has been no improvement to your pain, we would suggest stopping the treatment, however, if it has been effective then we recommend starting some HRT to remove/reduce the side effects and protect your bones, blood vessels and heart. This HRT should be a low-dose continuous combined preparation (i.e. it contains a low dose of both estrogen and progestogen and the same dose is taken every day), however, it doesn't matter whether this is a tablet or a patch. Some preparations that are commonly used include Kliovance, Tibolone [Livial] and Evorel Conti. If you have a Mirena coil (that was inserted less than 5 years ago) then you can use this as the progestogen part of the HRT and therefore only need an estrogen. Estrogen-only preparations commonly used include Elleste Solo (1mg), Evorel and Sandrena. Your GP will be able to discuss these options over the phone as they are very familiar with prescribing low dose HRT to post-menopausal women. Please note that the risks of HRT you may have heard about in the media, apply to women of menopausal age. If you are using these drugs to replace hormones taken away by the menopause injections but would not otherwise be menopausal the benefits far outweigh the risks.

Important: Menopause injections are not contraceptive. Although it is unlikely that you would conceive on them, we have seen this occur, and the effect of these injections on a developing baby are not known. Therefore you should use condoms if you require contraception and are using this treatment.

Surgical

We can only imagine how disappointing it must be to have had your surgery postponed due to the pandemic, especially if you had been waiting a long time for it. Whilst there is nothing we can do to alter that situation, we would like to offer you some reassurances and suggest alternative strategies to get you through the coming weeks to months as best as possible:

- There is no evidence that endometriosis is a progressive disease. Therefore not operating on less surgically complex stage I (mild) disease does not mean that by the time you do get your surgery you will have, for example, more complex stage III (severe) disease.
- Current recommendations are that endometriosis can be managed with either medical treatment (with hormones) or surgical treatment as a first line. There is no good evidence that one is better than the other. Therefore if this was to be your first operation and you have not tried hormonal treatments before, we would strongly suggest that you read the section above on medical treatment and then discuss with your GP about starting one of the treatments that are currently available. Even if you have tried hormones before it would still be worth reading this information, as there may be different options to consider or different ways of taking a treatment that may work better for you.
- Some clinicians believe that retrograde menstruation (bleeding from the womb into your pelvis through your fallopian tubes at the same time as your period) may continue to gradually increase the amount of endometriosis present and therefore recommend therapies that stop your periods in combination with surgery. Even if this is not the case, the experience of painful periods is unpleasant and may exacerbate other pains. Therefore, unless you have a reason why you don't want to take hormones, we would recommend considering a hormonal treatment that stops your periods whilst waiting for repeat surgery. Possible options available to start despite the current situation are suggested in the section above on medical treatments.
- Surgery for endometriosis often does not remove all the pain. There are a number of explanations for this observation, but one possible reason is that there are other factors that contribute to the pain too. In our experience factors that contribute to chronic pelvic pain in women without endometriosis, commonly also occur in women with endometriosis too. We describe some of these factors in the section below on endometriosis-associated pain, along with some strategies you can put in place yourself to start to help with these. Whilst they may not take away the pain altogether, they may help clarify how much of your pain is driven by endometriosis and mean that when you do finally get your surgery it has the best chance of being effective.
- If surgery is being done to improve fertility or before fertility treatments, there is some evidence that this is best done immediately before trying to conceive/IVF treatment. Therefore, given the current recommendations on planning for pregnancy during this

pandemic (see below), it would probably have been advisable to delay surgery until this is over anyway.

After the acute period of the pandemic is over the NHS will start to reschedule surgery and routine appointments. This will be on the same basis as it was done before the pandemic, with treatments and appointments likely to be arranged in the order they would have been previously scheduled.

Fertility treatment or plans to start trying for a pregnancy

We know that many women have had their fertility treatment delayed and this is another source of considerable distress and anxiety. As with surgery, there is nothing that can be done to change that, however, it is worth bearing in mind current guidance about COVID-19 and pregnancy and think about how this time could be used to maintain or optimise your health for fertility treatment/a pregnancy in the future. Alternatively you may have been planning to stop your hormonal treatments around this time to start trying to conceive naturally, and are now unsure whether that should still be your plan.

The current advice is that now may not be the best time to stop contraception to plan a pregnancy. This is because:

- 1) We have limited information about the risks of COVID-19 on pregnant women and their unborn babies.
- 2) Clinical care during pregnancy and labour involves contact between healthcare professionals and women and therefore increases the risk of COVID-19 transmission.
- 3) Medical resources are likely to be very overstretched in the coming weeks/months and therefore if complications relating to pregnancy occur (including miscarriage and ectopic pregnancy) it may be harder to access the care you need. Again, any such care would increase the risk of COVID-19.
- 4) If you need your coil or implant removed before starting to try to get pregnant, it is unlikely that GPs or family planning/sexual health clinics will be able to provide this service during the pandemic.

It is recommended that both you and your partner use this time to optimise your health:

- Aim to stop/don't start smoking, lose weight if you need to, moderate/reduce your alcohol intake. We acknowledge that all of these are likely to be much harder to do than they would normally be. However, it is important that at the end of this pandemic you don't realise that you are no longer suitable for fertility treatment (*e.g.* because you are overweight or a smoker) or reduce your chances of pregnancy occurring because of these factors.
- Make sure any other chronic medical problems continue to be well-managed including diabetes, asthma, high blood pressure. This is important both because some medical

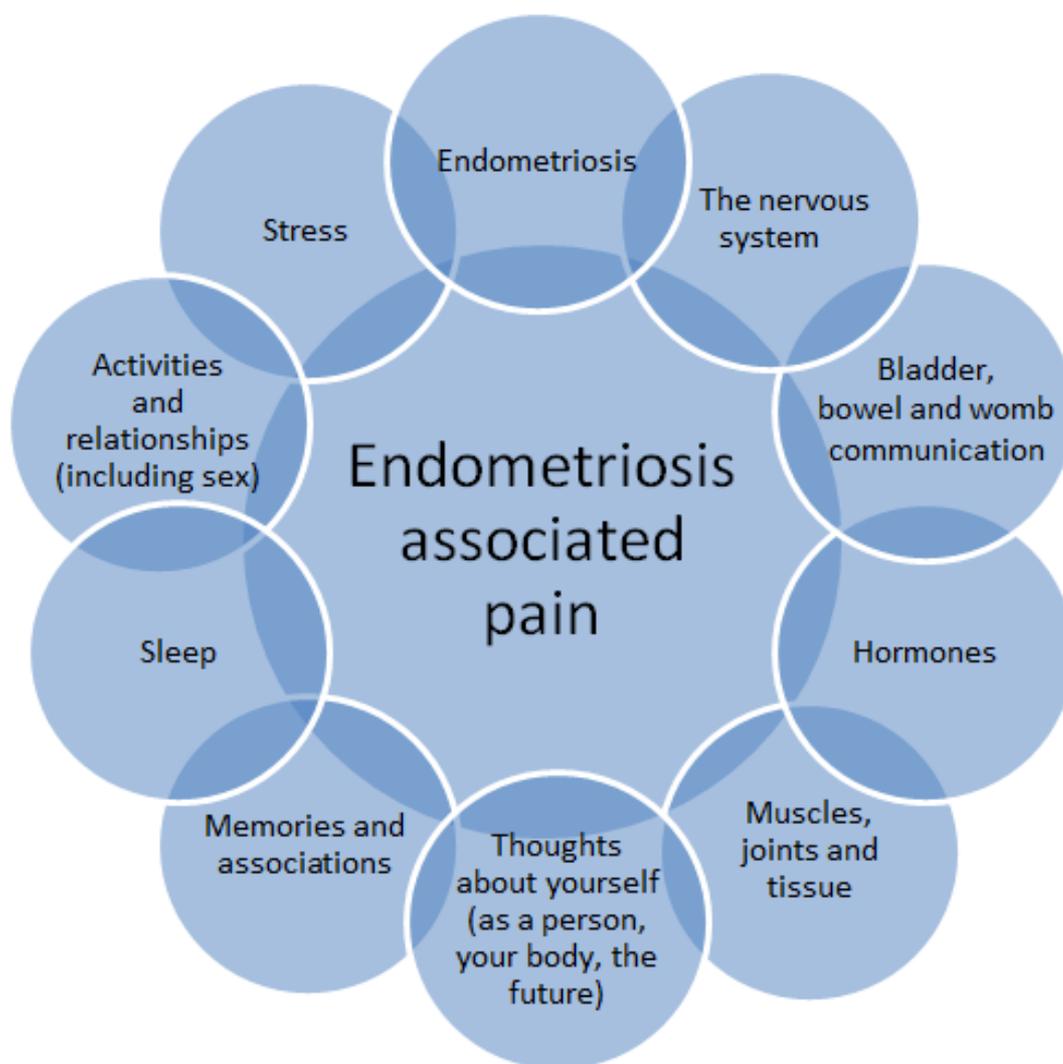
conditions increase the risk associated with COVID-19 and because of their impact on a future pregnancy.

- Continue to take/or start taking folic acid. The current advice is to take folic acid supplements for 3 months before pregnancy if possible. There is no harm in taking folic acid supplements for many months and therefore it is far better to continue with these than stop them and not have restarted in time.

Clearly if you do fall pregnant during this pandemic, everyone will do their best to offer you the care that you need. However, it would probably be sensible to let your GP know earlier than you might do normally.

Endometriosis-associated pain

Endometriosis-associated pain is complicated! As you may be aware, there is no relationship between the amount or location of disease and the amount or type of pain experienced. This is also true in other chronic pain conditions such as lower back pain. We know that a variety of different factors can contribute to the experience of pain. Some of the factors known to have a role in chronic pelvic pain are shown in the diagram below. Whilst endometriosis is clearly important, the presence of one or more of the other factors may explain why treatment just targeting the endometriosis (*e.g.* hormones or surgery) isn't always successful at removing all the pain.



In addition to changes to your clinical care, it is likely that the COVID-19 pandemic is impacting on many of these other factors, potentially leading to a worsening of your pain currently. We would like to offer you some suggestions as to how you might be able to address these factors during this time. You might be surprised how much help some of these suggestions can be and may even decide that some of them are strategies you wish to continue with even when all of this is over and you can have the treatments previously planned. It is worth remembering that in lots of other conditions associated with chronic pain, a team approach is usually standard

care including physiotherapy and psychology, however, in endometriosis we tend to focus only on targeting the disease and only bring in these other options after many years of repeated or unsuccessful treatments.

The nervous system

The nerves in the spinal cord, the brainstem and the brain itself become more sensitive to painful stimuli over time which is known as central sensitisation. Painful periods over many years may contribute to 'central sensitisation'. Things that used to only be mildly painful can become very painful. Even non-painful experiences, like clothing or a duvet resting on the skin, can become painful or the nervous system may just generate a painful signal without a trigger at all. People can be more sensitive to a variety of experiences including bright lights and loud noises. You can think of this as like turning up the volume of the pain sensing system. This type of pain is difficult to treat: it doesn't respond to painkillers traditionally prescribed for endometriosis-associated pain and needs to be approached differently.

If none of the other strategies described here are helping, or your pain feels very like nerve-related pain (burning, tingling, electric-shock like), then it might be worth discussing with your GP whether a trial of a drug targeting nerve pain (known as neuropathic pain) might be a good idea. These drugs are not licensed for endometriosis-associated pain and have never been tested for this reason, however, they are licensed for neuropathic pain and are used in a variety of other chronic pain conditions including fibromyalgia, so your GP will be familiar with them. Possible drugs to consider are:

- Gabapentin
- Pregabalin
- Duloxetine
- Amitriptyline

Your GP will be able to discuss the risks and benefits of these and advise you which would suit you best.

Bladder – Bowel – Womb communication

Bladder and bowel symptoms are common in women with endometriosis even if they do not have disease on their bladder/bowel. The same nerves supply the womb, bowel, bladder and the top of the vagina and discomfort in one organ may result in discomfort in other areas over time (known as 'crosstalk'). We also know that bladder and bowel symptoms can be dependent on diet and that bowel symptoms particularly are worsened during times of stress or anxiety.

The current situation is therefore likely to be impacting on bowel and bladder symptoms in at least two ways and therefore potentially increasing the amount of pain from your pelvis. Things you could think about to improve this include:

- *Taking care of your diet.* The current restrictions on access to shopping and limited availability of supermarket home deliveries means many people's diets may have changed considerably. A lack of fresh fruit and vegetables or a focus on dried/tinned beans and pulses may well have altered your bowel function causing either diarrhoea or constipation. It might be worth exploring whether there are local farms or shops who are delivering some of your more familiar foods to help with this.
- *Avoiding too much comfort food/alcohol.* Being stuck inside and a bit anxious/unsettled often means we resort to comfort foods like chocolate and cake or feel the temptation to have a bit more alcohol in the evenings than we would otherwise. These foods can again impact on bowel function and women with sensitive bladders for whatever reason will often describe their pain being worsened by alcohol.
- *Staying well hydrated.* Not drinking enough fluid as you are out of your routine or don't feel so thirsty because of a change in your activity levels can lead to constipation and to more concentrated urine which can irritate your bowels and bladder respectively.
- *Trying to reduce stress and anxiety.* Whilst we understand how difficult this is currently, it is likely to have benefit for your bowel function particularly as well as your pain in general. We offer some suggestions for how to go about this in the section on "Emotional well-being and managing stress" below.

The musculoskeletal system

Muscles, joints and other tissues can very commonly be involved in chronic endometriosis-associated pain. We often see these become dysfunctional and then begin to create problems of their own. Some examples of this are:

- The pelvic floor muscles become tense and painful which can cause pain during intercourse and/or bladder and bowel issues.
- The back joints can become stiff which can cause pain when sitting or standing.
- The pelvic joints can become irritated causing pain on walking and rolling.

We envisage that lots of people will have increasing levels of musculoskeletal pain as activity levels fall during the pandemic. This is likely to have a significant impact on your general levels of pain if you already experience pelvic pain. Things you could consider to reduce this impact are:

- 1) *Making sure you get outside for some daily exercise* as long as you stick within current Government recommendations for social distancing/isolation. If long walks flare your pain, then this can just be a slow, gentle walk or bike ride. However, the benefits of being outside for your mental health as well as your physical health are huge.

- 2) *Making time within your day to do some gentle “pelvis friendly” exercises* at home. You may already have a routine that was given to you by a physiotherapist or personal trainer, in which case please continue with this. Otherwise we have put together a set of exercises that may be helpful to you and are available [here](#).
- 3) *Keeping an eye on your diet and your weight*. Constipation is likely to worsen any pain from your pelvic floor, whilst carrying excess weight puts a strain on muscles, which if they are already weak can cause or exacerbate pain.

Emotional well-being and managing stress

Living with chronic pain is incredibly difficult. It is likely to have a big impact on how you think, feel and what you feel/are able to do. The experience of constant/repeated episodes of pain is stressful and can make it difficult to relax. The current situation is likely to have made the situation worse; therefore, here are some suggestions for how you can look after your own emotional well-being during this time. As mentioned, you may find that some of them are so helpful that you choose to continue them in the future too.

The importance of taking care of ourselves

It is especially important to consider how we can best take care of ourselves during this unsettling and stressful time. You might be experiencing additional challenges for a number of reasons, including: worries about accessing medical treatment, additional stress and disturbed sleep which may exacerbate pain or reduce confidence to cope, and loss of routine and reduced opportunities for socialising or physical activity, or other things which helped you to cope.

Understandable increased sense of threat

The coronavirus may well contribute to an increased sense of threat. However, for women who have been living with endometriosis, this sense of threat may already be ‘online’ more of the time as it can also be triggered by health concerns, pain, unpredictability and medical treatments. Some common experiences that come along with the sense of threat include:

Thoughts: I can't cope, there is nothing I can do, things are out of control, what if...

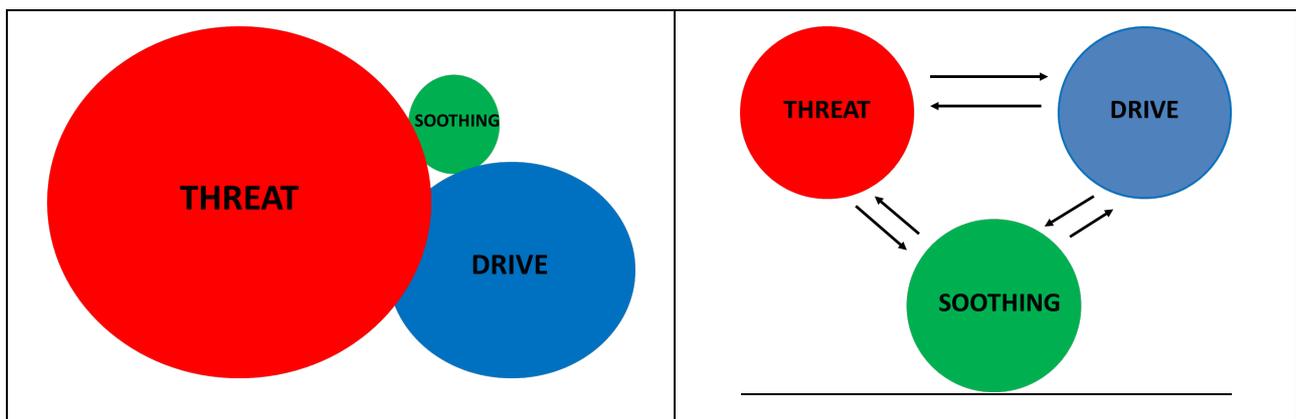
Body: heart racing, palpitations, muscle tension, stomach ache, tearful, poor concentration, pain.

Emotions: Stressed, worried, irritable, numb, disconnected, sad, angry, frustrated, self-criticism.

Behaviour: Push self, withdraw, skip meals/comfort eat, snap at others, stay up late, difficulty relaxing.

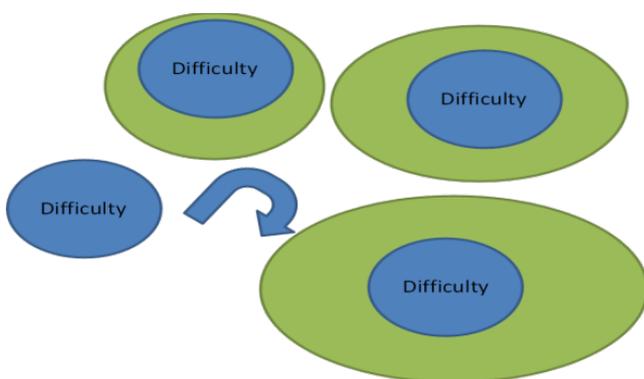
***** IT IS COMPLETELY UNDERSTANDABLE AND NORMAL TO FEEL LIKE THIS AT THIS TIME *****

Humans have three basic emotional regulation systems: threat, drive and soothing systems. All serve very useful functions, but we need balance. The threat system may be especially online at the moment. To maintain balance, enable us to rest and for our well-being we need to bring the 'soothing system' online. Some tips strategies for this are described in the next section.



Tips and strategies for taking care of ourselves

- *Establish a routine:* Build in a range of activities into your life so that your time does not feel entirely taken over by worries about your health and the current situation. Of course, these concerns will be there but see if you can 'grow' around the challenges you are facing.



Each day try to tick off a few from this list:

- Being active/exercise
- Contact with others (friends/family)
- Pleasurable activity
- Time to relax
- Do something fun
- Give yourself a challenge (e.g. puzzle)

- *Limit exposure to 'threat' information:* The empty shelves, news, social media, school and shop closures all keep this threat at the fore of our attention. Thoughts and worries about managing endometriosis at this time may add to this and will inevitably affect how we are thinking and feeling. Limit the amount of time you listen to the news, look

on social media or spend looking up health information. Try to have some conversations or some allocated time which is 'threat' free.

- *Taking in the good*: Negative events are like Velcro, positives are like Teflon: we notice and remember negative information more easily (e.g. we notice/remember what went wrong in our day, not what went well). In the current circumstances we may need to take some steps to balance our inbuilt negative attention bias by focusing on some of the good in our lives. For example,
 - At the end of the day, see if you can think of 10 things you appreciate (e.g. the smile from a stranger, the smell of your coffee)
 - Make time for pleasurable experiences and give them your full attention. You can do this for brief experiences (e.g. the feel of the sun on your skin) as well as longer ones (e.g. watch your favourite film)
 - Do something kind – call a friend, make a cup of tea for someone, smile at someone
- *Look after your body*: Try to eat healthily and regularly; if your appetite is low eat little and often, choose things you find easy to eat. Take a bath or long shower. Try to keep active.
- *Our thoughts*: We may find ourselves overwhelmed with negative thoughts; how we think about a situation will affect how we feel. Remember, thoughts are not facts, and it might be helpful to keep other perspectives in mind, such as....
 - *I am limited in what I can do, but I will do what I can*
 - *I can't control many things, but I can look after myself*
 - *This will end, we will get through this*
 - *I'm not alone/others are facing challenges too*

This isn't about positive thinking. It's about holding a balanced perspective in mind.

- *Living with uncertainty*: It is common to find uncertainty difficult to live with, but sometimes our need for certainty can end up adding to our problems. For example, we might find ourselves going over and over things in our mind, feeling more stressed or frustrated, but the situation stays the same. Sometimes, no matter how hard we try to solve a problem, there is nothing we can do to change the situation or resolve the issue. Learning to accept situations we can't change may sometimes be the most helpful thing to do. A helpful question to ask yourself is: *Is this a worry I can do something about?* If the answer is 'no', try the steps for accepting uncertainty (below).

Steps for accepting uncertainty:

- **Be aware** – What do you notice yourself thinking and feeling when the need for certainty comes up?

- **Don't respond** – What can you tell yourself to help you not respond? (e.g. These feelings will pass)
 - **Let go** – What can you do to help you let go of the need for certainty? (e.g. I can't fix/change this)
 - **Focus on the present** – See the grounding techniques below.
 - **Deal with a wandering mind** – Notice when your mind wanders, perhaps automatically getting caught up in worry again and again. Each time gently bring your attention back to the present moment.
- *Acknowledging and naming emotions:* Acknowledging and naming the emotion, either to ourselves or talking with someone else, can be helpful. Research shows this can help to give perspective and to calm emotions. For example, *you could say to yourself "I notice I am feeling overwhelmed; I can see that I am feeling irritable"*. Keeping a diary might be helpful.
 - *Grounding techniques:* When overwhelmed with emotion we can feel lost and disconnected from the present moment: our ability to think clearly and rationally may go 'off-line'. Grounding techniques are a way of helping us to feel a little steadier and manage strong emotions, helping us connect with the present moment – the here and now. They can be quick strategies (like taking five mindful breaths) or longer, more formal exercises (like mindfulness meditation or yoga). Different strategies work for different people, and there is no "wrong" way to ground yourself. The main aim is to keep your mind and body connected and working together. Some ideas include:
 - Come into your senses – stop, notice 5 things you can see, close your eyes and notice 5 things you can hear, and then notice 5 points of contact between your body and something else. Breathe. Then open your eyes.
 - Take 5 breaths, paying full attention to the sensations of the breath.
 - Focus on sensations in your feet as you walk from one place to another.
 - Get outside – notice nature around you if you can access this. Feel the air on your skin.

Sleep

Sleep is incredibly important. We know that poor quality or insufficient sleep makes it difficult to cope with things that you would normally manage fine. There is also increasing evidence that sleep deprivation can amplify pain, such that sensations that were previously only mildly painful become more severe. Even if your sleep is not disrupted by pain it can be difficult to get off to or to stay asleep during these unsettled times. Here are some top tips for getting your sleep back on track during this time:

- *Routine*: Establish a relaxing bedtime routine and give yourself longer to wind down at bed time (up to 90 minutes can be helpful)
- *Keep bed for sleep (if you can)*: If you spend time in bed for reading, watching TV or resting, your body/mind may not associated bed with sleep. It's important to create a strong link between bed and sleep by avoiding using bed for other activities.
- *Rise time*: If you haven't slept well it can be tempting to have a lie in to catch up. Unfortunately, this is likely to decrease the likelihood of a good night sleep the following night, because you won't have been awake long enough to build up 'sleep pressure' across the day. Set a regular rise time and see if you can stick to it. It might be hard work in the short term but will improve your chances of falling asleep each night. To help with getting out of bed at your rise time, plan some things to help get you going; perhaps a lively piece of music, a nice breakfast or a shower.
- *Napping*: If you can, it is best to avoid napping as it can lead to a disrupted sleep at night. The longer we are awake, the greater the 'sleep pressure' will be at night. If you do need to nap, try to keep it short (20 minutes) and earlier in the day to allow sleep pressure to build up again.
- *Avoid stimulants before bed* (caffeine, alcohol, nicotine)
- *Natural light*: Natural light suppresses the production of melatonin (a hormone associated with sleep). Try to avoid bright light before bedtime to promote melatonin production. It is also helpful to expose yourself to lots of natural daylight when it's time to be awake (particularly early morning). This will help you to feel awake, alert and ready for the day.
- *Screens/blue light*: Avoid screens for an hour (or more) before bed as the blue light can suppress melatonin production.
- *Relaxation/mindfulness*: Do a relaxation or mindfulness exercise (e.g. look on the internet for progressive muscle relaxation or a body scan) to help your mind and body wind down and ready for sleep.

If you can't sleep, try not to worry about your sleep and see it as a time for rest – the more you worry, the less you will sleep! Try a relaxation exercise or mundane mental activity (e.g. counting down from 100 in 7's; remember the details of a walk you know well).

Activities and relationships

We know that some activities can improve pain whilst others worsen it and this is likely to be different for different women. Similarly some relationships are helpful whilst others can make us feel worse. How we structure our day and interact with other people is likely to have changed significantly since the COVID-19 pandemic and particularly since the stricter

government recommendations have come into force. If you have noticed a marked change in your pain (for better or worse...), it might be worth spending some time reflecting on what has changed and how this might be having an impact. If you think these changes have worsened your pain, then you may need to alter the way you structure your day, either to avoid doing things that make the pain worse; give yourself more/longer rest periods; increase or alter your social interactions. On the other hand, you may notice benefit, in which case it would be worth remembering these things for the future to see if positive changes could be incorporated into your life going forwards.

Things to consider include:

- *Are you doing more activities like housework?*
If you are normally used to a desk job but are spending your time hoovering or moving furniture around to keep yourself busy, this may have put more of a strain on your muscles or alternatively may have improved the back pain you normally get from sitting all day.
- *Are you spending lots of time sitting on the sofa watching TV or listening to music?*
If you normally keep active, this might be worsening your pain and your mood. On the other hand, making some time for relaxation is really important and therefore this bit of “me-time” may actually be making you feel better.
- *Are you interacting less with your extended family/friends/work colleagues?*
This may be making you feel isolated and lonely and thus worsening the situation. In which case why not look into novel ways of linking up. Many people are using technology to have virtual coffee mornings, dinner parties or an evening drink. Alternatively, if that technology isn’t available a simple phone call may be enough to help you stay in touch. Or have you noticed that you feel much better not interacting with a certain person? In which case this may be something to think about for the future.
- *Is spending 24/7 with your close family stressful or enjoyable?*
Many people are enjoying the opportunity to play games or watch films with their family that they wouldn’t normally. Maybe this is something you can continue to plan in the future? However, it is challenging to spend all our time at home and this may be even more difficult if you are trying to both homeschool and work from home, or if one of your family is particularly stressed or anxious about the current situation. If you don’t feel safe at home then you should seek some advice, [this resource may be helpful](#). If you are in immediate danger, call 999 and ask for the police - the police will continue to respond to emergency calls. If you are in danger and unable to talk on the phone, call 999 and then press 55. This will transfer your call to the relevant police force who will assist you without you having to speak.

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