



endolink *Magazine*

FOCUS:

Endometriosis & The Bladder

PLUS

Top tips for using a catheter

Research Update

How leaving a legacy could help

ISSUE SUMMER 2012

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From the editor...



I am very pleased to introduce this particular edition of Endolink Magazine. We have chosen to focus this issue on endometriosis and the bladder which can be a complex and difficult area. Thanks to Caroline Overton, consultant at Bristol and her urology colleague, Tim Whittlestone for their input. In addition, those of you undergoing surgery involving the bladder may find you have to use a catheter and so the article on “do’s and don’t’s” on page 8 we hope will prove very useful.

Staffing

We would like to introduce Patrick Hinton who joins us on a part-time basis as our Communications Officer. Pat will be focusing in the main on the website and electronic communications but his considerable writing talents will not be wasted as he will also carry the responsibility for information and media.

Pat joins our small team which includes Fiona – our Membership and Fundraising Officer – and Liz, our Support Network Manager, as well as me. We are eternally grateful for the regular volunteers who continue to support our work in the office. If you are interested to help on a regular basis we are always pleased to hear from you: email us at admin@endometriosis-uk.org.

Wonderful Carol!

I want to give a particularly large ‘thank you’ and ‘well done’ to Carol Pearson. Carol is one of our trustees (all charities have to have a board of voluntary trustees or ‘directors’ who oversee the charity’s activities) and is our Treasurer. She is also a support group leader in Guildford and co-leader of the West Sussex group. Not only that but she

has spearheaded the ‘Pink Pants’ fundraising events over the past few years which has raised over £30,000 including the recent Snowdon Horseshoe trek (see the Fundraising pages).

We know at Endometriosis UK that Carol is a star and it appears that the accountancy profession also thinks the same! As recognition of all Carol’s work for us, she has been successful in the ICAEW Everybody Counts Awards, scooping a prize of £2,000 to be donated to Endometriosis UK. The Award was presented on 25th June.

Last but not least Carol has contributed a great deal to this particular edition of Endolink as endometriosis and the bladder is a subject close to her heart, and additionally by sharing her reasons as to why she is leaving a legacy to the charity in her Will. Thank you Carol for all of your input and support – it is so greatly appreciated.

Development Funding for Diagnostic Bio-Markers

News has come through from Australia that the Endometriosis Research Group at the University of Adelaide has just secured funding to develop its discovery of the bio-markers (microRNAs) in human blood that are indicative of endometriosis into a prototype blood test. This would be a real break-through and would address many of the shortcomings of existing endometriosis diagnosis.

Membership Survey

As members we hope you will have taken the time to complete our ‘Tell Us What You Think’ survey that has been running for the past few weeks. Sent out by email and post (to those without email addresses) it is part of our activity to learn from you what we do well and what we don’t. This will

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Next Information Day & AGM -
just booked for Saturday 6th October in
London. Watch out for more details soon!

help us shape and inform our future services and activities. We will report back on this in future editions and at the next AGM.

BSGE Scientific Meeting

I was very pleased to deliver a short presentation about Endometriosis UK at the recent BSGE Scientific Meeting in Cardiff in April. As part of a focus on endometriosis featuring presentations from patients, nurses and other specialists we were able to present elements of the charity's activities and encourage all clinicians to work together with us and patients to recognise the chronic nature of this disease and the need for improved treatment and care for sufferers throughout the UK with the aim to extend the number of specialist care centres.

Funding

Here at Endometriosis UK we continue to try to provide all the services that you and others need. We are doing our best to bring new and additional funds into the charity but if you can make an additional donation at this point too – or on a regular monthly basis - this would be a great boost. However we know that not everyone can make a donation now, so I hope you will consider remembering Endometriosis UK in your Will – there is more information on this later in the magazine.

We appreciate your input as members and volunteers and please know that we are committed to providing support and information to women with endometriosis and working to improve services however we can.

With warmest wishes

Helen

Research...

Whilst our funds to pay for research are negligible, Endometriosis UK remains fully committed to research into endometriosis and its effects on sufferers.

Research - Volunteer

Showing this commitment means that I am pleased to introduce a new volunteer – Eleni Bourantani – who is completing her Masters degree and will be giving us some time to collate and review information on recent research activity with a particular focus on the social and emotional impacts of endometriosis. Eleni's findings will be included on the website in due course.

Research - Endopart

We are also delighted to be supporting researchers at De Montfort, Birmingham City and Nottingham Universities who are running the Endopart Study – looking at improving the well-being of couples. Led by Prof Lorraine Culley, the team will be looking to work with couples and use their findings to make recommendations about how women and their partners can be best supported. More information can be found on our website or at www.endopart.co.uk

Research - Clinical

Finally, as reported in a previous Endolink, Endometriosis UK is part of the Clinical Studies Group set up by the RCOG to look into Menstrual Disorders including endometriosis. We are pleased to be part of this and ensure the patients' viewpoint is represented as well as helping to shape new research proposals. At the recent meeting held in Cardiff in April, reports were given on the MEDAL programme, looking into the use of MRI to replace or triage the need for laparoscopy in the diagnosis of endometriosis (see www.birmingham.ac.uk/medal), the ECLIPSE trial which has submitted a paper that looked at the effectiveness of using of IUDs in primary care to control pelvic pain (www.eclipse.bham.ac.uk) and the upcoming PRE-EMPT research study, looking at preventing the recurrence of endometriosis by means of long-acting progestogen therapy. Future studies were also discussed and Endometriosis UK will be pleased to report back to members on these in future editions including how the research can be supported.

Bladder Endometriosis: Your Questions Answered

Bladder endometriosis is rare but treatable. Urinary tract infection (cystitis) and overactive bladder are much more common and have similar symptoms to bladder endometriosis.



Mrs Caroline Overton, Consultant Gynaecologist and lead surgeon, and Mr Tim Whittlestone, Consultant Urological Surgeon, both at St Michael's Hospital in Bristol, a BSGE accredited Endometriosis Centre, look at some of the main points.

How does endometriosis affect the bladder?

Most women with endometriosis of the bladder have no symptoms at all, because endometriosis is only found on the outer surface of the bladder. This does not require any specific treatment.

If endometriosis involves the muscle of the bladder, some women may have bladder pain as the bladder fills or empties, and they can have bladder spasms and an urgent desire to pass urine and/or frequency of passing urine. Rarely, endometriosis of the bladder causes blood in the urine that can be visible to the naked eye or invisible (picked up

on dipstick testing). Typically these symptoms are cyclical i.e. there is a link with the monthly period cycle.

If I get lots of Urinary Tract Infections, does this mean I have endometriosis of the bladder?

Not necessarily. Endometriosis of the bladder is rare and urinary tract infections are common. Antibiotics will treat a urinary tract infection. Almost all women will have a urinary tract infection at some time in their lives. Endometriosis is a rare cause of recurrent urinary tract infections but is always a consideration when antibiotics have failed to cure the problem. Endometriosis in the bladder predisposes women to urinary tract infection because the bladder lining is roughened by the endometriosis and becomes attractive to bacteria. Urinary tract infections associated with endometriosis are usually resistant to standard antibiotics and symptoms return rapidly after antibiotics have finished.

What sort of scans do you use to look at bladder endometriosis?

It would be unusual to detect bladder endometriosis with a standard ultrasound scan unless there was a nodule indenting the bladder muscle or blockage of one or both of the

ureters (the drainage tubes from the kidneys). If it is suspected that there is a nodule of endometriosis within the muscle of the bladder wall, an MRI can help define how much of the bladder muscle is involved (Fedele et al 1997). An Intravenous urogram can be used to scan the kidneys and ureters in more detail.

How do you diagnose endometriosis of the bladder?

A cystoscopy involves passing a tiny telescope in through the urethra to look inside the lining of the bladder. This can be performed with a local anaesthetic or general anaesthetic. A biopsy can be performed at this time that may help in the diagnosis of endometriosis and exclude other problems. Often a combination of laparoscopy (to look inside the abdomen) & cystoscopy as a combined operation with a Urological surgeon is required.

How do you treat endometriosis on the bladder?

There is no medical treatment that will completely eradicate endometriosis of the bladder. If the endometriosis is confined to the inner lining of the bladder then it is possible to cut away this area by using a special telescope that can cut under direct vision. If the endometriosis involves the full thickness of the muscle of

the bladder, then the operation is carried out either laparoscopically or as an open operation to cut out part of the bladder wall and the bladder wall then stitched closed. Any symptoms that persist can then be treated medically.

What painkillers and medical treatments can be used to manage the symptoms?

Any combination of painkillers – paracetamol and ibuprofen are a good initial combination, but stronger painkillers may be required. The advice is to take your painkillers regularly and “stay ahead of the pain” Exercise can help if you can face it.

What happens if endometriosis affects other parts of the urinary system like the ureters or kidneys?

Endometriosis affecting the ureter may present as a hydronephrosis (back pressure on the kidney) resulting in loin pain on the affected side. The pain can be severe, colicky in nature and radiate to the loin/flank. Treatment is to excise the area of endometriosis. Medical treatment to shrink the endometriosis may be sufficient to “unblock” the ureter.

What can I expect after surgery for bladder endometriosis?

Surgery for endometriosis in

the urinary tract is bespoke to the individual patient - no two operations are the same. Experts in endometriosis surgery will include gynaecologists and urologists with special training who work in teams to plan the most suitable surgical approach. Very superficial deposits of endometriosis on the outer surface of the bladder can be simply burnt away using cautery devices. Endometriosis affecting the bladder muscle needs to be resected (cut away) and the defect in the bladder repaired using stitches. If the ureters are diseased then the diseased segments are removed and/or the ureters re-connected into the bladder.

Because the nature of the surgery varies, the period of recovery ranges from 24 hours up to many weeks. Simple cautery of endometriosis deposits is often carried out as a day case procedure and involves 2 weeks convalescence. More complex excision of endometriosis and reconstruction of the bladder will mean a 4-5 day hospital stay and 4-6 weeks convalescence.

What can I do to help my recovery from surgery on the bladder?

These depend on what your operation requires. In general, you will need regular painkillers when

you first go home. Expect to feel tired and rest as you feel you need to.

It is safe for you to climb the stairs the same day you go home. Gentle exercise is important in helping your recovery. Start with daily walks, gradually increasing the distance and speed, until you can manage brisk walks of 20-30 minutes. Don't expect to have a big appetite, but eat small meals. You should watch your calorie intake until you are fully active again. 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.

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. Particularly, you should get in touch if you develop any of the following:

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

What is a catheter and why is it used?

A catheter is usually inserted

Bladder Endometriosis: Your Questions Answered

at the end of the operation to improve the drainage of urine and to allow the bladder to heal. This is usually removed after 7 – 14 days. A special X ray called a cystogram may be arranged to check that the bladder stitches have healed and that the catheter can be removed.

If endometriosis has involved the ureters, stents (plastic tubes) are inserted into the ureters to aid urinary drainage. These stents are internal and temporary. While inside they can cause some bladder urgency. They are usually removed after 7-14 days. A cystoscopy to check inside the bladder is carried out under local anaesthetic and the stents removed through the urethra. This is generally a quick and easy process.

I don't have endometriosis on the bladder but I have bladder symptoms - what does this mean?

Overactive bladder, urethritis, urethral syndrome, trigonitis, are terms used to describe urinary frequency and urgency symptoms. There are fortunately simple tests that can be a guide to the cause of these symptoms.

What is interstitial cystitis and what are the symptoms?

The symptoms of interstitial cystitis

can vary greatly. The most common symptoms are blood in the urine (haematuria), pain with intercourse (dyspareunia), pelvic pain, pain passing urine (dysuria), and back pain. Many women with interstitial cystitis pass urine frequently during the day and night (nocturia). In a few women, the symptoms can be so severe that they need to pass urine as often as every five minutes. This makes going out from the house almost impossible.

For many years interstitial cystitis was thought to be a chronic bacterial infection. The theory was that the bacteria would persist inside the bladder and become resistant to normal antibiotic treatment.

We now believe that interstitial cystitis is part of an immune system dysfunction that allows the protective coating of the bladder to be denuded in small areas. The protective coating (glycosaminoglycan layer) protects the bladder from the chemicals in the urine. When this layer is missing, the bladder can become irritated.

Making a diagnosis of interstitial cystitis can be tricky and many patients are misdiagnosed. The best way to make a diagnosis of interstitial cystitis is on direct inspection of the bladder (cystoscopy) and biopsy of the bladder.

Is interstitial cystitis related to endometriosis?

It is unknown how many undiagnosed cases of interstitial cystitis may be present in women with endometriosis, but data suggests that as many as 1 in 4 women with endometriosis may have interstitial cystitis (Parsons & Tatsis 2004). This may help explain why some patients treated for endometriosis have not had relief from pain after surgical and medical therapies.

Who gets interstitial cystitis?

Any woman can get interstitial cystitis but the peak age range is in late 20's to early 30's. There is an association between interstitial cystitis and other 'allergic' conditions such as asthma and irritable bowel disease. There is also an association with interstitial cystitis and chronic fatigue syndrome and fibromyalgia.

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Case Study

Meg's Story...

I started to notice symptoms of pelvic pain in 2009 when I was 37. It came on quite suddenly and wasn't typical period pain. After a few months and some research on the internet I had worked out what I thought was wrong with me. I was fairly sure I had endometriosis and I went to my GP. She agreed with the working diagnosis but since I didn't consider my symptoms to be severe enough we decided to leave things as they were for then. She advised me to return if the situation deteriorated.

About a year or so later things were worse and in particular I had started to suffer some bladder symptoms. On returning to the GP she arranged for me to be referred to a gynaecologist for a laparoscopy which was carried out in June of 2011. The diagnosis of endometriosis was confirmed and the deposits were treated with diathermy (cauterised). That included some endometriosis on my bladder which the gynaecologist described as white endometriosis.

My bladder symptoms mainly consist of pain but also a change in the sensitivity of my bladder to filling. I get pain low down in my abdomen, just above the bone. It feels like my bladder is really full but when I get to the toilet there is very little urine to pass. I end up spending most of the time feeling like I need

to pee but never being quite sure if I really do! Sometimes I will decide this is ridiculous and leave it a while before going to the toilet. I distract myself with work or chores and the sensation/pain stays very much the same but when I do pass urine there is a huge volume. Then I worry I'm going to over stretch my bladder - I just can't win.

After my laparoscopy and diathermy of endometriosis on the back of my bladder I was determined to go home. The usual rules about needing to eat and drink, walk around safely and pass urine applied. It took a long time for my bladder to fill. I couldn't tell where I was with that aspect because of the surgery and pain so the nurses did a bladder scan using ultrasound. Once there was a reasonable amount I went and forced myself to urinate, mostly using my tummy muscles. In retrospect I probably should have had a catheter as I ended up needing to use all the tricks I know to help my bladder work for the next 24 hours! Unfortunately in my hospital they wouldn't have discharged a day case patient with a catheter, especially on a Friday night!

That first night after surgery I needed to sit in a bath of warm water to help me empty my bladder and also to be so patient as it took so long! I set myself a deadline - if things weren't working normally by midday on the

day after the operation I would go back to the hospital. Fortunately late on in the morning I got a fairly normal message from my bladder and went to the toilet where I was pleasantly surprised to find myself peeing easily. What a relief, my bladder muscle had woken up again! I wasn't worried about having a catheter in itself, after all it is only a soft tube held in place by a balloon that sits inside the bladder, but I had been really worried about needing to return to hospital when all I wanted to do was recover in the quiet privacy of my own home with my husband and my cats.

Now my symptoms are fairly stable and mostly I manage day to day. I make sure I stay well hydrated, despite the temptation to reduce the amount of urine my body produces. This is for 2 reasons, firstly concentrated urine is more irritant to the bladder and so will make the problem worse and secondly I feel shockingly rough when I'm borderline dehydrated. Caffeine is also irritant to the bladder so I keep that to a minimum too. I kind of know when I will need to get access to a toilet and mostly that's not a problem, even at work. I'm not terribly fussy, having been brought up in a hill walking family, so I will even use a convenient hedge if we are out and about if the need arises!

Endometriosis, Surgery & Catheters

After her own experiences, Carol Pearson, shares her 'top tips' for catheters...

If you are having surgery for endometriosis, your consultant will advise you if you are likely to have a urinary catheter when you wake up. Sometimes this is just for a very short period whilst your body recovers from the trauma of surgery. However, if you have surgery that cuts into bladder tissue, it is possible that you might have a catheter for a couple of weeks.

What sort of catheter?

For recovery from surgery or to allow the bladder time to heal, there are indwelling catheters where the tube comes out of the urethra and into a large drainage bag on a stand. If you have a catheter for more than a day or so after surgery, you may have a leg bag, which is smaller, more portable, and straps onto your thigh.

Some women with endometriosis perform intermittent self-catheterisation where short disposable tubes are used if the bladder doesn't empty properly. There are many reasons why this might happen because the nerves to the bladder are

very sensitive. It's not normally suitable if you have had surgery on the bladder, as the bag itself is important as it allows time for the bladder to heal.

How will I feel?

This is very individual and will depend on the type of surgery you have had but your catheter itself should not be painful. If the tube site (urethra) gets

sore, local anaesthetic gel can help. Depending on the type of surgery you have had, having a catheter alone should not stop you driving or going out.

Resuming some normal activities can help your wellbeing, although you should always be guided by your consultant and how you feel in yourself.

Top tips for an indwelling catheter...

- Make sure you drink around 2 litres of fluid a day – this should include a glass of cranberry juice which is helpful for the bladder.
- Ask hospital staff for a stretchy 'stocking' to hold the leg bag in place – much more comfortable than straps alone and more secure.
- If the type of surgery allows it, bathing with your catheter can be very helpful – it just floats on the top of the water and it's very soothing if things are a bit sore.
- Tight trousers should be avoided as they can cause the tube to block: sticky to baggy trousers or skirts.
- If you need any help with your catheter at home, your GP may be able

to provide a district nurse or help from the local continence service.

- Treat yourself to some lovely special underwear – after all, you deserve it and it makes you feel a bit better about things.
- When removing night bags in the morning, double check you have switched the valve to 'off' correctly – an easy mistake when you are half asleep...
- Don't stop doing things just because of the catheter: be guided by your consultant and common sense though
- Remember you are not alone – if you have any worries at all, speak to your gynae nurse specialist, urology nurse specialist, GP, consultant's secretary or ward staff – they are all there to help you.

If you have any queries about bladder endometriosis, bladder function problems or catheterisation, you may find invaluable support from your local group (for details see www.endometriosis-uk.org/support/local6.html) You may also like to visit <http://endometriosis-uk.healthunlocked.com/>. Other useful resources include www.bladderandbowelfoundation.org.

Later this year you can see an interview Carol gave to Health Talk Online www.healthtalkonline.org describing her personal experiences of bladder endometriosis & catheters.

Top tips for self-catheterisation

It can be upsetting to realise that your bladder isn't functioning correctly but self-catheterisation can be easy and straightforward to perform once you get used to it.

- Take your time learning. You are likely to be taught by a nurse specialist who will show you how to find your urethra with a mirror.

This might seem difficult at first but once you have got used to it, it gets much quicker and easier to do.

- Try out different products. Some of the catheters are already lubricated and are packaged discreetly. Find a product that suits you best, both in terms of ease of usage and your particular lifestyle. Some compact products are lipstick sized and easy to carry round, for example.

- Wash your hands well before performing self catheterisation and don't touch any of the parts that enter your urethra in order to minimise the risk of infection.

- You may find that some companies who supply products for self-catheterisation also provide products to use with them, like hand gel, wipes and disposal bags. This can make the whole process easier for you so talk to your specialist nurse or GP about this.

Charlotte's Story...

I have experienced bladder pain since the age of 17. This started as typical cystitis symptoms: intense burning, stinging and pressure in my lower abdomen but I was also experiencing sharp shooting pains and cramps around my period.

As the pain got worse I went to my GP who did a urine test and prescribed antibiotics for a bladder infection but my urine test then and others since never showed anything abnormal. During my late twenties, the pain had got so bad that it was taking over my life. My husband had noticed me wincing during intercourse and I could not hide that those moments filled me with absolute dread. I knew something had to be done.

Eventually I went to see a GP in my hometown and he was surprised that I had never been referred to a specialist before. A few weeks later, after a laparoscopy, I was diagnosed with severe endometriosis which shocked me as I had never heard of the condition.

When the extent of my illness was explained, how my bladder and uterus had become fused together, I was very upset. The gynaecologist and urologist that I saw recommended that as the endometriosis had penetrated my bladder, the best course of action was to cut away the disease. I was very apprehensive but trusted their decision.

After the operation, I felt unwell and was unable to get out of bed as my lower abdominal muscles had been cut. I felt so helpless. The catheter felt very strange: the urine I passed was blood red and I felt ill when I looked at it. When I needed to open my bowels, I took the bag with me on a stand as I did whilst showering. It was fine if it got wet and it was very important for both mind and body to keep clean. Sleeping with the bag was a challenge but I got used to it.

When I was discharged, I was given a leg bag for day use and a number to call at the hospital if I needed help. The bag was easy to use but did fill quickly. To empty it, you just flicked a valve under the base of the bag and emptied it into the toilet. The larger night bag was emptied by disconnecting the bag from the tubing. In total, I had the catheter for just over two weeks. I did get used to it, but was very relieved when it had gone!

Once my scar had healed, my bladder was working normally and I felt much better. I do find that I have to go to the toilet more often but I managed to get a radar key for the disabled toilet from the council, which is useful. Just over two years on, I am now having some further investigations for severe pain which has returned but the wonderful thing is that I have a son of ten months who was conceived without IVF! We count ourselves very lucky indeed for our miracle.



Looking to the future: how the gift of a legacy just keeps giving

In 1996 a generous lady decided to write her Will. With her family in mind she first made provision for them, making sure she could help them as best she could. She then decided to leave the rest of her estate – what she thought would be a small amount - to two charities that were close to her heart.

One of those charities was the charity Endometriosis UK – and when unfortunately this lady died, what she thought would probably be a small donation had grown beyond all expectations. This meant that in 2006 EUK received a cheque for £140,000. This amazing amount of money has since then been a lifeline for this charity allowing us to continue our vital support to women with endometriosis.

Thinking about writing a Will can be a difficult thing to do but it is an important step to take even if you think you have nothing to leave. Whatever your situation, making sure everything is written down and clear for your family or friends is something you can do to ease the burden when the time comes.

When making a Will obviously family comes first, but there are a few reasons why you might want to consider leaving a gift (a bequest or

legacy) to a particular charity. You may want to ensure that your own hopes or ideas for the future can be realised or continued, or you may want to make a larger donation that simply wasn't possible during your lifetime.

Additionally a legacy to charity is tax-free so that charitable gifts can reduce the inheritance tax that has to be paid on a person's estate. Currently tax of 40% is applied to estates in excess of £325,000. The Government may change these levels from time to time but consideration of tax may come into your plans. Currently the average house in the UK is worth £226,000 and in some areas is considerably more.

As you have seen above, the legacy we received in 2006 gave a huge long-term boost to Endometriosis UK and on the next page you can see why two other members – Carol Pearson and Victoria Fitzgerald – have both decided to leave a legacy to Endometriosis UK. All legacy gifts we receive are gratefully received and warmly remembered.

If you would like to discuss any aspect about leaving a legacy or find out more details, please contact our Chief Executive, Helen North by emailing her on ceo@endometriosis-uk.org.

Tips

To ensure that your legacy reaches the charity or charities you want them to go to, or that it is used in the way you wish, here are some tips to follow:

- *Always ensure that you include the registered charity number of the charity that you wish to receive your legacy;*
- *Consult a solicitor or suitably qualified professional to help write your Will.*
- *Appoint executors to your Will (these are the people who will make sure that your wishes are carried out properly) and make provision to allow for change if your chosen executors are no longer able to carry out the task.*
- *If you want your legacy gift to pay for something specific, e.g. a service or piece of research, consider how it could be used if that project or piece of research is no longer needed. Bequests that can be used at the discretion of the charity's trustees may be of most use.*

Types

There are a number of different types of legacy so you can consider which type would suit your situation best:

- *Pecuniary: a cash gift of a specific amount, e.g. £5,000*
- *Residuary: a share or percentage of an estate, e.g. 10%, or a share of what is left when all other bequests have been made*
- *Revisionary: a legacy that goes to charity only after someone else has benefitted from it during their lifetime, e.g. house*
- *Specific: a gift of a specific item, e.g. a painting or piece of jewellery.*

It is also possible to specify that life insurance and death in service payments be given to charity.



My Mum died a few years' ago from cancer. It was a terrible time and dealing with her affairs after her death was one of the hardest things I have ever done. It took so much energy out of me, we were so close and it was the last thing I ever wanted to be doing. But she left my brother and me a list of her wishes and fulfilling these meant so much to us – being able to donate some of her estate to causes close to her heart was a real honour and some of the letters we had in response to this were incredibly touching. They brought some small comfort at such a horrible time, knowing that my Mum would have been so proud to have helped charities close to her heart.

It has made me sort my own affairs out because one day when I die, I want my family to make sure the causes that matter to me receive some of my estate to help them continue their great work. And Endometriosis UK is top priority here – I have seen firsthand, both as a group leader and as a trustee, the importance of the work this small charity has to undertake. It's not an easy task! I am constantly in awe of what our staff and volunteers achieve – so much work with such limited resources. This is something I want to change, so I have made sure that Endometriosis UK is in my will. Nobody wants to think about making a will but it is the responsible thing to do – I don't want my loved ones to go through the administrative nightmare that happens if someone dies without making a will (called 'intestate'). This way, everyone is clear about my wishes. And giving money to charity in this way is tax efficient too.

I want the future for women with endometriosis to be better. It would be great to see a cure in my lifetime. More must be done for the thousands of women suffering every day. I want to play my small part in this – leaving a legacy is just one way to make a difference.



I was diagnosed with endometriosis in 2002, at the age of 36. I have had extensive surgery and drug treatments to control the condition. At the start, my husband and I dealt with everything pretty much on our own. Then after my surgery in 2005 I called the Helpline for the first time, and it was a real support to talk with someone else who understood what I was going through. However, I felt that I wanted more support and would have liked to have gone to a support group. As there was no group at the time in Bristol, I set up and ran the Bristol Local Group from 2006 for 4 years. Endometriosis UK was amazing in training, guiding and supporting me to run a group, which really helped me in my journey with endometriosis and gave women who came along valuable support.

It is because of all this, when my husband and I reviewed our wills this year that we decided we wanted to include Endometriosis UK as a beneficiary. We went and discussed it with a local solicitor, who drew up mirror wills for us. We agreed that when we are both gone, a certain percentage of our estate will be a legacy to Endometriosis UK and the rest will go to our siblings. We ensured that the solicitor had the correct name and address for Endometriosis UK, but most importantly that the Charity Number was included in the wording of our wills.

Some people specify how they want their charity legacies to be spent. But, we decided that we would leave our legacy without any special conditions, and have the confidence that the Trustees and Management of Endometriosis UK will put the funds to the best use for the Charity and the women it supports.

We are both hoping for a long and fulfilling life. But when we do both go, it is good to know that we will be leaving a financial legacy to Endometriosis UK, the wonderful charity which has supported us so much in our challenging times. over the last ten years.

Fundraising



Pink Pants

In May, twenty intrepid adventurers (including Endometriosis UK Trustees) took part in our annual Pink Pants Challenge. The team of men and women were ready to face the Snowdon Horseshoe, a focal point of the national park. The route took them up the Pyg track to the summit of Yr Wyddfa (the highest peak in Wales) continuing to the peak of Y Lliwedd, before descending into the Cwm to join the original miner's track.

The route, covering 17.5km and a duration of 11 hours, proved to be challenging but exceptionally rewarding as the fabulous fundraisers conquered fears of height and difficult terrain whilst forming lasting friendships along the way. Many of the participants were long term sufferers of endometriosis, which makes their accomplishment all the more impressive.

Indie's Inspirational Story

After suffering with chronic pain for years, Indie was diagnosed with endometriosis in 2011 and spent four consecutive weeks in hospital enduring multiple operations. After leaving hospital she wanted to challenge herself to do something special, giving something back to Endometriosis UK.

However, nothing could prepare Indie for the intensity of the Horseshoe. She kept her £1200 fundraising total and the support of her friends and family in mind as she embarked on the ascent. At the 3560 ft summit of Snowdon she could not stop the tears from flowing.

It wasn't over yet though, a steep descent awaited and that really tested her fear of heights, scrambling across scree slopes and windy ridges. Without the support of the fantastic leaders and fellow team members she wouldn't have made it. Eleven hours after departing the Bunk House, she had done it!

Remembering how weak she had been after surgery, eight months later she had made it to the top of the world and back!



"I have suffered a great deal, like us all, but I have never given up. This trek proved to me how determined and strong I actually am. I am a fighter and I love it. I love everyone who supported me to achieve what I did and learn things about myself. Most of all, I would like to say thank you to my husband for being with me every step of the way. Through the good times (yes there have been a few!) and the bad times."

Indie, Pink Pants Participant May 2012

Our huge congratulations and thanks to the team and their guides (Andrew and Stuart). We are so very proud that they kept smiling all the way round. The donations just keep coming in and so far they have raised an exceptional £10,000! Details of the next Pink Pants Challenge will be announced very soon. If you want to register your interest and join one of our great adventurers email fundraising@endometriosis-uk.org.

We can't wait to hear from you!

A huge thank you to all our recent fundraisers!



• Sue took part in the gruelling Caledonian Etape, an 81 mile cycle in Highland Perthshire. Undeterred by a strong headwind and heavy rains she completed the cycle with the support of her friend, Sarah. A tremendous thank you to her for raising over £900 to support our work.

• Kelly is holding a number of fundraising events during 2012 including family fun days, raffles, pamper evenings and quiz nights. So far she has raised over £1000! Her Summer Fun Day will take place on 23 August at The Greenhouse Bar & Restaurant, Leigh on Sea.

• Katie organised a Film Night at her university in Birmingham. The night was a tremendous success, raising over £1000 and increasing student's awareness of the chronic condition.

• Michelle held a cake sale and raffle at work, Deborah held a charity clothes sale fair and Jolene organised a 'Walk for Endo' in Belfast.

• Nilesh tackled the Three Peaks Challenge in May raising £300 and conquering Ben Nevis, Scafell Pike

and Snowdon in the process!

• Congratulations to Kellianne who has raised over £800 by completing the Machu Pichu trek in April. We are currently seeking participants for our overseas challenges. If you would like to fundraise for Endometriosis UK, see the world and take on a personal challenge get in touch!



• Sally ran the Bupa 10K in May and will be putting her running shoes on again in July to complete the British 10K.

• Caz and Mikey completed a 10K in Knole Park raising over £400. April completed the Edinburgh Half Marathon and Laura Smith followed our Pink Pant-ers and climbed Snowdon!

• Thanks to our marathon runners Antoine, Rob and Lee. Together they have raised over £2000 to support Endometriosis UK.



• Mel completed a bike-a-thon in May raising over £150 for Endometriosis UK as she cycled 50

Upcoming events:

Best of luck to our 12 wonderful runners who will be taking part in the **British 10K** on Sunday 8 July 2012. They will be passing some of London's most iconic landmarks as they raise money for Endometriosis UK.

Registrations have been coming in for the **5K Big Fun Run** at Crystal Palace Park on Saturday 8 September. There is still time to join them for a wonderful day out, raising money for Endometriosis UK in the process! Email fundraising@endometriosis-uk.org to find out how.

We are always looking for individuals who would like to organise their own event to raise money and awareness. If that is you, contact us for details of how we can support you.

Good luck to...

Jo and Kayley will be Running to the Beat...Tim and Dean will be completing the Great North Run...Michelle is tackling the Birmingham Half Marathon...Amy is running the Dublin Marathon...Helen is cycling from Manchester to Blackpool...Emma is running Leicester Marathon... Kelly will challenge everyone with her quiz night...Tracey and friends will be tackling the Three Peaks...Liz will be swimming the equivalent of The Channel in her local pool.

CEO, Helen and Chair of Trustees, Trevor will be jumping out of a plane! On 23rd September the charity's two leaders will each undertake a tandem parachute jump from 10,000 feet up – with the aim of raising £10,000! You can sponsor them at: <http://www.doitforcharity.com/helen-north1> or join them: contact Fiona in fundraising.

Support Network Update

Endometriosis Awareness Week March 2012

This yearly initiative is an excellent chance for us to raise the profile of Endometriosis and this year we focused on teenagers and young women.

We called upon our support network of volunteers to get involved and as ever their response was amazing. Some hosted events in their workplace or local area, many gave out leaflets and posters in their local community and fitness centres, some gave out leaflets in their GP surgery or held a stand in their local hospital. Below are some of the highlights from our volunteers:

Lynn Carr – Local Group Leader for Lanarkshire

Lynn arranged for her company to send out a global email to 15,000 employees. The email gave links to our web site to inform people about the condition and also raise awareness about our campaign.

Carol Pearson – Local Group Leader for Guildford

Carol and other group members held a stall at the Royal Surrey County Hospital. They gave out leaflets and information to people - it was the same day as the endometriosis clinic so they also saw a few patients too.

Melissa Stratton – Local Group Leader for Enfield

Melissa contacted her local paper the Enfield Independent and they did an article about her, the condition and her local group. Melissa said :

“Endometriosis is a condition that isolates its sufferers and makes them feel like they have no one to turn to. I set up this group not only to provide a forum for women with the condition to offer and share advice, but also to raise awareness around a condition that affects women of all ages.”

To read the full article go to: http://www.enfieldindependent.co.uk/news/localnews/9533339.Support_group_set_up_for_Enfield_endometriosis_sufferers/

Michelle Middleton – Local Group Leader for Bradford and Leeds

Michelle is studying for her Masters degree at Bradford College of Art and is using this medium to get the message across about endometriosis which has dominated her life. She came up with the idea to showcase her video installation and soundtrack which focuses on endometriosis as a taboo subject. She managed to secure a large feature in her local paper (Telegraph and Argus) Michelle said: “The work is to highlight how it feels and try

and represent it within my artwork. Managing the condition and your lifestyle is one of the key coping mechanisms. It is like a shadow – I have to learn to live with it – but having the support group for myself and other women is critical”

To read the full article go to: http://www.thetelegraphandargus.co.uk/news/news_behind/9652264.Highlighting_cause_that___s_close_to_art/

Hannah Pinnock & Sara Gadd – Local Group Leaders for Cornwall

Hannah and Sara had lots of support from their clinic at Royal Cornwall Hospital Trust to make their awareness week activities a real success. They received help from the press office at the hospital to write a press release which enabled them to attract media interest from Pirate FM, BBC Radio Cornwall and they had an article printed in their local paper: West Briton. They held a stand at the Trust which was visited by lots of staff and women and Sara said:

“Thanks to everyone at the clinic including gynaecologist Dominic Byrne and Specialist Nurse Cathy Dean and everyone else who helped keep our stand going and helped us with our media interest”

And.....they also managed to raise £150 for Endometriosis UK!

Helen Murphy – Local Group Leader for Bootle and Widnes groups

Helen and three of the women from her support groups attended a local community centre: Blackburn House. They spoke to around thirty women about endometriosis and held a stand.

Anne Keeping - Local Group Leader for Southampton & Volunteer help - liner

Anne liaised with the staff at The Princess Anne Hospital in Southampton. They put up two displays about endometriosis and the work we are doing. One was in Outpatients and the other in the staff area.

Anna Jaminson - Local Group Leader for Belfast

After lots of letters to her local press Anna secured a lengthy article in The Belfast Telegraph which explained how endometriosis affects women from all backgrounds. The article went on to focus on local women and celebrities who live with the condition. Anna Jaminson said: "I started up a local support group for sufferers 27 years ago in Belfast in order to remove that sense of helplessness. She says: "There was very little help and advice when I needed it. You were patted on the head and told to have a hysterectomy. Now there's more hope and better treatment, but it's important to catch it early."

To read the full article go to:
<http://www.belfasttelegraph.co.uk/woman/life/what-does-belfast-mum-caroline-mccormick-have-in-common-with-these-famous-faces-16140821.html>

Other Support Network News...new volunteers

Our recent Information & Training weekend in April was a real success and was attended by 16 new volunteers. Thanks to Pearl Mensah (helpline volunteer) and Jenny Genge (volunteer group leader Taunton & Bridgwater) for leading the training.

All our volunteers are now set up to start volunteering for our support network and they are as follows:

Helpline : Keeley Cross ,Andrea Hearn ,Sukhy Hogwood

Moderators : Gillian Davie, Caroline Highy

Group leaders: Aimee Fletcher & Stacey Brown : South Staffordshire
 Meg Haver: Sheffield*

Ruth Semple: Birmingham *

Hannah Pinnock: Cornwall **

Anna Rae: Coventry & Warwickshire

Sandra Engstrom: Edinburgh

Annette Bailey: Hertfordshire

Clair Bottomley: Manchester*

Stephanie McCulloch: Glasgow

Claire Wishart: Taunton***

*Taken over current group or become a co leader

**Hannah will be running the group

with Sara Gadd who will be coming to the next training day

***Claire will be running the group with Jenny Genge

This means that we now have 17 helpline volunteers and 40 local groups. Thank you! However, we still need more volunteers. If you are interested in joining our support network as a volunteer please contact the Support Network Manager : support@endometriosis-uk.org or go to our web site at the following link: <http://www.endometriosis-uk.org/getinvolved/volunteering.html> You will find out all about the different volunteering roles.

Virtual Support Groups

This summer we will be setting up a programme of virtual support groups meetings. These 'meetings' take place using Skype and are a brilliant way for women to talk to other women. They are particularly useful for women who can't get to a group meeting or don't have one locally. The programme will be highlighted on our website as soon as it is finalised. If you would like to apply to become a virtual support group leader contact: Liz, the Support Network Manager: support@endometriosis-uk.org or go to our web site at the following link: http://www.endometriosis-uk.org/support/virtual_support_groups.html

ENDOMETRIOSIS UK CURRENT LOCAL GROUPS

Our volunteer-led groups offer information and support to women living with endometriosis and their partners and families. For more information about groups in your area or to join a group, visit www.endometriosis-uk.org or call 020 7222 2781.

ENGLAND (EAST)

HUNTINGDON
NORWICH

ENGLAND (MIDLANDS)

BIRMINGHAM
SHEFFIELD
NOTTINGHAM
SOUTH STAFFORDSHIRE
STAFFORDSHIRE
COVENTRY AND WARWICKSHIRE

ENGLAND (SOUTH-WEST)

BOURNEMOUTH
BRISTOL
CORNWALL
READING
TAUNTON & BRIDGWATER

ENGLAND (SOUTH-EAST)

EAST BERKSHIRE
GUILDFORD
NORTH SURREY
SOUTHAMPTON
SUSSEX COAST
WEST DRAYTON
HERTFORDSHIRE

ENGLAND (NORTH)

BLACKBURN
BOOTLE
BRADFORD, LEEDS AND SKIPTON
HULL
MANCHESTER
TEESSIDE & DURHAM
WARRINGTON
WIDNES

LONDON

BARNET
CENTRAL LONDON
ENFIELD
SOUTH-WEST LONDON

NORTHERN IRELAND

BELFAST
LONDONDERRY / DERRY

SCOTLAND

LANARKSHIRE
EDINBURGH
GLASGOW

WALES

CARDIFF/SOUTH WALES
OSWESTRY/WREXHAM
WYEVALLEY



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www.endometriosis-uk.org helpline: 0808 808 2227

providing support increasing understanding