

## Is a hysterectomy the right option for me? – Making the decision

When considering a hysterectomy, it's so important to spend plenty of time beforehand weighing up the pros and cons so you can decide whether or not it's the right choice for you.

It is a huge decision to make, but you don't have to do it all on your own (though remember, it is your body and the final choice is yours – do what feels right for you). Talk it through with your GP or gynaecologist, and your family and friends. Endometriosis UK has a range of services that enable you to talk to other women who may be (or have been) in the same situation as you; try visiting your local support group, calling our free helpline, or using our online message-board or Facebook group, for the chance to discuss your concerns with others who understand.

When you are in pain, you may feel like a hysterectomy is the answer, but making this decision when your symptoms are severe could lead to you regretting your choice later. If possible, work with your gynaecologist to try and find a treatment that reduces your pain, or go back on a treatment that successfully reduced it in the past, so you can make the decision as rationally as possible.

Get yourself as clued up as you can; familiarise yourself with the information in this pack, and get any questions you have answered so you can be satisfied that you make the right decision for you.

### Will a hysterectomy cure my endometriosis?

For many women, a hysterectomy will be a positive step and will put an end to symptoms such as pain, but unfortunately this cannot be guaranteed. The likelihood of endometriosis recurring depends on factors such as whether or not you also have your ovaries removed, whether any endometriosis is left behind and how severe your disease is. These factors, along with statistics, are discussed in this factsheet.

There is a useful way of gauging whether a hysterectomy will be successful for you: by trialling a Gonadotrophin-releasing hormone agonist (GnRHa) – more details of this are contained further on in this factsheet.

### What exactly is a hysterectomy?

A hysterectomy is an operation to remove the uterus (womb). If the cervix (entrance to the womb) is removed, it is a **total hysterectomy**. If the cervix is kept, it is a **subtotal hysterectomy**.

### Should I have a subtotal or total hysterectomy?

The type of hysterectomy you have will usually depend on your own medical history, but as long as your womb, tubes and ovaries look healthy at the time of the operation, and you've always had normal smears, you have the option to keep your cervix. It may be a case of personal preference; some women may opt for subtotal hysterectomy because they want the 'least amount possible' removed.

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If you have a subtotal hysterectomy, then you will need to continue having smear tests. You may continue to have light periods from the lining inside the cervix. These can be regular or irregular.

The cervix produces a slippery discharge, so without it, intercourse may be slightly drier. However, the vagina itself produces a lubricating discharge. Contrary to popular belief, the cervix does not contain the 'G spot.' There are some studies that suggest that orgasm is less satisfying after the cervix is removed, whilst other studies suggest that removal of the cervix makes no difference to sexual satisfaction. There is also much data that suggests that orgasm and sex drive is better after hysterectomy.

Some of the pelvic floor ligaments insert into the cervix. If the cervix is removed, these ligaments remain attached to the top of your vagina where they will continue to give lift and support. Some studies suggest that urinary incontinence is more common after hysterectomy, but the greatest risk of problems afterwards seems to be for women who have urinary incontinence before hysterectomy.

Successful relief of symptoms relies on removing all of the endometriosis, but the disease is often found on the cervix so a subtotal hysterectomy may not be the right option for you if you have endometriosis on your cervix. Discuss this with your gynaecologist before you make the decision.

### How is a hysterectomy procedure done?

A hysterectomy can be carried out in three different ways:

#### **Abdominal hysterectomy**

This is when the womb is removed through an abdominal incision. You would have the option to keep your ovaries and cervix, though occasionally this decision has to be modified due to the findings during the operation. Speak to your surgeon about this beforehand.

#### **Vaginal hysterectomy**

This is the removal of the womb **and cervix** through the vagina – there are no abdominal cuts. It would be normal to keep your ovaries, if they are healthy.

#### **Laparoscopic hysterectomy**

A thin camera (laparoscope) is inserted into a small cut in or near the belly button so the surgeon can see inside. The womb, and sometimes the ovaries, are freed, and along with the cervix, are removed through the vagina.

Though uncommon, if there are unexpected complications, the surgeon may change to an abdominal incision to complete the operation.

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### Should I keep my ovaries?

This is an important question to consider, especially for someone with endometriosis. The ovaries produce the hormone oestrogen, which stimulates endometriosis and causes it to grow. So if the ovaries are left in place, it could cause endometriosis to remain active. This would be more likely if any traces of endometriosis were left behind after the operation.

If you opt to keep your ovaries, there is a small chance of needing further treatment or surgery for the endometriosis, usually because your symptoms have returned. The chance of recurrence depends on the severity of your endometriosis:

- With mild endometriosis, the chance of needing further treatment is 4 out of 100 women
- For severe endometriosis, the chance of needing further treatment is 13 out of 100 women within three years and 40 out of 100 women within five years.

A useful 'test' to find out if a hysterectomy and removal of the ovaries (oophorectomy) will be successful for you, is a three-month trial of a Gonadotrophin-releasing hormone agonist (GnRHa). This produces a temporary menopause and will give you a good idea as to whether hysterectomy and oophorectomy will improve your symptoms.

If you do keep your ovaries, there is research that suggests that menopause may occur earlier than normal with as many as one in six women going through the menopause within two years of the hysterectomy. If you suspect that you are going through the menopause, a blood test can show if your ovaries are working normally.

### Will I need HRT?

If your ovaries are removed at the time of the hysterectomy, you will start the menopause, so hormone replacement therapy (HRT) is usually recommended (depending on your age) until you are around 50. You can discuss this with your surgeon or GP and review the situation when you reach 50. HRT prevents premature menopause symptoms and longer-term problems such as thinning of the bones (osteoporosis). HRT, in this instance, is replacing the hormones that your ovaries would have produced if they had not been removed (so it's not associated with the risks of taking HRT after the natural menopause age of around 50). Sometimes HRT can cause endometriosis symptoms to return, in which case, the dose can be reduced or even stopped.

A good way to find out if HRT would cause your symptoms to return after an oophorectomy (ovary removal) would be to combine HRT with the GnRHa trial (mentioned above). If your symptoms are reduced and the HRT does not bring them back, it suggests that HRT would not cause your endometriosis to return after a hysterectomy and oophorectomy.

You may need additional HRT if you are still getting symptoms of the menopause, and there are also treatments to improve your libido, so do mention this if it is a problem.

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HRT is not suitable for all women. The type of HRT you choose should be discussed with your surgeon.

### What are the risks?

As with any operation, there are some risks involved. Minor problems are common, but serious complications are less so, occurring in four women in every 100. A small number of women may develop an infection after the operation and this may involve the chest, wound, urinary system or pelvis. Your surgeon may discuss prophylactic (i.e. preventative) antibiotics at the time of the operation to reduce the risk of infection.

Thrombosis (blood clots) in veins and lungs can occur infrequently after surgery. Specific steps are taken to minimise this risk including; asking you to wear pressure (TED) stockings, an injection of an anti-clogging medicine called heparin, and early mobilisation after the operation.

Bleeding problems or damage to other structures, such as bowel, bladder and the ureters (tubes connecting the kidneys to the bladder) are rare complications that may make a further operation necessary.

### Complication statistics:

Venous thrombosis or pulmonary embolus	40 in 10,000 operations
Blood loss requiring transfusion	23 in 1000 operations
Bladder or ureter damage and/or bladder problems postoperatively	7 in 1000 operations
Return to theatre	7 in 1,000 operations
Pelvic abscess or infection	2 in 1,000 operations
Bowel damage	4 in 10,000 operations
Risk of death within six weeks	33 in 100,000 operations

The precise risks depend on your individual situation and past medical details. The risks of surgery are increased by previous operations, presence of adhesions and being overweight.

**Helpline: 0808 808 2227**

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## Preparation & Recovery

If you are certain that you want to go ahead with a hysterectomy, spend some time beforehand preparing for both the operation and the recovery. Hopefully, by knowing what to expect, you will be able to help things go as smoothly as possible.

### What can I do before the operation?

It is important that you are as fit and healthy as possible, so that your body can heal more efficiently and you can reduce your chances of getting any infections that could slow your recovery.

If you smoke, try to give up as soon as possible, as smokers are much more likely to develop chest infections. If you are overweight, try to reduce your weight as this will make the operation easier and reduce the risk of complications, especially wound infection.

Before your operation you will have the chance to ask questions of a nurse and an anaesthetist. If you have any particular concerns, write them down so you don't forget them.

*"It was coming up to my 40<sup>th</sup> birthday and I had decided that I wanted to be physically and mentally fit for the operation, so I embarked on a health plan with the help of a nutritionist. I ate healthily, took a range of supplements to boost my immune system and started to walk more. I felt that if I had optimum health then my recovery would be speedier. In fact I felt so well before the operation that I began to think that I may not need it!"*

### What will happen during the operation?

The operation is performed under a general anaesthetic. In addition, you may be offered an epidural anaesthetic for pain relief. The operation time varies, but usually takes between one to two hours. Abdominal hysterectomy is usually carried out through a bikini line incision, but if your womb is very large, a vertical incision is sometimes required.

*"My operation was at 9am and I was awake by lunchtime. Although there was a certain amount of discomfort, I wasn't in any pain (albeit I was on a morphine drip!). I actually felt really good but very tired. Some of my visitors asked if I had the operation as I was looking so well and my husband phoned work to tell them I was sitting up and had my make up on. I didn't - it was lip balm!"*

### What happens afterwards?

On return from theatre, you will have a drip in your arm to give you fluids until you can drink properly. You will also have a thin tube, known as a catheter, in your bladder to keep it empty, as most women have difficulty passing urine immediately after a hysterectomy. You may have a drainage tube from your wound to reduce internal bruising. These are normally removed the following day, or as you recover and become more mobile.

On the first day, you will have help with washing, and then a daily shower or bath is advised.

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You will probably be encouraged to move around early on (with assistance if you need it), to help speed up recovery. It will also help to improve your circulation, avoid the risk of blood clots and can help relieve trapped wind. Ask at the hospital for advice about moving around.

Your nurse will advise you on when to drink, and then eat, and gradually your appetite will return. Eat small light meals until your bowels start moving again.

Slight vaginal bleeding or discharge is quite common following the operation and may continue for two to three weeks. Use sanitary pads instead of tampons because there is more chance of introducing an infection with tampons. If this discharge or bleeding becomes smelly or heavy or there are symptoms that worry you, contact the ward or your GP.

### Going to the toilet

There can be some pain at the end of passing urine due to the internal stitches, but this will settle with time. If you have any difficulty in passing urine or problems with bladder control, tell your nurse or doctor.

It is normal not to have a bowel movement for the first two days and this can also mean painful trapped wind. If needed, a suppository and/or laxative can be given. Constipation is a common problem after surgery, so try to drink plenty of fluids and include fresh fruit, vegetables and fibre in your diet.

Most women are ready to go home 2-3 days after a laparoscopic, abdominal or vaginal hysterectomy but this will depend on how you are and the severity of your endometriosis prior to surgery. Before you go, your nurse will explain how you should care for your wound/s. A follow up appointment is not always necessary – ask at the hospital if you will need one.

### Will it hurt?

It is normal to be uncomfortable after the operation. Women often describe a strong period-like pain in the lower back or above the pubic bone. You will be given pain relief before you wake up from the operation and may need more as this wears off. Pain is normally controlled using a Patient Controlled Analgesia pump. This is a pump attached to a drip in your arm, with a handset for you to hold. When you press the button on the handset, pain relief medicine is sent through the drip. You can press this as often as you need, as there are presets that prevent you from overdosing. The pump is usually only needed for the first 24 hours and after this, you will be prescribed regular painkillers, normally a combination of paracetamol, non-steroidal anti-inflammatory drugs and codeine. Ask for extra if you need them.

### Will I have scars?

If your hysterectomy is carried out abdominally or laparoscopically, there will be one or more scars on your tummy. These will be reddish pink at first, but will fade to white with time.

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There can be some altered sensation in the tummy cuts; women describe numbness, tingling or hypersensitivity. This will improve with time, but can take weeks or months to resolve and you may be left with a small numb or hypersensitive area of skin. Some women form a keloid scar where the scar is raised, so let your surgeon know if you have healed unusually after previous surgery or cuts.

*“My wound was around 6 inches and had been stapled. The first time I saw the scar, I was devastated as it looked like an angry face with teeth and I had expected it to be tiny. However it faded with time and I am used to it now.”*

### Once you are home

For the first week, you will probably feel quite tired, so it's important to have help at home to allow you to rest and relax for this time.

*“I wasn't allowed to drive or do anything strenuous for six weeks but walked short distances to try and build my strength. Despite feeling well, I still felt very tired and weak. Once the six weeks were up, I was able to drive, although I built this up gradually. The first day I went shopping, I had to go home because I was exhausted.”*

### Will I be able to bath or shower?

You should take either a bath or shower daily. Take it slowly – especially getting up from the bath. Keep the cut dry by leaving the dressings in place and replacing them after showering or bathing. Your nurse will advise when you can remove the dressings completely. You may be given additional dressings when you are discharged from hospital.

### Will I be able to exercise? Is it recommended?

It is safe for you to climb the stairs the same day you go home. After the first week, progressive exercise is important to speed your recovery. Start with daily walks, gradually increasing the distance and speed, until by six weeks you should be taking brisk walks of 20-30 minutes. In addition continue with the exercises taught by the physiotherapist.

If you play any sports, it should be safe to start up again after your six-week check up, although gentle swimming can be started 2-3 weeks after the operation.

### What sort of diet should I follow?

A well balanced diet containing high fibre foods is essential and will help avoid constipation. Drink plenty of fluids. If you do have a problem with constipation, take a laxative as necessary. You should watch your calorie intake until you are fully active again.



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### Is it ok to lift things?

The general advice is not to lift anything heavier than a full kettle for the six weeks following your hysterectomy. Do not lift heavy objects like shopping bags, or move furniture for six weeks. When you do lift anything, remember to bend your knees, keep a straight back, hold the object close to you and lift by straightening your knees.

### When can I drive again?

You should be able to drive again when you feel able to concentrate fully, can wear a seatbelt and make an emergency stop without discomfort. This would usually be between 3-8 weeks, depending on the type of operation you had. It may be a good idea to take someone with you the first time you drive again in case you have any problems.

Some car insurance companies require a certificate from a GP that states you are fit to drive after surgery. Check whether this is the case with your insurance company, and if so visit your GP to check you are ok to drive.

### Will I be able to do housework?

For the first week at home, you should have plenty of rest, but you will be able to make a cup of tea, do dusting and easy household jobs. Sit in a chair when possible to reduce standing. Gradually increase household jobs e.g. cooking, ironing and using a vacuum cleaner, until by six weeks you are able to do most jobs with the exception of heavy lifting.

### When will I be able to go back to work?

*"I returned to work on a phased basis over a four week period and this helped enormously."*

Most women who have a hysterectomy are able to return to work anywhere between 4-12 weeks depending on the type of hysterectomy, the location and severity of endometriosis and the amount of previous surgery. Recovery is an individual process and it is important to consider how you feel, the type of work you do and what is realistic for you with regards to your work. You should discuss this with your GP, but it is ultimately up to you when you return. Talk to your employers before you return if you are worried about feeling tired; depending on the type of work you do, a phased return might be the best way of gradually building up your strength as you return to normal work activities.

### How long should I wait before I have sex?

It is advisable to refrain from full penetration for about six weeks after your operation. Wait until you feel comfortable and relaxed.

There are a lot of myths about a woman's sex life after a hysterectomy, but generally it should not affect sexual desire. Two studies showed that the majority of women found their sex lives to be improved or unchanged, though a few said they had less interest in sex after a hysterectomy.



## Preparation & Recovery

If your hysterectomy relieves your endometriosis symptoms, your sex life may be enhanced, as you may no longer need to worry about pain.

If vaginal dryness is a problem, try a vaginal lubricant, which you can buy from any chemist.

### Will I need to keep having smear tests?

If you have a subtotal hysterectomy (keep your cervix), you will need to continue having smears until you are 65. If you have a total hysterectomy (cervix removed) and you have not had any abnormal smears in the past, you will not need any further smears.

### Do I need a follow up visit?

It is usual to have a check up at six weeks after your operation. If you have stitches, you will be examined to ensure that they have healed well. This is a good time to ask if you have any questions about your recovery.

If you are worried that you are not recovering as you should when you get home, you can contact your GP or the hospital ward where you were admitted.

You should get in touch with your GP or hospital ward if you develop any of the following:

- Severe pain or fever after going home
- Nausea or vomiting
- Increased bleeding from the cuts
- Smelly discharge from the cuts
- One or more of the cuts become painful
- Smelly vaginal discharge

## Preparation & Recovery

### How will I feel afterwards?

The decision to have a hysterectomy is a very personal thing, so how you feel after will be unique to you. Most women are relieved that troublesome symptoms have gone, while others have said that they feel a sense of loss.

The surer you are that a hysterectomy is the right choice for you, the less likely you are to feel depressed or sad once you have had the operation.

If you do feel low afterwards, it is important to talk about your feelings with friends, family, or a professional counsellor. It can be very reassuring, and a great source of support, to talk to other women who have been in your situation. Try calling the Endometriosis UK helpline, through which you can be referred to someone who has had a hysterectomy, or visit your local support group or use our online message-board or Facebook group.

*"Lots of people asked me if I feel a sense of loss; I have to be honest and say absolutely not, but I appreciate everyone's situation is different."*

*"When I returned for my biopsy results after the operation, I was told my endometriosis was extensive and that I also had fibroids, ovarian cysts and adenomyosis. After 10 years of being made to feel like it was all in my head, I finally felt vindicated. The results confirmed that not only did I make the right decision, it was the only sensible one for me."*

*"I felt pretty hopeless after my operation; I felt like I'd lost interest in things, had trouble sleeping and generally lacked energy. I put this down to the hysterectomy and decided to join a support group that was recommended by a friend. After a month or so, I was feeling much better and I started to live normally again. I think I just needed time to adjust after this big change."*

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providing support increasing understanding



## Hysterectomy – further information

### **The Hysterectomy Association**

*Helpline and information for women who want to make informed choices about hysterectomy. Sell books and leaflets, and provide free information via the website.*

**Website:** [www.hysterectomy-association.org.uk](http://www.hysterectomy-association.org.uk)

**Email:** [info@hysterectomy-association.org.uk](mailto:info@hysterectomy-association.org.uk)

**Helpline** 10am - 4pm: **0844 3575917** (national rate)

Peeverell Avenue East  
Dorchester  
Dorset  
DT1 3WE

### **Hysterectomy Support Network**

*The Hysterectomy Support Network keep a database of volunteers who have had hysterectomies for various reasons and are prepared to talk to other women who are contemplating one, or who have had one recently. The aim is to put callers in touch with a volunteer whose circumstances match the callers as closely as possible.*

**Helpline** 9.30am - 1.30pm: **0845 125 5254** (local rate)

52-54 Featherstone Street  
London  
EC1Y 8RT  
Tel: 020 725 16580

### **The Daisy Network**

*The Daisy Network Premature Menopause Support Group is a registered charity for women who have experienced a premature menopause. They offer a wide range of benefits for members, including a list of telephone contacts who members can call to talk about their situation, a counselling service, a quarterly newsletter, factsheets and an online forum. Their website provides information for members and non members.*

**Website:** [www.daisynetwork.org.uk](http://www.daisynetwork.org.uk)

**Email:** [daisy@daisynetwork.org.uk](mailto:daisy@daisynetwork.org.uk)

The Daisy Network  
PO Box 183  
Rossendale  
BB4 6WZ



## Hysterectomy – further information

### **101 Handy Hints for a Happy Hysterectomy (Paperback)**

by Linda Parkinson-Hardman

This book was written by Linda Parkinson-Hardman, Director of the Hysterectomy Association. It provides practical information, tips and advice for both pre and post surgery.

**Price:** eBook: £4.99  
Paperback: £7.00

Available from [www.hysterectomy-association.org.uk](http://www.hysterectomy-association.org.uk)

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