

The GP's Role in Improving the Lives of Endometriosis Patients

Why is this even an issue?

- Endometriosis is estimated to affect **one in ten** girls and women across the globe, making it as prevalent as diabetes or asthma. Despite this, it still takes, on average, **8 years** to get a diagnosis.

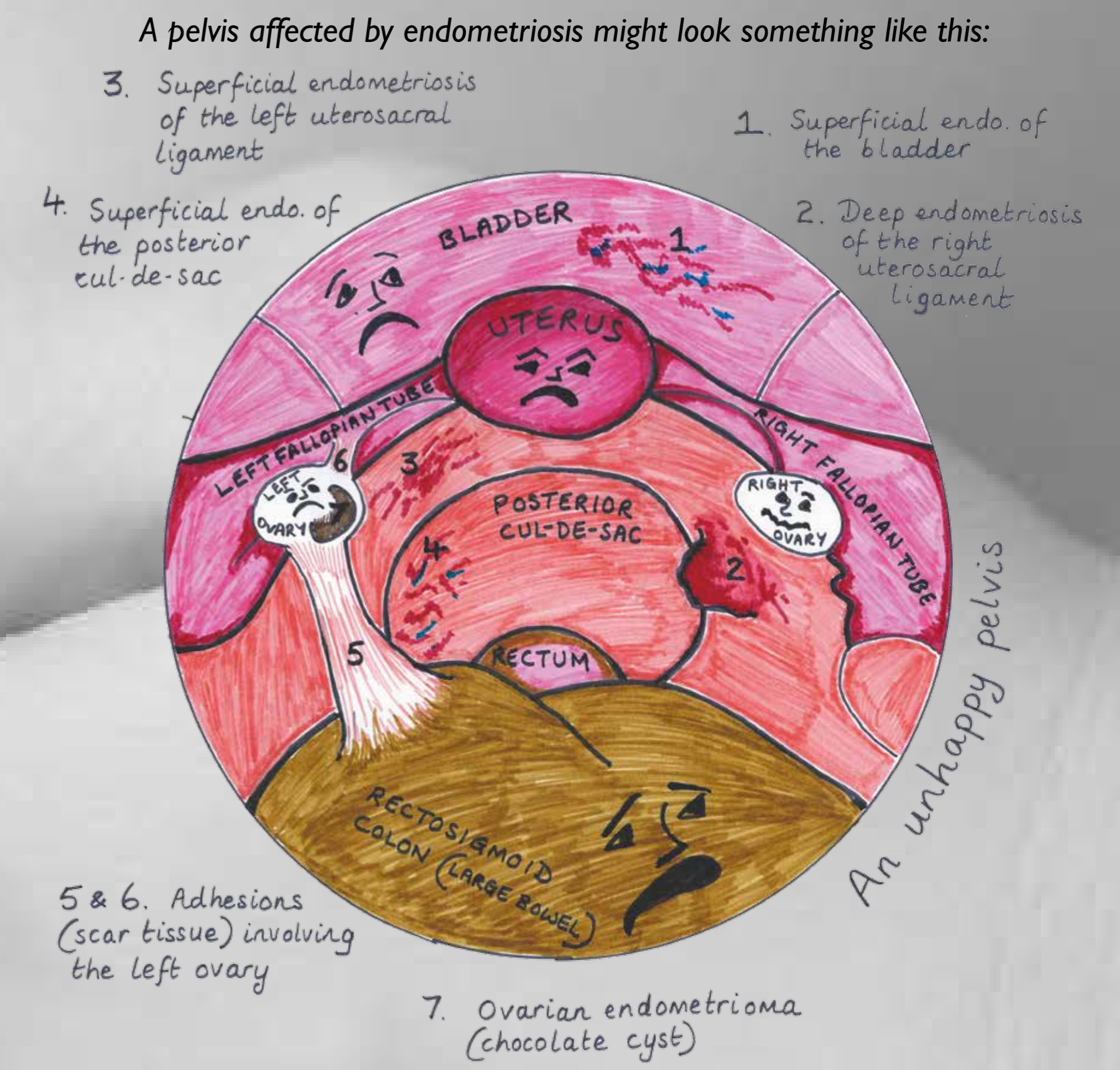
The annual cost to the UK, in terms of healthcare, benefits, and loss of productivity, has been calculated to be in the region of **£8.2 billion**.

- Patients report, on average, more than 50 visits to the GP during the period up to diagnosis, adding to the pressures experienced in the Primary Care setting, and the negative impact on patients.

- In order to improve the patient experience, it is vital that GPs become, as a first step, more aware of the range of symptoms that present with endometriosis (and adenomyosis*) and the need to refer on to gynaecology for further investigations.
*Adenomyosis is a uterine condition, in which tissue similar to the endometrium is found within the muscular walls of the uterus. It can be diffuse or focalised (a mass, called an 'adenomyoma'). It can cause heavy menstrual bleeding and labour-like cramping, as well as bladder and rectal pain, and back/ leg-ache. It is also associated with fatigue and general malaise.

- Whilst not every patient will report all of the following issues, a combination of any / all of them should be an immediate **red flag** for endo:

- Cyclical pelvic pain
- Non-cyclical pelvic pain
- Pain during / after sex
- Bleeding during / after sex
- Intestinal cramping
- Pain during bowel movements
- Rectal bleeding
- Urinary frequency / difficulty emptying bladder
- Pain upon emptying bladder or with bladder fullness
- Constipation / diarrhoea
- Bloating
- Fatigue
- Back / leg ache
- Nausea / vomiting usually, but not necessarily, associated with menses
- Large / painful ovarian cysts (possible endometrioma, aka 'chocolate' cyst)
- Episodes of intense / sharp pain resulting in temporary loss of consciousness
- Infertility
- Cyclical right shoulder / chest pain (can indicate rarer diaphragmatic endo)



Many patients report their medical practitioners giving them inaccurate or conflicting information about this disease.

It is incumbent upon GPs and practice nurses to be aware of the common myths associated with endometriosis so as to break the cycle of misinformation and unsatisfactory care:

Pain during menstruation that interferes with everyday life is a 'normal' part of being a woman
If pain is severe enough to be reported, or is causing the patient difficulties in carrying out every day activities, that is not normal and needs investigating further.

The patient is over-sensitive / has a low pain threshold
The pain associated with endometriosis (and adenomyosis) can be hugely debilitating and, according to studies, comparable to labour pains.

'You're too young / too old to be experiencing endo. symptoms'
Symptoms may commence at menarche or at any age, even with no prior history of symptoms or infertility. In some instances, women report continuing symptoms post-menopause.

That painful periods during teenage years are transitory, ie 'You'll grow out of it / them'
Patients' suffering should not be dismissed as a consequence of their age. This is an important stage in young women's lives so it's crucial they be taken seriously and investigated further.

'You've probably got a UTI / STD, or PID'
Endo symptoms often resemble these conditions and women are often given inappropriate treatment based upon these misdiagnoses. If symptoms do not respond to first-line treatment then further investigation is warranted. Given the antibiotic crisis, it is important that these are not prescribed unnecessarily and repeatedly.

'It's just IBS'
IBS describes a set of symptoms and is not an actual diagnosis. In conjunction with other issues, IBS symptoms can be a strong indicator for endo, and require more than dietary changes and / or medication.

'Endometriosis is not a cause of fatigue - you just need more sleep!'
Many women with endo cite chronic fatigue as being one of their most debilitating issues. GPs should be wary of dismissing fatigue as something that can be resolved through diet, vitamin supplements, sleep, and / or exercise.

'You've had children; you can't possibly have endometriosis!'
It is possible for endometriosis sufferers to get pregnant without any medical or surgical intervention. This doesn't mean that their fertility won't be affected in the future, or that they're not experiencing endo-related pain / symptoms.

Women with endometriosis will inevitably be infertile
Whilst one third of women requiring fertility treatment have confirmed endometriosis, their chances of conceiving naturally or with IVE, improve considerably if their disease is thoroughly excised beforehand. This would be strongly recommended before embarking on invasive and costly infertility treatment. Even without treatment, endometriosis doesn't necessarily mean that the patient will never get pregnant.

'Scans, pelvic exams, and scopes would show up any problems'
For a significant proportion of women, endometriosis will not be visible on any sort of scan. However, endometriomas (chocolate cysts) should be seen; an immediate referral to gynaecology is warranted, as they generally indicate disease elsewhere. Pelvic exams are normally inconclusive. Scopes are, in most cases, clear, unless an endometriosis nodule has penetrated the full thickness of the bowel wall. A patient can still experience bowel-related symptoms regardless.

Hormone medications are the only real solution to endometriosis
Whilst it is true that for some patients, contraceptive medications and devices can be a way of reducing / relieving symptoms, others will not find them helpful, or experience intolerable side-effects. It is important that GPs are aware of the limitations of hormone-based therapy: it might temporarily suppress symptoms but disease can continue to progress. As such, it should not be seen as a 'solution' or cure for endometriosis. Periods may or may not cease during these treatments, and symptoms can similarly persist. Hormone medications are not a cure for either endo or adeno.

If a patient experiences continuing symptoms whilst in temporary, medically-induced menopause (using GnRH analogues) then it can't possibly be endometriosis!
As with all hormone-based therapy, individual patients will experience different results. In addition, it is essential that practitioners administering these drugs are aware of the contraindications, such as their not being advised for under-23s, and the need for add-back HRT to avoid loss of bone density and ameliorate menopausal symptoms. Failure to respond to these medications does not rule out endo or adeno.

The patient has what's been described as 'superficial' endo. They can't possibly be in that much pain!
There is absolutely no correlation between stage / extent of disease and pain. Some patients with advanced disease may experience little pain and few / no symptoms whilst, conversely, patients with apparently minor disease can suffer significant pain and debilitating symptoms.

This might be down to location of disease, nerve involvement, or presence / density of adhesions, for example.

'You've been to a gynaecologist and had surgery. You can't still have endo.'
In the vast majority of regular gynaecology departments, 'burning' is the surgical technique most commonly utilised - often referred to as 'ablation' / 'diathermy' / 'coagulation' / 'cauterisation'. These techniques simply burn off the top of lesions, often leaving the bulk of the disease behind. Recent research has shown that 'burning' techniques leave endo behind in 80-90% of cases. The GP should not be surprised therefore if patients experience continuing pain / symptoms. Excision surgery aims to remove all disease, so referral to a BSGE-accredited endometriosis centre, where this should be performed, is recommended. The *Endo-Iceberg* is a useful visual representation of the differences between burning and excision as surgical techniques (see Figure 2).

Pregnancy is a valid way of alleviating symptoms - or even a cure for the condition
Whilst some women may experience relief of symptoms during pregnancy, others have on-going or worsening issues throughout. Symptoms often return after birth and / or conclusion of breast-feeding. For some, pregnancy actually marks the on-set of symptoms or an increase in their severity.

Hysterectomy is a cure
Hysterectomy will alleviate heavy bleeding and associated pain / symptoms for some women but this is usually because a uterine condition, such as adenomyosis, is responsible. Endometriosis, by definition, is outside of the uterus. Therefore, removing the uterus will not provide a solution to disease located elsewhere in / outside of the pelvis.

Oophorectomy is a cure
Whilst removing ovaries can, in some instances, offer patients relief from symptoms, this procedure doesn't actually remove disease or associated adhesions. Immediately plunging patients into surgical menopause, often at a young age, can have severely detrimental implications for long-term health, as well as causing debilitating menopausal symptoms. If disease has not been fully removed, subsequent treatment with HRT can result in resurgence of symptoms. Furthermore, studies have shown that endo can produce sufficient hormones to sustain itself, irrespective of ovarian presence. Therefore, even if all reproductive organs are removed, symptoms can persist. Wherever possible, disease should be excised, and healthy organs preserved.

Now that we've demythologised endometriosis, what next?

We asked patients to suggest ways in which the GP could improve the endometriosis sufferer's experience of the primary care setting, positively impacting on outcomes for the patient, and reducing pressure on NHS resources.

Here is what they had to say:

- Be willing to work with patients on piecing together the complex puzzle that is Endometriosis. This disease has a range of non-specific symptoms so it's vital that GPs appreciate that fact. Symptom trackers and check-lists can be hugely helpful tools and should be utilised in moving towards a speedy referral, diagnosis, and effective treatment.
- Be prepared to take the time needed to get the full picture of the patient's experience. Rushing to get through everything in a ten minute appointment can actually be a false economy: vital information can be missed which potentially delays diagnosis further, prolongs patient suffering, and results in frequent returns to the practice.
- Be appreciative of the fact that girls and women

become very familiar with their bodies from a young age - they know when something doesn't feel 'right'.

- Don't be offended if the endometriosis patient knows more about their disease than you do. Many have been forced to undertake a great deal of research to find answers to their previously unexplained symptoms and want to play an active role in establishing the treatment plan that is right for them.
- Appreciate the detrimental effect endo can have on the 'whole person'. Pain and other symptoms can negatively impact on everyday activities, education, employment, relationships, and both physical and mental well-being. Be understanding, supportive, and approachable; many endo patients report being afraid to tell their GP the full extent of their issues for fear they will be dismissed, seen as 'time-wasting', neurotic, or over-sensitive.
- Understand that some endometriosis patients may become depressed, but that this is often subsequent to years of chronic pain and other long-standing symptoms. Patients report developing mental health problems as a result of not being taken seriously and /

or repeated ineffective or inappropriate interventions. It is incumbent upon the GP to halt this cycle. Anti-depressants won't resolve endometriosis, but ensuring that patients access effective treatment for their endometriosis may well resolve depression!

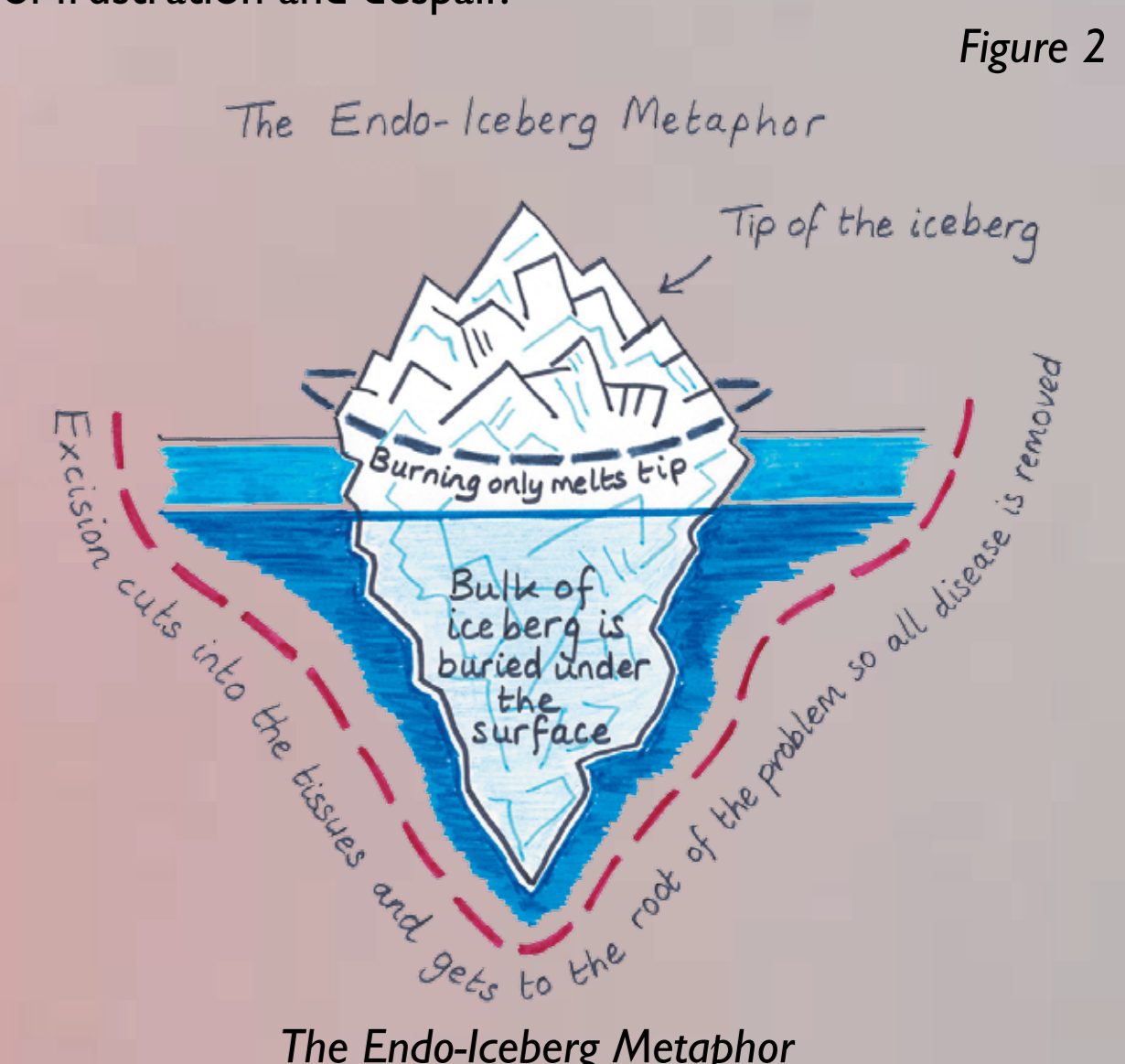
- Don't hesitate to make a referral to gynaecology if symptoms are suggestive of endometriosis. By all means send patients for investigative tests - but alongside a referral, not instead of. Patients report waiting years to be referred to a gynaecologist whilst spending years undergoing repeated, inconclusive tests and suffering debilitating pain / symptoms.
- Be aware that hormone therapies are not necessarily right for all so avoid dismissing patients who may well have their reasons for not wishing to pursue them. Accept that, for many, hormone therapy is not an acceptable alternative to excision surgery.
- Be aware that there are almost 50 specialist endometriosis centres, accredited by the British Society for Gynaecological Endoscopy, across the UK. These centres provide the multi-disciplinary (bowel, urology, gynaecology) excision surgery that is recommended by

NICE as 'gold-standard' for endometriosis patients. It is within the GP's remit to refer directly to these tertiary centres, particularly if the patient has experienced no relief from their regular gynaecologist. The specialists state that surgery is less complex, and patient outcomes improved, if referrals are made directly to them rather than patients having had repeated 'burning' procedures beforehand. Direct referral also means fewer visits to the primary care setting, fewer inconclusive tests, less inappropriate, long-term medication being prescribed, and a reduction in cost to the NHS and economy in general.

10) Be cognisant of the fact that a referral to gynaecology doesn't mean that the GP's role in providing care for the endometriosis patient ceases. An effective pain-management strategy should be put in place to help patients cope with both chronic and acute pain. It should not be necessary for the endometriosis patient to have to visit A&E for pain medication, something that many of our respondents report having to do on multiple occasions.

11) Avoid offering advice which might be seen as patronising, or which requires the endometriosis

patient to make lifestyle changes which would be deemed unacceptable under normal circumstances, such as avoiding sex; adopting restrictive diets; getting pregnant; reducing hours at work, or just trying to sleep or exercise more. None of these suggestions will actually treat endometriosis but may add to the patient's feelings of frustration and despair.



So, in summary, what is the GP's role in improving the lives of endometriosis patients?

- Listen to them
- Appreciate their expertise
- Be cognisant of the wide range of symptoms
- Recognise the limitations of hormone-based therapies
- Be aware of the potential benefits of excision over other forms of surgery, including 'burning', hysterectomy, and oophorectomy
- Be prepared to make a referral to a tertiary, BSGE-accredited, specialist centre
- Remember that prompt diagnosis and referral can potentially save considerable NHS resources as well as improve patient well-being.

