PLUS
Growing Up With Endometriosis - 2 women share their stories
New images launched in Awareness Week 2012
Virtual Support Groups
Fundraising Ideas

FOCUS: IS IT NORMAL?
What every teenager & young woman needs to know

ISSUE SPRING 2012
Hello and welcome to the first Endolink Magazine of 2012.

In the office over the past few weeks we have been working hard to pull together activity and information for Awareness Week 2012 which took place from Sat 5th – Mon 7th March. We are therefore dedicating this edition to that theme – ‘Is it normal?’

What every teenage girl and young woman should know?

Time and again we hear how a woman’s endo journey began during their teenage years and with an average of 7.5 years to be diagnosed we are determined to use this campaign to raise awareness of endometriosis now and through the year.

Please do share this magazine – and the accompanying online resources - with anyone who you think may be suffering with the symptoms of endometriosis.

We would also like to say a big thank you to everyone who got involved with this year’s Awareness week. If you haven’t had a chance to make your mark yet – don’t worry! Posters and leaflets are available on the website or by email from our office so feel free to forward them on or print them off for display or use elsewhere.

From the editor...

Finally it’s goodbye from me. This is my last magazine as I am moving to pastures new. Although my time here has been short I have thoroughly enjoyed it. I have learnt so much and have developed such a great respect for all of you who manage to keep so positive, active, engaged and dynamic. May I wish you all the best for the future.

Best wishes,
Aaron Hussey
Communications & PR Officer

I hope this latest edition will be of interest to many of you focusing on the issue of endometriosis in teenagers and young women. When we launched our ‘Bring it Down’ campaign last year for Awareness Week, for which our work still continues with Government and the Department of Health, our study then showed that there was an average delay of two years before a woman approached their GP highlighting the ongoing need to raise awareness amongst women.

This is even more true for teenagers and younger women who are given so much information on many areas of health and well-being but the issues of periods and pelvic pain still go unrecognised. I hope you have any fundraising or membership queries you can contact Fiona by emailing admin@endometriosis-uk.org.

HealthUnlocked

A big thank you to everyone who has signed up to our HealthUnlocked site. We now have over 500 members on this social media platform and there are always interesting conversations going on. To sign up and get involved just visit www.endometriosis-uk.healthunlocked.com.

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FOR ENDOMETRIOSIS AWARENESS WEEK 2012 we wanted to try and address the issue that faces all teenage girls and young women as they start their periods: ‘is what I am experiencing normal?’ As many of you have told us that your symptoms started as early as your first period it is clear that many young women never experience what could be considered a normal period so they have nothing to compare their experiences against. 

As a result we’ve written two leaflets aimed particularly at teenagers and young girls, Is this normal? About my periods: what every girl should know and Is this normal? About endometriosis: what every girl should know. We have also developed a new website called www.aboutmyperiods.wordpress.com featuring some of the same information and case studies and inviting other young women to join in through their blogs. Alongside this we have also started an aboutmyperiods twitter account – @aboutmyperiods – so do follow us there if you are a tweeter.

We are also delighted to have received pro-bono support from talented creative designer, Kaye Sedgwick. Kaye has developed a series of new images, particularly with a teenage audience in mind. You will see a number of Kaye’s designs throughout the magazine and on our website. To see the full range and to see Kaye’s other work, visit her website – www.kayesedgwick.co.uk or on twitter @kaye_sedgwick.

Awareness Week is just the launch of this campaign; over the next year we aim to distribute the posters and leaflets wherever we can, developing a presentation for schools and contacting school nurses, college and university health centres as well as GP surgeries. All support and help to deliver this activity would be gratefully received so do contact us at information@endometriosis-uk.org if you want to find out more or lend us a hand.

Over the next couple of pages we’ve included some of the information available in the leaflets, and later on you’ll find two case studies from young women who have struggled with endo from an early age. We thank them for sharing their stories with us.

Excerpts from our ‘Is it normal?’ leaflets and Aboutmyperiods blog-site

What is a period?

Every woman goes through something called the menstrual cycle, every 28 to 35 days, and this is how it works: a girl bleeds from her vagina for a couple of days to a week. Every girl will bleed different amounts. During the heaviest part of your period, you will probably need to change your tampon or towel every 3 to 4 hours. After the period, you will bleed different amounts. During the heaviest part of your period, you will probably need to change your tampon or towel every 3 to 4 hours.

I don’t think I’m having a ‘normal’ period!

Most girls have some pain and discomfort, leading up to, during and after their period. This is normal. In fact, the NHS says that 3 in 4 young women experience strong or moderate pain. But the pain should not be so intense that you cannot still get up, go to school or college and carry on with your normal life. If it is then you should speak to somebody. You might also experience what’s known as ‘heavy bleeding’. This is normal as your body gets used to the menstrual cycle. But it is not normal for periods ALWAYS to be really heavy. Again, if they are then speak to somebody.

How can I help myself?

Simple measures can help with period pains. This includes gentle exercise, drinking plenty of water and eating a healthy diet. A hot water bottle or a warm bath can also help. Over-the-counter remedies such as Paracetamol and Ibuprofen are also very useful. Every woman has been through the same, so ask your mum, sister, aunty, cousin or friend if they might be able to help. If you think your periods are not normal though... ask to speak to your school or college nurse or your doctor.

DON’T BE SCARED!

The sooner you speak to somebody, the sooner you will be able to get everything sorted and you might be able to stop the pain.

But remember... sometimes, what you’re going through is not normal. Trust your body. You know better than anybody how you feel. Most girls get told that their periods will calm down in a couple of years as hormone levels become more settled. That’s right... for most girls.

But some girls’ periods won’t settle down. If they don’t then keep speaking to people about it. Go back to your doctor, or speak to your nurse.

You might have endometriosis if you suffer from:

- Severe pelvic pain during periods or after sex
- Pain when going to the toilet
- Pain going to the toilet - Tiredness all the time - Severe pelvic pain between periods
- Severe pain during or after sex

So I think I have endometriosis... What does this mean?

It means that you are just one of around 1.5million women in the UK who have it. It can affect all girls and women who are at an age where they are able to have babies. You are not alone. As many women have endometriosis as have diabetes... it’s just that people don’t talk about it.

You need to go to a doctor...

If you think you might have endometriosis, book an appointment with your doctor. It is sometimes difficult to get diagnosed with endo so before you go, be prepared. The more information you can give your doctor, the more chance they have to recognise it. You might want to keep a diary of all your symptoms.

Things you might want to include in your symptom diary are:

When do you experience pain? When is it most painful? (before, during, after your period?) How long does the pain last far? How do you feel? (Tired? Moody? Tearful? Down?) Does it hurt anywhere else? Do you have any problems when you’re going to the loo? Does it hurt when you have sex? (if you don’t know, don’t worry?) Information is king! So take as much with you as you can!

The doctor says I have endometriosis... HELP!!

Even though there is no cure there are a number of ways to treat it. Some of the treatments include hormonal medications such as oral contraceptives (the ‘Pill’). This is usually the first option and can work well for many women. Other treatments include laparoscopic surgery and sometimes diagnosis and treatment can happen at the same time. What treatment you need or decide to try will depend on your personal circumstances so make sure you ask lots of questions before you go ahead.
Case Study

Melissa’s Story

I started my period when I was thirteen years old. My symptoms came on straight away. These were very heavy bleeding, blood clots, and extreme pain, especially during ovulation. These began at the end of Year Nine, by Year Ten I was struggling so much due to being ill. I ended up having a lot of time off school. When I eventually went back I had no friends, I was so behind, and was still trying to cope with being ill. I could not manage full weeks at school. When I was there I used to leak through my sanitary pads onto my underwear and clothes. My symptoms were bad and my life before that was non existent, my friendships disappeared, and my relationship with my partner suffered a lot. I went back to the doctors time and again but nothing changed. Finally at 18, I went back to the doctors and asked to be put on a contraceptive to stop my periods. I’d been up! My symptoms were bad and my periods lasted two weeks with five days of heavy bleeding, blood clots, and even bled during sex (which was very nervous about). My GP diagnosed me with endometriosis and referred me on. When I received my first period at thirteen years old just to alleviate her symptoms. I had such a painful period, which was non existent, my friendships disappeared, and my relationship with my partner suffered a lot. I went back to the doctors time and again but nothing changed. Finally at 18, I went back to the doctors and asked to be put on a contraceptive to stop my periods. I’d been up! My symptoms were bad and my periods lasted two weeks with five days of heavy bleeding, blood clots, and even bled during sex (which was very painful)!

I finally felt that I was being taken seriously. Swabs and blood samples were taken and an ultrasound scan was done. They found a cyst on my ovary but ruled out polycystic ovaries due to a normal hormone level. I finally saw a gynaecologist at 19 who said that she doubted I had endometriosis but be rudely dismissed. I was so shocked that could have in laparoscopy to put my mind at rest. Yet again I was worried that it was all just in my head!

As the years went by my symptoms got progressively worse. College was hard and I had to put so much more effort in than others just to get through the day. I lost three jobs, my social life was nonexistent, my friendships disappeared, and my relationship with my partner suffered a lot.

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I had my lap at 19 and found out I did in fact have endometriosis. I was so shocked that could have in my head but then the reality hit me that I was stuck with an illness with no cure and very little understanding or awareness. The medics suggested two options: fitting the mirena coil or getting pregnant. I tried the coil which made me awful. I did not even entertain the idea of getting pregnant and was disgusted that this was even suggested to a 19 year old just to alleviate her symptoms.

“My advice to young girls going through what I’ve been through is simple... don’t give up!”

I refused as I was too young and I was in agony. About a year later my pains were not getting any better so my mum suggested that I go on the mini pill to try and help it but I refused as I was too young and didn’t understand what it was.

I had been visiting my local GP for many, many years about my problem and have only recently been diagnosed. I feel so let down by the system as I feel I should have been referred to a specialist a long time ago. I have lost count of how many smear tests I have had and urine samples taken and rarely was anything ever found.

“I’ve had even got to the point that I was so embarrassed about phoning up for an appointment and attending as I felt like “oh there’s that girl again, she’s always here”.

About four months ago I had another examination with my GP, and he had told me I had a bad infection and had something called ‘erosions’ but at least he referred me on. When I received my second examination with the specialist it was a completely different story. Haing spoken with his consultant, he diagnosed me with endometriosis with the conclusion that the best solution for this would be surgery. This is due to happen in a few months, which I am very nervous about.

From reading through other wom- en’s personal stories it has giv en me a better insight into what endometriosis is as until then I didn’t fully understand how serious it can be. I know I am only 20 years old and do not want children right now but I’m scared about my future although having a diagnosis has helped enormously.

“I feel like everything is falling together now, that I have finally got an answer to my problems”

This is affecting my everyday life. From a young age I suffered from extremely heavy discharge, it’s something that still affects me and I feel it has got worse. I have to wear a pad every day. Being a full time student and with my part time job I find it hard to function. Consequently I’m not the sociable girl I was anymore, I’m constantly so tired and I’ve no energy. In a way I am happy that I have finally found out what the problem is, but I am finding it hard to deal with.

I’m going to attend my local group about endometriosis which I hope will help me as I find it really hard to talk to my family, friends and my boyfriend as they don’t understand what I am going through every day. Listen- ing to other women’s experiences will help me and show me how to cope better with this condition.
Support Network

The Endometriosis UK Support Network involves local community Support Group meetings for those with endometriosis as well as their family and friends. We also run a free Helpline service, available most days of the year. Our goal for these services is to allow those affected by endometriosis to understand their condition and take control of it. They are complemented by our online presence in the form of our message board, Facebook page, Twitter account and our new social network platform, HealthUnlocked.

All of our Support Network services are run by volunteers living with endometriosis who have a wide range of knowledge and experience of the condition. The extent of the activity our Support Network generates and the amount of women helped by our volunteers is growing. The extent of the activity our Support Network involves local community Support Group meetings, local helpline calls and our online presence via our HealthUnlocked social network platform, HealthUnlocked.

• We now have 36 active groups (for a full list, see the back of this magazine)
• In 2011 there were 111 group meetings and 1,751 women attend these.

If you would like to join a group or start a group have a look at our website or get in touch with our Support Network Manager Liz. Helpline 0808 808 2227

• Our helpline is open 7 days per week, 365 days a year, depending on volunteer capacity.
• As it is run by wonderful volunteers we try to have as much coverage as possible, this is usually 2 to 4 hours a day.
• It can operate from 9am to 10pm and many of our volunteers are kindly prepared to work over the holidays and at weekends.
• Demand for the helpline is high. In 2011, 6,562 calls were made to the helpline.

Calls to our helpline have increased dramatically this year, as a result we are always looking for new volunteers. Don’t worry, full support and training will be offered before you begin talking calls. If you are interested contact Liz: (support@endometriosis-uk.org)

Other methods of support:
• Message Board - the Endometriosis UK message board can be accessed via www.endometriosis-uk.org and receives an average of 1,662 visits per day.
• Facebook profile - Our Facebook page now has over 3,600 friends and is an extremely active community for women to get support and share their experiences.
• HealthUnlocked - We are thrilled to have now reached over 500 members on our HealthUnlocked site. If you have not signed up yet, visit www.endometriosis-uk.healthunlocked.com
• Twitter - We are relatively new to Twitter but already we have over 1,750 followers. If you are a tweeter, don’t forget to follow @endometriosisuk.
• @endometriosisuk

Help us support more women

Endometriosis can be a very confusing and often isolating illness and as such, demand for support is extremely high. We would like to increase our Support Network so that we can help every single person that needs it. But to do that, we need you!

Why not run a group, listen on our helpline, help with the message board or run a virtual support group?

Endometriosis UK provides free training and there are regular events for you to meet fellow volunteers and others with endometriosis.

Our next training day for volunteers is taking place in April. New volunteers will also have free access to our Information Day. We had some fantastic feedback from our last training day.

“Thank you for giving me the chance to be part of this fantastic charity”

“Friendly, fabulous and informative”

Awareness Week

Thank you to everyone who got involved with Awareness Week, holding an event, raising awareness or writing to their local paper. Don’t worry if you didn’t get a chance to take part – the campaign goes on! Posters, leaflets and a template Letter to the Editor are all available to download from the Endo UK website and can be used at any time.

Funding to help us support women in a different way - Virtual Support Groups

We are delighted to announce that we have received funding from Big Lottery’s Awards for All scheme towards our new initiative to support women with endometriosis.

In 2011 we ran a pilot scheme of six virtual support group meetings using skype technology. The aim was to extend support to women and others who are unable to travel or who live in remote locations and who can’t easily reach their local group.

The pilot was really successful and women logged in from across the UK all from the comfort of their own homes. We had great feedback from those who took part.

Our aim is to run a programme of Virtual Support Groups throughout the year with guest speakers and topic-based sessions. Thanks to this funding we can train volunteers interested in facilitating these sessions and help even more women.
FUNDRAISING

Fancy running the British 10k?
Have you been caught up in the Olympic excitement? Do you fancy running the UK’s most prestigious and sought-after 10km road race which is staged on the world’s greatest route through the heart of central London? Then join our team for the British 10k which takes place just 19 days before the start of the games on 8th July. Along with 25,000 other runners you will have the unique chance to run past many of the country’s greatest landmarks including Big Ben, The London Eye, St Paul’s Cathedral, Trafalgar Square and Westminster Abbey.

For more information contact Fiona on fundraising@endometriosis-uk.org

Overseas Challenges
At the time of going to press, Harjot Sehmi and James Harvey will have their trainers full of sand as they trek across the Sahara Desert on one of our overseas challenges. We’re exceptionally grateful to them as so far they have raised an amazing amount for Endometriosis UK.

If you’d like to follow in their footsteps, or try a different challenge, please visit our web pages for more information:

http://www.endometriosis-uk.org/get-involved/fundraising_events/overseas_challenges.html

Get your Pink Pants on for Endometriosis UK

It’s not too late to join our Pink Pants team for the Snowden Horseshoe Challenge on 12th May. We’ve had lots of people sign up so contact us today if you’d like to join us on this challenge, exclusive to Endometriosis UK. It’s a great way to challenge yourself and also make some great friends!

2012...

In 2012 we’ve got lots of lovely fundraisers undertaking all sorts of challenges across the country. If you’d like to do something yourself, then please do visit www.endometriosis-uk.org/get-involved for ideas. Below is a little peak at what some of our fundraisers are doing soon:

Tania is pushing a Smart car along Brighton Seafront...
Heather is walking Hadrian’s Wall...
Stacey, Anne-Marie & Hannah are holding events during Awareness week…..
Kellianne is trekking to Machu Pichu….
Katie is running an open air cinema night....
Kirstie is throwing a black & white party...
Debbie is holding a charity clothes fair...
Sonya is doing a human raffle!

And finally...

We’d also like to wish our Brighton Marathon and London Marathon runners lots of luck. If you’re in the area at all during the races, then please do go along to support them.


Thank yous
A big thanks to the Brewer family for making a donation to allow us to pay for training for our wonderful volunteers.

STOP PRESS: THE BIG JUMP.
Helen (CEO) and Trevor (Chair) have challenged themselves to take the plunge with a parachute jump in September. To join them — or sponsor them — email fundraising@endometriosis-uk.org.

Why Don’t You... hold a bake sale?

It seems like a lifetime ago that we all vowed to back away from sugary goodness as part of our New Year’s resolutions. How is it holding up? If you’re anything like us in the Endometriosis UK office, probably not that well.

Well, we have the perfect solution for you… why not have a bake sale in your workplace, gym or community centre? This is your chance to prepare and eat some delicious baked goods whilst raising money for Endometriosis UK. Send in your pictures too — and let’s see who can decorate them to raise awareness!

Those treats suddenly aren’t so naughty! It’s all for a good cause… honestly!
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.

SCOTLAND
- LANARKSHIRE

ENGLAND (NORTH)
- BLACKBURN
- BRADFORD, LEEDS & SKPTON
- HULL
- LIVERPOOL
- MANCHESTER
- TEESIDE & DURHAM
- WARRINGTON
- WIDNES

ENGLAND (EAST)
- NORWICH
- HUNTINGDON

ENGLAND (MIDLANDS)
- BIRMINGHAM
- CHESTERFIELD & SHEFFIELD
- STAFFORDSHIRE
- NOTTINGHAM

ENGLAND (SOUTH EAST)
- EAST BERKSHIRE
- GUILDFORD
- NORTH SURREY
- SOUTHAMPTON
- SUSSEX COAST
- WEST DRAYTON

ENGLAND (SOUTH WEST)
- BOURNEMOUTH
- BRISTOL
- CORNWALL
- TAUNTON & BRIDGWATER
- READING

LONDON
- CENTRAL LONDON
- BARNET
- ENFIELD
- SOUTH EAST LONDON
- SOUTH WEST LONDON

WALES
- CARDIFF & SOUTH WALES
- OSWESTRY & WREXHAM
- WYE VALLEY

NORTHERN IRELAND
- BELFAST
- LONDONDERRY