

# endolink

A photograph of a smiling woman with dark hair, wearing a white jacket, holding a red apple. The background is a simple indoor setting with light-colored walls and curtains.

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**CAN CHANGING YOUR DIET  
IMPROVE YOUR SYMPTOMS?**

## **Herbal Help**

**Vitamins and Supplements explained**

**PLUS**

**Your personal stories  
Awareness Week update  
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**spring edition 2008  
endometriosis uk**

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# Letter from the Editor



Dear Reader,  
**Welcome to the 2008 Spring edition from a new editor of Endolink.**

I have Endometriosis and have been a member of the charity for 20 years. I have volunteered for the charity Helpline and am now a Patient Trustee.

## Rob music moves on

We have to say goodbye and congratulations to Rob Music. Rob and his wife Cari have had a new baby girl, Phoebe, and Rob has left to take six months at home with his family. We all wish them much happiness.

Rob started here in 2002 and has overseen an increase in the charity's financial turnover of 250%. We thank him very much for his enormous contribution.

Recruitment for a new Chief Executive has started. Until the position is filled, Nemone Warner will be taking charge with Diane Hicks looking after the Support Network and Information Services.

## Staff changes

We also say goodbye to Jill Exon, Admin Assistant, Joanna Quayle, Information Manager and Katie Norris, fundraising volunteer. We wish them well in their future careers.

*A very warm welcome to:*

**James Nowland** - Admin Assistant. James previously worked for the International HIV/AIDS Alliance.

**Claire Mc Keever** - Fundraising Assistant. Claire joins us from the Sports Relief campaign with Comic Relief.

**Lucy Tully** - Information Assistant. Lucy will be producing Endolink and editing the website.

## Trustee changes

Lone Hummelshøj and Gill Rose are standing down and we thank them for all they have done. We welcome new Trustees Caroline Overton, Consultant Gynaecologist and Georgina Jones, Social Scientist specialising in Endometriosis research.

## This issue

This issue focuses on nutrition. Please remember to consult your GP or a qualified nutritionist or dietician before making changes to your diet.

We have an overview of the World Congress on Endometriosis, including an exciting update on funding of international research.

In addition we are delighted to report on the activities that took place during Awareness Week. A big thank you to everyone who took part.

## Welcome to this issue!

**Samantha Falconer** - Trustee

If there is a particular topic you would like to be discussed in Endolink, please let us know by emailing [lucy@endometriosis-uk.org](mailto:lucy@endometriosis-uk.org)

We plan to include more personal stories in future issues, so if you want to share your experiences, contact Lucy at the same address.

# The 2008 Flora London Marathon

The weather might not have held up but our runner did! Neil Kelly completed the marathon in three hours 56 minutes and raised over £8,000 for Endometriosis UK.

Neil, 33, from Basingstoke, ran on behalf of his wife who suffers from endometriosis.

He said: *“Endometriosis UK provided vital support and information for my wife Kerry when she was diagnosed in 2002. It took 4 years for her to receive a*

*correct diagnosis which I find truly shocking. I really want to raise awareness of the condition so that we can decrease the time it takes to diagnose. This would mean that women like Kerry will receive the correct treatment and support earlier.*

*“I have always wanted to run the London Marathon and have been waiting for a chance to do so for Endometriosis UK. It was a great opportunity for me to show my support for a charity that has provided so much for my wife.”*



We were bowled over by the generosity of our members who responded so kindly to our appeal to support Neil. We would like to take this chance to say a huge thank you to Neil and his supportive family and friends, our members and everyone involved in making this year's marathon such a great success for Endometriosis UK!

## Girls on Wax party



**Our fundraising volunteer Katie sported a bunny outfit (cunningly accessorised with a collection bucket) for the Endometriosis UK Girls on Wax party.**

Katie said: “It was a great night combining an important message with some fantastic music. To emphasise the fact that it's a girly issue, I had a

line-up of female DJs who played some brilliant sets and soon had the whole bar jumping!

*“With people paying £3 at the door and my vigorous bucket shaking (aided no doubt by my bunny outfit) we raised £580. The whole night was a huge success. Thanks to everyone's enthusiasm and hard work.”*

# Awareness Week 2008 3-9 March

**It goes without saying that Endometriosis Awareness Week is an important time of the year for us! It's a great opportunity to boost awareness of the condition as well as raise the profile of our charity.**

We're delighted to say that 2008's Awareness Week was a success, with lots of events taking place to get much needed recognition for Endometriosis - from the simple but effective distribution of leaflets, to a feature on *This Morning!*

## Media coverage

We received national coverage in the media, including features on *This Morning*, *The Wright Stuff* and the *Sunday Mirror*. There was also some local media interest in the *Nottingham Evening Post* and local BBC stations.

## Reaching out to employers

Some endo sufferers feel they don't get enough support from their boss or

colleagues. If this applies to you, you'll be pleased to know that during awareness week we had a stand at the annual 'Health and Wellbeing at Work' conference in Birmingham. This enabled us to reach over 2,800 employers, giving us the chance to tell them about the problems of the condition and how it can interfere with your job.

## Street collections

Some of our members and staff - armed with collection tins - braved the cold weather and busy London streets to go street fundraising. They managed to raise nearly £1,000!

## Understanding the impact of periods on teenagers

We launched an online survey aimed at 13-21 year olds. It's being targeted at schools, colleges and universities so we can understand their experiences with menstrual health, and also increase awareness of endometriosis among younger women.

To take the survey, visit our website: [www.endometriosis-uk.org](http://www.endometriosis-uk.org)



## NHS awareness

Throughout Awareness Week, NHS Careers highlighted the NHS staff helping patients with endometriosis.

## Local support

Our supporters were fantastic at raising awareness, with fundraising events held throughout the week and thousands of leaflets and posters distributed. We'd like to say a very big thank you and well done!

## We need help all year round

We must ensure we continue to raise the profile of endometriosis and increase funds for our vital work all year round, so if you feel you can help in any way, please visit our website to find out how you can get involved at [www.endometriosis-uk.org](http://www.endometriosis-uk.org)

# World Congress on Endometriosis

## What is the World Congress on Endometriosis (WCE)?

The WCE is held every two to three years. Nearly 1000 specialists from around the world meet to discuss findings on the condition. Their goal is to understand the disease, move towards better treatments and ultimately, to find a cure. The tenth WCE was held in March this year in Melbourne. Here's a round-up of news from the conference.

## \$2.6 million funding!

A massive \$2.6 million was awarded to The International Endogene Consortium, which is studying the genetic background of endometriosis.

The funding is from the UK's Wellcome Trust and Australia's National Health and Medical Research Council.

Dr Krina Zondervan from Oxford University said: "We have been given an unprecedented opportunity to make real headway with understanding the genetics of the disease."

Dr Grant Montgomery from the Queensland Institute of Medical

Research said the upcoming research was possible thanks to women with endometriosis who have contributed blood samples and their valuable time.

"We are extremely grateful for their efforts, and hope to be able to provide exciting results from these studies in the near future" he said.

## Risk for women with easily burned skin

The risk of endometriosis is higher among women with moles, freckles and skin that burns easily, according to research revealed at the WCE.

The study by the National Institute of Health and Medical Research compared the lifestyle and medical history of 97,213 women – 4,000 of which had endometriosis.

## Green tea helps control endometriosis

Green tea has long been recognised for its health benefits, and now it has been suggested that it can help control endometriosis.

Researchers at the Chinese University of Hong Kong said that antioxidant



Members from the International Endogene Consortium

compounds in green tea restrict the formation of new blood vessels, which assist in spreading endometriosis. Better put the kettle on!

## Underweight 16-year-olds at greater risk

Girls who are underweight at 16 have a higher risk of endometriosis, according to a study by Dr Christina Nagle.

Dr Nagle, from the Queensland Institute of Medical Research, gathered weight information from 268 women with endometriosis.

Dr Nagle said: "We suspect it's the result of different hormonal influences before and after the first occurrence of menstruation, rather than the direct result of dietary or exercise patterns."

We thank [www.endometriosis.org](http://www.endometriosis.org) for allowing us to publish this extract. For more information on the WCE visit [www.wce2008.com](http://www.wce2008.com)

# Optimum Nutrition and Endometriosis



**Meghna Nanda Dasgupta, a qualified nutritionist, gives us her advice on an endometriosis-friendly diet.**

Optimum Nutrition is about providing your body and mind with the right nutrients, so you can be at your best, physically and mentally. The optimal functioning of the body relies on a diet that focuses on increasing the intake of nutrients and reducing the body burdens.

Eating right for your body can bring about many positive physical and metabolic changes leading to good health. We are aware that most illnesses do respond very positively to changes in the diet and Endometriosis is no exception.

Endometriosis can be triggered by a combination of factors including hormone imbalances (oestrogen dominance), stress and nutritional deficiencies, so a multi-factorial approach is the best way to tackle it. I have outlined the causative factors

and the plan of action below, to address the issues associated with endometriosis as well as to help the body to reach optimal health, so it can start fighting its own battles.

**Oestrogen dominance:** Elevated oestrogen levels have been linked to hormone related illnesses such as PMS, endometriosis, fibroids. This could be due to impaired detoxification and elimination capacity of the body. The liver is responsible for converting the carcinogenic oestrogens, oestrodiol and oestrone, into the non-carcinogenic oestriol. It is probable that a compromised liver, along with nutritional deficiencies (poor digestion and/or imbalanced diet) prevents this conversion, resulting in oestrogen dominance. A sluggish colon further adds to this problem as in constipated individuals the excreted oestrogen is absorbed back into the bloodstream.

**Xenostrogens:** are oestrogen like chemicals found in pesticides and plastics. Exposure to these is a big factor in oestrogen dominance.

Xenoestrogens are lipophilic in nature; hence overweight individuals tend to have higher concentrations in their body.

**Blood sugar imbalance:** Maintaining blood sugar stability is paramount for keeping energy and weight within the desired level, thereby preventing other body imbalances.

**Stress:** is a significant component of many recurrent and chronic health problems, including fibroids and endometriosis. On the physiological level, stress increases the cortisone output from the adrenal glands, impairs immune function, elevates blood pressure and heart rate, and affects hormonal balance. In women with endometriosis, stress may negatively affect hormonal balance and muscle tone, upsetting the estrogen and progesterone balance and triggering excessive output of adrenal stress hormones. This can impair the body's ability to limit the scarring and inflammation caused by the endometrial implants.

**Fatty acid imbalance:** Essential Fatty Acids (EFA's) are extremely important for women with endometriosis. The hormone inflammatory prostaglandin is released as the uterine lining breaks down, causing the uterus to go into spasm and hurt. Endometrial cells also release these harmful prostaglandins which irritate pain receptors in our bodies, making them much more sensitive to repeated stimulation. However, if you have high amounts of EFA's in your system, your body will produce less of the harmful prostaglandins and instead create more of a different hormone (anti-inflammatory prostaglandins) that helps prevent cramps and pain. Your body produces beneficial prostaglandins from essential fatty acids, which help to reduce period pains. They also have an anti-inflammatory response, which is particularly beneficial to endometriosis sufferers.

## Dietary changes

➤ Eat your five a day. Make sure you include different coloured fruits and vegetables everyday. They are high in micronutrients and antioxidants

which are crucial for immune health.

- Replace white foods (white bread, white rice) with brown. Complex carbohydrates such as wholegrains e.g. brown rice, oats, rye, millet, quinoa, and buckwheat are high in fibre and rich in B vitamins, vitamin E, trace minerals and phytochemicals.
- Eat phytoestrogens, including beans such as lentils, chickpeas and Soya products.
- Increase your essential fatty acid intake such as oily fish, nuts and seeds. Try and eat oily fish at least 3 times a week.
- Reduce your intake of saturated fat from dairy products, red meats, cakes and confectionery.
- Drink enough fluids in the form of water and herbal teas.
- Increase your intake of fibre via wholegrains, fruits and vegetables. Fibre binds to oestrogen and helps to get rid of it from the body.
- Avoid additives, preservatives and chemicals such as artificial sweeteners to reduce the load on the liver.
- Reduce your intake of caffeine and alcohol. These are stimulants and

stimulate the release of stress hormones. They are also dehydrating and put extra pressure on the liver.

- Balance your blood sugar levels by eating more complex carbohydrates, reducing sugar in the diet and ensuring protein intake at every meal.
- Do not skip meals especially breakfast. Eat little and often.

## Lifestyle changes

- Build exercise into your routine. Any exercise that increases the heart rate has been seen to improve cardio-vascular, bowel, lymphatic and digestive function. It also helps to ward off those extra pounds and keeps you happy.
- Avoid heating foods in plastic containers and storing fatty foods in plastic wraps.
- Do not eat on the go. Relax and eat slowly. Make sure you chew your food.
- Build some relaxation techniques into your life such as yoga, tai-chi, deep breathing exercises.
- Buy organic foods where possible.

(Text continued ➤)

# Optimum Nutrition and Endometriosis (Cntd.)

## Questions & Answer's

**Q** *I've been told that red meat makes endometriosis worse, is this true?*

**A** Endometriosis is an oestrogen-related disease. Saturated fats have been linked to high concentrations of oestrogen in the body. Red meat is high in saturated fat and may also contain growth hormones (e.g. oestrogens). Therefore, it might be beneficial to eat it in moderation or avoid it.

**Q** *What are the best substitutes for people who have to give up dairy?*

**A** There are a number of alternatives available in supermarkets (in the free-from aisle) and health foods stores these days. Soya milk, soya yoghurt, soya cheese, rice milk, oats milk, brazil nut milk are good choices.

**Q** *Is organic food better for you if you have endometriosis?*

**A** Organic food is a good option where possible, as it is beneficial because of less toxic content and some studies have proven that they contain more vitamins & minerals. But it is more important to eat a varied diet, high in fruits, wholegrains and vegetables.

**Q** *Will nutrition advice help all women with endometriosis, or just those with digestive/bowel problems?*

**A** Yes, nutrition will help all women with endometriosis. Diet has been shown to modify the risk of a number of oestrogen-related diseases such as endometrial and ovarian cancer, therefore everyone will benefit from healthy eating.

**Q** *Why are people told to give up wheat and dairy – what do they actually do?*

**A** Dairy is high in saturated fats, which has been linked to increased concentrations of oestrogens in the body. Also, dairy is believed to produce the inflammatory prostaglandins that promote pain and inflammation. Wheat can be a difficult to digest as digestion is impaired in most endometriosis sufferers. Also, we tend to eat wheat too much and too frequently, which does have a negative impact on digestion. It is best to experiment with other grains and eat wheat in moderation.

**Q** *Is nutrition going to help pain?*

**A** Yes, optimum nutrition can help. A diet high in essential fatty acids is said to increase the production of beneficial prostaglandins that are anti-inflammatory in nature and can help reduce pain. Also, the overlooked nutrient magnesium is believed to be anti-spasmodic and helps with cramps and pain. Magnesium is found in green leafy vegetables, seeds and nuts.

# Nutrition for the Menopause

## What is the menopause?

The menopause is a natural stage in every woman's life, characterised by a drop in the hormones oestrogen and progesterone. For some the transition is symptom-free, whilst other women are plagued with problems. The healthier we are the, better equipped we are to cope with the changes. Nutrition, alongside exercise, relaxation and sufficient sleep, is a cornerstone of good health.

### **BLOOD SUGAR CONTROL:**

Fluctuations in blood sugar levels can negatively affect hormone balance. Even blood sugar levels can be achieved by eating the right foods at the right time.

**Eat regularly.** It's better to have five to six small meals and snacks per day, ideally not leaving more than three hours between meals and snacks.

**Choose slow releasing starchy foods.** This includes porridge, muesli, rye or Burgen bread, wholemeal pasta and bulgur wheat. White bread, white

rice, mashed or baked potatoes, are fast releasing and should be avoided. Boiled potatoes, brown basmati rice and granary or wholemeal pitta bread are in between.

**Have protein with every meal.** This can slow the release of sugar into the blood stream, so protein with every meal can improve blood sugar control. Protein can be found in meat, pulses, nuts, seeds and soy products.

**Avoid refined carbohydrates and stimulants.** Sugar, cakes, white bread, caffeine and alcohol can cause large fluctuations in blood sugar.

**FAT FACTS:** Sticking to a very low fat diet is not good for hormonal balance. It is important that we eat the right kind of fats.

**Essential fats.** Omega 3 and 6 essential fats are vital for good health and hormonal balance. Oily fish such as salmon, mackerel and sardines, is the best source of omega 3 essential fats. Nuts, seeds and their cold pressed oils contain Omega 3 and 6.

### **Fats to avoid.**

Excessive consumption of saturated fat has been associated with high cholesterol levels. We should avoid trans fats or hydrogenated fats as they have been shown to have adverse health effects. Deep fried foods, industrially produced vegetable oils and processed foods, including cakes, biscuits and ready made meals are sources of these unhealthy fats.

The best fats for light cooking are coconut oil or butter which are heat stable. Cold pressed seed or nut oils are best for salad dressings. Extra virgin olive oil is a good oil for light cooking and salad dressings.

**PHYTOESTROGENS:** These have been shown to have a beneficial effect on menopausal symptoms. Sources include soya products, e.g. tofu, miso or soya milk, lentils, beans, chickpeas, linseeds and whole grains.

*Karin Elgar is a nutritional therapist with a particular interest in female hormone related conditions.*



# Herbal Help for Endometriosis

By Linda Smith

**For those women suffering from endometriosis there is a confusing array of herbs and supplements but with inadequate information to indicate what they do, or what dosages to take.**

Because endometriosis is a complex disorder, which can affect the digestive, nervous, immune and reproductive systems, professional back-up is needed and **self-treatment is not recommended** since it cannot be treated with a single herb or supplement.

*The main aims of any herbal interventions are:*

- to balance the immune system and any oestrogen excess
- reduce the pain by regulating the prostaglandin synthesis
- to tone the uterine muscle so it returns to normal function and menstrual flow.

Other herbs may be appropriate for digestive problems, stress or depression or if the woman wishes to improve fertility.

Although supplements can be bought to help alleviate symptoms, it is balancing hormone levels that will tackle the underlying problems. For herbs that influence hormones, I would advise consulting with a medical herbalist rather than buying them over the counter because:

- Individuals may have different degrees and symptoms of endometriosis
- It's often necessary to commence on high doses to help suppress some of the most unpleasant symptoms and then decrease the dose to maintain a balance
- Monitoring is essential in order to adjust dosage

*Vitex agnus castus* is referred to as a 'normaliser.' It balances the hormone levels by stimulating the production of progesterone and reducing oestrogen, which may help to lessen the risk of endometrial cancer. It shouldn't be used in pregnancy or be given alongside hormonal drugs as it is likely to interfere with the contraceptive pill.

Other herbs that may be combined with *Vitex agnus castus* include *Dong Quai* (*Dang Gui*, *Angelica sinensis*). This tones the uterine muscle, normalising contraction and assisting relaxation, while assisting pelvic congestion and pain. It contains essential oils that are antispasmodic and other constituents that are anti-inflammatory, slow the heart rate and protect the liver from toxins and is said to strengthen the action of vitamin E. It is not advised in pregnancy and may increase bleeding.

*Black cohosh* (*Cimicifuga racemosa*) is anti-inflammatory and can also be used to tone the uterine muscle to assist in heavy or painful periods (avoid in pregnancy).

It does have oestrogenic-type effects but clinically it has not been shown to affect endometrial tissue or hormone levels and can be used in the treatment of fibroids or endometriosis.



**Wild Yam** (*Dioscorea villosa*) is weakly oestrogenic due to diosgenin. It is antispasmodic and calming and can be used to help with the pain. Some herbalists believe that such oestrogen-promoting herbs like *Dioscorea villosa* and *Chamaelirium luteum* (False Unicorn) should be avoided.

### **Chamaelirium luteum**

(False Unicorn) also contains diosgenin, which may have an influence on steroid metabolism and is used to normalise ovarian function

increasing fertility. Hormone balancers and uterine tonics are best professionally prescribed by a herbalist, but some supplements can be self administered to help alleviate other symptoms.

**Ginger** (*Zingiber officinale*) can help against inflammation and pain and can be effective if taken in tablet form in doses of up to 1gm every 4-8 hours. (Lower doses in pregnancy). Ginger

helps the digestive system against bloating and nausea.

### **Omega 3 essential fatty acids** -

such as fish oils, star flower oil and evening primrose oil - alter prostaglandin and leukotriene levels and may be capable of improving fertility.

**Vitamin E** may enhance the release of the body's own natural painkilling chemicals. It also seems to improve fertility. Large doses of vitamin E (ie. Exceeding 500 iu) should not be given immediately pre or post operatively as there is a slight chance that it may cause bleeding.

**Milk Thistle** (*Silybum marianum*), can improve the function of the liver and help with constipation. It improves bile flow and helps the liver to break down the excess oestrogen hormones.

**B6** helps with PMS symptoms. (Daily dose should not exceed 200mg or 25mg in pregnancy).

**Magnesium** has a relaxing effect on the muscular wall of the uterus and is

essential for the absorption and use of vitamin B1 and B6. A deficiency affects the nervous system causing PMS symptoms and muscle cramps. (Recommended dosage: Magnesium aspirate 250mg, 1-2 times a day the day before and the first two days of the menstrual period.)

**Vitamin C** (300mg) and Niacin (100mg) and rutin (60mg) taken during the premenstrual week can help to stop painful cramping.

Therefore, endometriosis can be effectively treated using a joint approach; a medical herbalist can help the underlying problem of balancing the hormones and complementing any orthodox treatment that the woman may be on and she can use self-help to ease the period pain and any digestive symptoms.

**The National Institute of Medical Herbalists is the UK's leading professional organisation of practitioners of herbal medicine. For more information: [www.nimh.org.uk](http://www.nimh.org.uk) or telephone: 01392 426022**

## Carolyn's Story

**Carolyn Axtell was diagnosed with endometriosis in 2004 through a laparoscopy.**

Like many other women I had suffered with painful periods and other symptoms such as bowel problems for years before I even got referred to a gynaecologist. I'd also been trying to conceive for a couple of years, unsuccessfully.

My periods were no less painful after the lap and I decided to try and manage the condition using the nutritional approach, supported by regular acupuncture.

I researched on the internet and read a book about endo and nutrition. I also began consultations with a nutritionist as I wouldn't have known what supplements I needed without speaking to a professional. I also started doing exercise including Yoga and Pilates.

Improving my health, managing my periods and trying to get pregnant all became a big project that needed time, money and effort. My general

health was poor - my immune system seemed not to be functioning properly and I suffered increasingly from chronic allergic rhinitis.

I gave up wheat and dairy and caffeine, and cut down on sweet things. I also tried to stick to organic fruit and veg. My husband was very supportive, doing the diet with me, and taking fertility supplements, which my nutritionist prescribed. I think other people thought I was faddy - it's difficult to eat at other people's houses if you can't have wheat or dairy.

My periods did not improve drastically but I felt stronger and healthier overall as a result of the whole programme.

In November 2004, I was amazed to discover that I was pregnant. I was less strict about the diet after that - although I was still careful what I ate and completely avoided caffeine, I started to eat dairy foods again. I gradually stopped going to see my nutritionist, but I continued with my acupuncture and Pilates which were both a great help with energy levels and fitness.



My daughter was born in July 2005 and my periods since then have been heavy and painful, with lots of congestion and bowel problems like before, but they have not been as debilitating to the point of having to take time off work during each period.

After more than a year of trying for another baby we became more pro-active and gave up caffeine again, started juicing every day and trying to eat lots of fresh food. I am now expecting our second baby in November, all being well.

You have to be committed to embark on a special diet and for those who are suffering with their endo it can seem too demanding. But I think it is worth the effort. Better nutrition can only be good for you and help to improve your general health, especially if you are trying to conceive.

# Elizabeth's Story

**Elizabeth Rayner found that by changing her diet, she could improve her endometriosis symptoms.**

After two years of going back and forth to my GP with either bowel, bladder, stomach or period pain, I finally got diagnosed with severe endometriosis. However, I have suffered from day one with painful periods so not sure how long I have been 'just getting on with it!'

I had an ultrasound scan and it showed endometriosis was suspected. This was then confirmed after a laparoscopy and surgery in December 2007.

Following my diagnosis, I didn't know whether to laugh or cry. I now felt it was real and not all in my head, which is what my GP told me. On the other hand, I had been trying to conceive for 16 months and had to face that I had a condition that could affect my fertility.

I naively thought that my operation would solve all my problems.

Unfortunately my first period arrived

on Christmas Day and I was doubled up in pain again, but I put this down to having surgery. My second period arrived in January and the pain returned. I expressed my concerns to my consultant but he just told me to take strong painkillers and manage the pain for the next six months, then try IVF. After this, I felt completely helpless and at a loss at what to do as I did not want to rely on pain killers to mask the pain.

My salvation came when my lovely husband bought me a book about endometriosis and nutrition. After I read the book it was like a dark cloud had lifted from over my head. The book included case studies that I could relate to and it gave me hope for the very first time. I went to see a nutritionist in London, who went through a very detailed medical history questionnaire and put me on a strict diet. I had to cut out yeast, cows' milk, caffeine, alcohol, chocolate, red meat and eggs and reduce my wheat intake. I also had to take various supplements. After just one week I



could feel the benefits and for the first time in ages I felt like I had energy!

My period arrived without much pain and I could get on with my life. I am now in my second month but I have struggled to keep with the strict diet. However, when I do stray I become bloated and I can really feel the difference. I am delighted to say my second period arrived almost pain free! I know it is still early days but I feel this is not a diet but a lifestyle change and so far I am feeling 100% better! I would definitely recommend it!

**If you would like to share your story, please contact Lucy at:**

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

# Profile on Nutritionists

**The British Association for Applied Nutrition and Nutritional Therapy (BANT) was founded in 1997.**

BANT's purpose was to draw together practitioners in order to ensure they attained the highest standards, knowledge and competence. It acts as a professional body monitoring the activities, training and Continuing Professional Development of its practitioners.

Nutritional Therapy encompasses the use of carefully compiled individual prescriptions for diet and lifestyle in order to treat or prevent ailments and promote optimal health. These recommendations may include guidance on lifestyle changes, exercise, natural detoxification procedures, methods to support digestion and absorption, the avoidance of ingestion

or inhalation of toxins or allergens and the appropriate use of supplementary nutrients that may include phytonutrients.

You can find a nutritional therapist near you by visiting [www.bant.org.uk](http://www.bant.org.uk) You do not need a referral from your GP, though it is best to inform your GP that you are working with a Nutritional Therapist (NT). You may like to call a few therapists, talk to them about your problems and then decide who you feel you can work with best.

At a typical first appointment, the therapist will go through your medical and family history, ask you questions about your diet, lifestyle and current medications and enquire about the specific reasons for your visit. You will usually be required to provide a current food diary. You will receive a personalised dietary, lifestyle and

nutritional supplement programme generated from the information gathered in your consultation and, when appropriate, from recommended laboratory tests. Follow-up consultations are advised to assess progress, make adjustments and keep you on a path of better health.

Practitioners should advise clients on a realistic time-scale for improvements at the first consultation. Patients are advised to inform their GP of the planned programme before making any major changes to their diet and to continue all medications unless advised otherwise by their GP.

The cost of nutritional therapy consultations can range from £40 to over £100 per appointment. Any laboratory tests or nutritional supplements are likely to be additional costs.

*By Jayne Nelson*

**The Institute for Optimum Nutrition in Richmond holds free Nutritionist consultations to members of the public. The consultations are carried out by 2nd and 3rd year students**

**so they can apply their knowledge and practice their skills. Each consultation is supervised by a fully qualified tutor.**

**For more information contact the Institute for Optimum Nutrition**

**Training Clinic:**

**T: 020 8614 7802**

**Email: [training-clinic@ion.ac.uk](mailto:training-clinic@ion.ac.uk)**

# Dietitians – under the spotlight

**You can't turn on the TV these days without seeing something about food and health. This means there is a need for trustworthy information about how food can affect health.**

There are many practitioners who can give expert advice on diet & nutrition but dietitians hold the only legally recognised graduate qualification in nutrition and dietetics in the UK.

## What is a Dietitian?

Registered Dietitians are qualified to translate information about food into practical dietary advice. They are trained to graduate level and undergo training within the medical team in the health service. Dietitians can advise about food problems in relation to ill health and disease. Dietitians need to be on the health professions council register and abide by a code of conduct.

## What do Dietitians do & where do they work?

Many dietitians work in the National

Health Service (NHS). Others work with people in the community. There are also a range of dietitians working outside the NHS such as the food industry, sports, scientific research, education and journalism.

Tanya Haffner is a prime example of the wide range of opportunities available to dietitians. After a career in the NHS and in commercial settings, Tanya set up a business in nutrition and health communications. "I still keep a clinic because contact with patients is my first love, but my second love is communicating to larger audiences, so I write a lot of articles on nutrition and health," she says.

"I also run wellbeing events, develop resources and run marketing campaigns for a number of health and commercial organisations. I really enjoy pulling people together to promote health."

## Can a dietician give information about endometriosis specifically?



*Tanya Haffner*

There are a number of dietitians specialised in women's health in the UK who provide dietary advice to people with endometriosis. In a number of cases dietary changes can help manage a number of symptoms. However, as each case is different one would have to be referred to a Dietitian for individual assessment.

## How do you access a Dietitian?

Most people will be able to see a Registered Dietitian within the NHS after being referred by medical staff. Consultations with dietitians within the NHS are free.

*By Sanjay Mistry*

If you wish to find a Registered Dietitian visit [www.bda.uk.com](http://www.bda.uk.com)

# Group News

## Awareness Week featured some exciting events for our local groups and some fantastic chances to raise the profile of endometriosis.

The Bristol group were invited to have a stand at the 'Women who make a difference awards.' The group are now hopefully joining the Council Women's forum in Bristol as an interest group.

Lynn from the Lanarkshire group did a brilliant job during Awareness Week. As a local government employee, Lynn spoke at a Corporate Health and Safety meeting about endometriosis. She wrote an article for her work magazine and distributed leaflets and posters, which were displayed in council buildings. Lynn managed to create awareness a bit further a-field by highlighting the condition in a global email.

Lynn held her first group meeting in March. For the second meeting on Tuesday 27th May, Nutritionist Christine Blakey will speak to the group about how nutrition can affect endometriosis. For details, see our

website [www.endometriosis-uk.org](http://www.endometriosis-uk.org) or contact the office on 020 7222 2781

A new group is starting in Ashford, Cheresey and a number of groups are restarting, including West Somerset and Southampton. For details, see the group list on the back page or visit our website: [www.endometriosis-uk.org](http://www.endometriosis-uk.org)

Unfortunately the Redhill group is closing. However, Karen will remain on our list as a local contact for any local ladies who'd like to talk to someone about endometriosis.

The Stockport group is temporarily closing as Anna and Maxine need to step down. We are hope to find a new group leader to keep this group going. Karen, Anna and Maxine have each done a sterling job and I'd like to say thanks for their hard work and commitment over the last few years.

We are always looking to expand our group network. If you are interested in running a group, or being a local contact and answering calls, please contact Diane at the office on 020 7222 2781 or [Dhicks@endometriosis-uk.org](mailto:Dhicks@endometriosis-uk.org)

## Helpline news

Calls increased during Awareness Week – good to know the aim to raise awareness was achieved! The Helpline is open every weekday evening, and on Wednesday and Thursday day. It is always nice to receive feedback from people who are grateful for the support they have been given through a call. Below is an extract from a letter we recently received:

*"It was refreshing to talk to someone who knows what I am going through. Endometriosis can be a lonely experience, especially as your friends and family are sometimes too embarrassed to talk about it. This was different, it was an opportunity for me to talk about the concerns I have.*

*"I came off the phone feeling so much better and clearer about how I want to move forward in managing my condition in partnership with my doctor. Thank you so much."*

**Michelle, Portsmouth**

# Be Inspired...

Kate Hardcastle, 31, has been blessed with good looks, a bubbly personality and a brain. The latter has helped the marketing director win more than 20 top awards, including Young Marketer of The Year.

And if she hadn't gone into marketing, Kate could have had a career on stage. She's been singing with various bands including *Barefaced Cheek* and *The Dreamgirls Yorkshire* since she was 15.

But unbeknown to most people Kate hides a secret heartache. It is unlikely she will ever be able to have children because she has endometriosis.

Kate's symptoms started eight years ago. She had abdominal pain, backache and was rundown but it took specialists two years to diagnose it. The illness affects her most days, and while she manages her pain, there are occasions when she has to go to hospital for help.

She says: *"The staff know what the score is now and give me morphine for my cramps. I have to wait until it calms down, which can sometimes mean an overnight stay."* Doctors tried, unsuccessfully, to induce an early menopause some years ago, which may have helped her symptoms.

*"As well as the pain and fatigue there is the mental damage. It can be a scary place to be and doesn't just affect a sufferer, their families go through it too,"* says Kate.

*"Despite being so common there is a severe lack of awareness and understanding about it, which is why I've decided to speak out."*

But rather than just voice her concerns, Kate is acting on them. She's organised a glamorous summer ball to raise money for Endometriosis UK and hopefully make the condition less of a taboo subject.



Kate is calling the ball, the first Butterfly Benefit - if it's a success, she plans more. The event begins with a drinks reception, followed by a three-course meal in the ballroom. Entertainment is from *The Soul and Motown All-Stars* featuring *The Dreamgirls Yorkshire*.

*"It's the first big fund-raiser for the condition so I hope people will get behind me and support it,"* she says.

The Butterfly Benefit takes place on 4th July in at the newly refurbished Rock Hotel in West Yorkshire Tickets are £50 each or £450 for a table of 10.

For bookings, please contact [butterflybenefit@hotmail.co.uk](mailto:butterflybenefit@hotmail.co.uk) or visit [www.butterflybenefit.co.uk](http://www.butterflybenefit.co.uk)

With thanks to the *Evening Courier*, Halifax for permission to print this story.



## Adidas Women's 5k Challenge!

Sunday 7th September 2008.

### Join our team!

The Adidas Women's 5k Challenge (previously the Hydro Active Challenge) will take place in London's Hyde Park, Liverpool's Sefton Park and Birmingham's City Centre. It's open to women of all ages and abilities and looks set to be a wonderful day out, with a warm welcome and carnival atmosphere awaiting you at the UK's biggest women's fun run!

With the summer months upon us, it's the perfect opportunity to get active and support Endometriosis UK. Why not ask a friend to join in! The more people participating, the greater the

funds and awareness we can raise for such an important cause.

This will be such a fantastic day and we really hope you will be able to join us and make this our most successful year yet!

Enter now at <http://www.womenschallenge.co.uk/onlinentry> and remember to choose Endometriosis UK as your chosen charity. (Entry for this event is very popular so please don't delay!)

As soon as you have signed up, please let us know so we can send you a fundraising pack and your very own t-shirt! Email us at [fundraising@endometriosis-uk.org](mailto:fundraising@endometriosis-uk.org) or call us on 020 7222 2781.

## ASICS British 10k run

Sunday 6th July 2008

### ...Places still available!

We only have a few guaranteed places left for the eighth annual ASICS British 10K London run taking place through central London this summer, so please get in touch soon at [fundraising@endometriosis-uk.org](mailto:fundraising@endometriosis-uk.org) or call us on 020 7222 2781 if you would like to be entered.

### Thank you Katie!

Katie Norris, our fundraising volunteer has completed her internship. She raised over £8,000 for the charity in three months! Katie started in January to help our marathon runner Neil Kelly with his fundraising. So how did she get on?

*"It's been a busy few months! I'm delighted with the money raised in the marathon. I'd like to thank all involved - especially Neil".*

Katie organised two parties during her stay, which raised over £2,000. She also arranged the street collections in London.

She said: *"I have really enjoyed the challenge of fundraising for Endometriosis UK, it's a wonderful charity and I'm delighted to have been able to contribute and raise a little more awareness of the condition."*

## Sky's the limit!

Lucinda Broad took up the challenge of doing a parachute jump for Endometriosis UK and raised an incredible £400.

She took part in the Great Warwick Jump – a charity event arranged by Warwick University Skydive Club.

Lucinda recalls being a little hesitant when first asked by a friend to do the jump:



*"I don't like heights, so the thought of jumping out of a plane at 15,000 feet in temperatures of around minus 30 degrees didn't seem like fun! However, I began to think it would be an unforgettable experience and a great way of raising money for charity; something I had wanted to do for a while... it was one of the most amazing and rewarding experiences of my life and I'd recommend it to anyone!"*

In the lead up to the big event, Lucinda and her friend raised money by organising different activities -

including a street collection in fancy dress! She also called on the support of friends and family who were more than willing to help.

Lucinda was keen to raise money and awareness for Endometriosis UK after several members of her family suffered from the condition. There is no doubt that she succeeded in doing just that and we are so grateful for her efforts. Thanks Lucinda!

## Free-falling!

If you're interested in fundraising for Endometriosis UK and would like to do a parachute jump, all you have to do is raise enough money in sponsorship and you can do it for free! There are three types of jumps available and you can jump from any one of twenty British Parachute Association approved airfields across the UK. All training is given and if you raise from £360 (depending on the type of jump you choose) you will receive your jump for free.

## Thank you!

...to everyone who raised funds for us this quarter, including:

- Susan Dee for raising £150 at her 50th birthday party
- Sam Gaden for her continued support and for raising £185 selling handmade cards
- Linda Coles for raising £160 via her Ivory Webb catalogue sales

For information on fundraising, please contact Nemone Warner on 020 7222 2782 or email [fundraising@endometriosis-uk.org](mailto:fundraising@endometriosis-uk.org)

# ENDOMETRIOSIS UK CURRENT LOCAL GROUPS

## SCOTLAND

### ABERDEEN

Lynette 07731 941515 (weekdays up to 9pm)  
[lynettemcr@tiscali.co.uk](mailto:lynettemcr@tiscali.co.uk)

### LANARKSHIRE

Lynn 07891 527212 (weekdays 6:30pm - 8:30pm)  
[lynn\\_carr@msn.com](mailto:lynn_carr@msn.com)

## ENGLAND (NORTH)

### BRADFORD

Michelle  
[endometriosisupportgroup@live.co.uk](mailto:endometriosisupportgroup@live.co.uk)

BLACKBURN - (for information please contact the office 020 7 222 2781)

### CREWE

Susie 01565 734574 (weekdays after 6.30pm)

### DONCASTER & ROTHERHAM

Christine 01709 818 426  
(weekdays 7.30pm - 9pm)

### STOCKPORT

In need of group leader

### WARRINGTON

Christine 01925 831 104  
[chrisfrance2000@yahoo.com](mailto:chrisfrance2000@yahoo.com)

### YORK

Carla 07701 080661 (weekdays 5:30pm - 7:30pm)  
[yorkendogroup@googlegmail.com](mailto:yorkendogroup@googlegmail.com)

## ENGLAND (MIDLANDS)

### BIRMINGHAM

Laura 07515 121414  
[birminghamendo@hotmail.co.uk](mailto:birminghamendo@hotmail.co.uk)

### CHESTERFIELD - (Derbyshire)

Sarah 07774 540003 (weekdays 7pm - 9pm)

### STAMFORD

Anna 07740 504854  
[stamfordendo@hotmail.co.uk](mailto:stamfordendo@hotmail.co.uk)

### OXFORD / SOUTH NORTHANTS

Julie  
[juliekoretz@gmail.com](mailto:juliekoretz@gmail.com)

## ENGLAND (EAST)

### CAMBRIDGE

Beth 01440 702201  
[kirkifive@googlemail.com](mailto:kirkifive@googlemail.com)

### NORWICH

Jodie 01603 250712 (weekdays after 6pm)  
[jbrister1975@aol.com](mailto:jbrister1975@aol.com)

## ENGLAND (SOUTH EAST)

### ASHFORD, STAINES AND CHERTSEY

Justine  
[ashfordendo@btinternet.com](mailto:ashfordendo@btinternet.com)

### BRIGHTON

Katherine 01273 579 692  
[Nursemaidleaylet@aol.com](mailto:Nursemaidleaylet@aol.com)

### GUILDFORD

Sue 01372 454717 (weekdays 7.30pm - 9.30pm, weekends 10am - 7pm)  
[susiejharding@tiscali.co.uk](mailto:susiejharding@tiscali.co.uk)

### LUTON

Jaswinder 01582 416783 (Mon & Fri 11am-4pm)  
[jaschalli@yahoo.co.uk](mailto:jaschalli@yahoo.co.uk)

### REDHILL - (Surrey)

Karen 01737 767853 (Monday or Tuesday evenings 8pm-10pm)  
[karenendo@btinternet.com](mailto:karenendo@btinternet.com)

### SOUTH BUCKS AND WINDSOR

Paula  
[southbucksendo@mail.com](mailto:southbucksendo@mail.com)

### TAUNTON, BRIDGWATER AND WEST SOMERSET

Jenny 07814 840425

### WEST DRAYTON

Tracey 01895 854 604  
[endo@bfcc.org.uk](mailto:endo@bfcc.org.uk)

## ENGLAND - SOUTH WEST

### BRISTOL

Victoria 07903 437905 (Tuesday - Thursday 7pm - 9pm)  
[bristolendogroup@btinternet.com](mailto:bristolendogroup@btinternet.com)

## ISLE OF MAN

Sarah 07624 24356 (7:30pm-9pm Monday-Saturday)  
[sarahgledhillmcclements@yahoo.co.uk](mailto:sarahgledhillmcclements@yahoo.co.uk)

## WALES

### OSWESTRY & WREXHAM

Cat 07746 502994 (after 7pm Mon-Thurs, anytime Fri-Sun)  
[catwhittall81@hotmail.co.uk](mailto:catwhittall81@hotmail.co.uk)

### SOUTH WALES

Claire 07740 533564 (6pm-10pm)  
[s.walesendo@hotmail.co.uk](mailto:s.walesendo@hotmail.co.uk)

## NORTHERN IRELAND

### BELFAST

Anna 028 9070 2542  
Tracey 028 9064 2896

## CHANNEL ISLANDS

### JERSEY

Roseanne 01534 871529



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50 Westminster Palace Gardens, Artillery Row, London SW1P 1RR tel: 020 7222 2781 fax: 020 7222 2786

[www.endometriosis-uk.org](http://www.endometriosis-uk.org) helpline: 0808 808 2227

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