



endometriosis uk

## Getting a diagnosis

***Tip: Most GP appointments are 5-10 minutes long – remember you can always ask to book a double appointment, which will give both you and your doctor more time to discuss the issue.***

### **What should I say to my GP?**

It takes around seven to eight years on average for a woman to get diagnosed with endometriosis from the time she starts experiencing symptoms. Whilst this has reduced from the eleven years measured previously, it is still far too long.

This is not a straightforward picture and it is worth remembering that it can be very difficult for GPs to diagnose – they are trained to deal with thousands of conditions, but do not specialise in endometriosis specifically. The symptoms of endometriosis can be wide-ranging and are similar to those of many other conditions, so it is not always apparent straight away that it could be endometriosis that is causing your symptoms.

For this reason, it is extremely important that you share as much information as possible about your symptoms with your doctor. This will benefit your care and hopefully speed up diagnosis should you have endometriosis.

To help you prepare, there is a questionnaire included in this pack, which will be very useful if you fill it out before your appointment and bring with you to show your doctor.

### **What will happen at the appointment?**

The doctor will ask you to describe your symptoms and will ask you questions. For an idea of the type of questions that may be asked, have a look at the questionnaire included in this information pack. Consider filling it out prior to your appointment so you can take it with you.

The GP may want to examine your abdomen, and possibly examine you internally (although you can refuse this if you want). Many women with endometriosis find internal examinations uncomfortable; if this is the reason you do not want one, tell the doctor. You are entitled to a chaperone during an examination – just ask if one isn't offered.

You may find that you become emotional when you are telling the doctor about your symptoms. This is perfectly normal and nothing to feel ashamed or embarrassed about. It may be the first time that you are telling anyone about your symptoms, you may feel embarrassed about the nature of the things you are discussing, or you may not know why you feel emotional. Please remember that the doctor will have seen it all before, many times – possibly even that same day.

### **Will I get a diagnosis from my GP?**

At the moment, the only way to diagnose endometriosis is through an operation called a laparoscopy (the factsheet 'Laparoscopic surgery for endometriosis' that is included in this pack has further information on this); therefore, your GP will be unable to give you a definite diagnosis. If they suspect you have endometriosis, your GP may check you for infections which can mimic symptoms of endometriosis and/or arrange for you to have an ultrasound scan. They can prescribe painkillers to help and/or antispasmodic treatment if you have bowel symptoms and even start treatment with the pill or hormones.

providing support increasing understanding

Endometriosis UK is a registered charity No. 1035810. Company Limited by Guarantee No: 2912853

## Getting a diagnosis

There are some GPs who have developed specialist interests in gynaecology and endometriosis. If your symptoms do not improve with treatment or you would like to see a hospital specialist, your GP can refer you. It is important that you have a good relationship with your GP as the hospital specialist will often ask your GP to continue prescribing or review the treatment that has been started.

### **I am not satisfied that my symptoms are being properly looked into by my GP. What should I do?**

You should not just have to 'put up' with your symptoms. Your GP should investigate your symptoms thoroughly to try and find the cause and a suitable treatment. Remember that endometriosis is not easy to diagnose and therefore it is very important that you keep your GP informed about your symptoms if you are not feeling better. You can always consider taking one of the following options:

**Option 1: try to communicate what you are experiencing to your healthcare professional.** Use a pain and symptom diary to demonstrate clearly how your symptoms are affecting your everyday life, and ask questions about anything you do not understand.

**Option 2: ask for a referral.** Your GP is not a specialist in endometriosis, so it may be beneficial for you to get referred to someone who is. Remember endometriosis can only be diagnosed definitively by a laparoscopy, which is usually performed by a gynaecologist. Please see the sheet 'How do I get a referral?' also enclosed in this pack for more information.

**Option 3: ask for a second opinion.** Although you do not have a legal right to a second opinion, you have the right to ask for one. A healthcare professional will rarely refuse to refer you for one unless there is sufficient reason. If you are registered at a multi-GP surgery, you could see another GP at the practice. Or you could change your GP altogether.

### **How do I get a referral?**

If your GP does not feel able to treat you, they should refer you to the relevant doctor. You can also ask your GP for a referral.

You may find it helpful to ask to be referred to an endometriosis specialist, as not all gynaecologists specialise in the condition. This may be particularly useful if it is suspected that you might have endometriosis affecting other organs such as the bowel or bladder as not all hospitals deal with these cases. For legal reasons, Endometriosis UK is unable to recommend a particular doctor or hospital.

A useful tool for finding a specialist in your area is the by looking on the British Society for Gynaecological Endoscopy website. You can try and find a doctor in your area that has an interest in endometriosis by having a look on [www.bsge.org.uk](http://www.bsge.org.uk) and going to the 'Endometriosis Treatment Centres' link. Here you can search for accredited endometriosis treatment centres.

Once you have found a person who has an interest in endometriosis, you can ask to be referred to them. It doesn't matter if they are not in the hospital where you are currently being treated - with patient choice, you can be referred out of the area.

## Getting a diagnosis

### How can I prepare for my appointment with the consultant?

You may have waited some time for this appointment so it is important to get the most from it. The information you prepared for your GP will be invaluable for this consultation; remember to bring it with you, and to update it if necessary. You may have to make some difficult decisions about treatment, so it is important that you have a good relationship with your specialist and that you trust them.

During the consultation, take notes if you can as it may be hard to remember everything. You might also want to take someone with you for support. You could ask that person to write everything down so that you can concentrate on what is being said.

You need to ask questions as well as listen to the doctor. It is worth writing down your questions the night before your appointment. Get everything clear in your mind, do some research on the internet or ring the Endometriosis UK helpline: 0808 808 2227. Some questions you may want to ask include:

- What do you think is causing the symptoms?
- Will you want me to have a scan? What sort of scan and what are you looking for?
- Will you want me to have a laparoscopy? What are you looking for? (Please see the separate sheet in this pack for more information on laparoscopic surgery)
- Do you think my fertility is affected?
- How can I control my symptoms?
- What treatments do you suggest and why?
- Are there any other options that I need to consider?

### What if I would like to see a different consultant?

If you would like a second opinion after seeing a consultant, you need to ask your GP to refer you again. If you are not happy with your existing consultant, you should not be afraid to ask to change, as it is important that you find someone who you trust and can be completely honest with. We are all different and the most important thing is that you are comfortable working with your consultant to get the right treatment plan for you.

The new consultant will be told that this is your second opinion and will be sent any relevant test results or X-rays previously carried out. A second opinion with a different consultant may be at a different hospital, which can sometimes mean travelling. However, finding the right person to look after you may mean that you accept travelling farther afield.

**Helpline: 0808 808 2227**

*Last updated April 2012 (For office use only)*

© Endometriosis UK. Suites 1 & 2, 46 Manchester Street, London, W1U 7LS  
t: 020 7222 2781

[information@endometriosis-uk.org](mailto:information@endometriosis-uk.org)

[www.endometriosis-uk.org](http://www.endometriosis-uk.org)