



What's eating you? Activism and IBS.

A rallying call by Julie Thompson, our resident dietitian.



Julie Thompson.
Dietitian and Trustee.

I have IBS too and I work for The IBS Network, but I have been surprised by how few network members engage with the issues and initiatives we have been working on. So I want to ask you, 'what is it that's preventing you from getting actively involved in making things better for people with IBS?' We would love to know.

Is coping with your own IBS bad enough without having to help everybody else? Getting involved can mean work, but only as much as you can manage, and believe me, you will feel so much better if you are doing something to help.

Or are you just too embarrassed to admit you have IBS? I can understand that. There have been times when I've not wanted to tell people "I have IBS", but as soon as I did so, I began to feel better.

Yes I HAVE IBS"! I'm not ashamed of that. It may be a 'functional' illness, but I should still be treated the same as any other ill person. I never discuss my symptoms publicly, but I can still be active on behalf of people with IBS.

Does your IBS make you feel inadequate, depressed and isolated? IBS is not a trivial diagnosis, but we do need to raise awareness of how debilitating it can be.

I am impressed at the support that our sister charities, Crohns & Colitis UK and Coeliac UK, can muster. So why is IBS being left behind? Is it the association with emotional upset?

Because IBS is not a disease with a well defined pathology, the help the medical profession can provide is always going to be limited. Alternative therapies may offer more

understanding, but bear in mind that you may be paying for treatments that are not supported by evidence and may still not work.

What seems to help most is talking to someone who understands and cares. We at The IBS Network do care, and we can work with healthcare professionals to help them help you better by facilitating understanding and enabling self care. Remember IBS is an individual illness; you may be the best person to direct health professionals to the treatments that will be more effective for you.

But we must get rid of a hovering stigma surrounding IBS. I have IBS too and have felt the stigma. Just because effective treatments are limited doesn't mean that we stop trying.

Guided self care seems to offer a real difference, but people need information, advice and support to obtain relief and maintain well being. The IBS Network is there to help. We can help you and your health professionals understand and best manage your symptoms, but we need YOUR SUPPORT to get the message across to the health professionals who can make a difference. Help us to help you better. TELL US what you think about the self care plan.

We are at a turning point in our healthcare system, and if management of IBS is going to be better, the support for it has to come from you, the people who know what it's like.

Have I aroused your passion? I hope so. Want your voice to be heard? Then why not get involved. We would be delighted to accept whatever time or support you can offer... We need volunteers to help with fundraising, marketing, business strategy, lobbying, writing, IT, setting up a self help group and anything else you feel may help. So get in touch and help us help you better!



Self-care for IBS

By Sue Backhouse

Sue Backhouse co-founded the IBS Network with Christine Dancey after having found virtually no useful information on and support with her symptoms.

She has co-written several books on IBS, including IBS: A Complete Guide To Relief From Irritable Bowel Syndrome, published by Constable Robinson. She lives by the sea in North Wales with her extended family, making very special chocolate.

The term 'self care' conjures up mixed feelings for me. On the one hand, it could be seen as allowing the medical profession to wash their hands of us. Doctors must feel great frustration not to be able to offer a cure, or even an effective treatment. So, after more serious illnesses have been ruled out, most of us are left to get on with it. On the other hand, one of the best things I have done for myself, my IBS and all aspects of my life, is concentrate on self care.

It is through my IBS that I developed a lasting passion for learning about food. It seemed clear to me there must be a direct connection between the food I was eating and my IBS symptoms. So I went into this thoroughly on many occasions over the years and have come to the conclusion that no particular foods can be implicated. I eat healthily because I love to but none of the classic 'problematic' foods make my bowels worse as far as I can tell. Eating healthily and for pleasure is my kind of self care.

Over the years, I have learnt to become more in tune with my body. I have also realised that acceptance makes my life much easier. I have allowed myself to be more open with people and more assertive. All this I would put under the heading of self care.

This emotional self care came when I realised that my attitude towards my condition was causing me shame and embarrassment. Through self awareness, I discovered that certain scenarios made my IBS worse. For example, going for a walk after I eat can cause me stress because I need to find a toilet. So now I tell people, 'if we go out for a meal, I won't be going for a stroll with you afterwards'. That way I feel more in control of my life.

I don't assume I will always have IBS. I don't want to accept IBS as part of my identity; I'm more than an illness. So, for instance, while travelling to India doesn't appeal to me at the moment because the challenges would probably outweigh the enjoyment... I don't assume I will never be able to go there.

Co-founding the IBS Network really helped me personally. Knowing that there were so many people suffering with IBS, having the same anxieties, the same discomfort - some much worse than me, gave me the confidence to gain control of my own condition and to help others as well. After all, it wasn't just me that felt outraged and frustrated at the state of our public toilets!

For me, self care means looking after my needs before I can be of use to my loved ones! Taking risks and doing exciting things when I can - I have camped for three nights in a cave with two friends and felt completely comfortable about it because I trusted them and was open with them. Speaking out when I need to - when I complained about the dreadful state of the toilets at the Glastonbury festival, the crew supplied me with my own private toilet! And not giving myself a hard time about the things I don't feel able to do - I tell my friends how going for a walk cause me tension. It wasn't always this way.

Oh, yes, I nearly forgot - humour. Try to see the funny side of it and it will lighten the burden of frustration.

So let's have compassion for ourselves - IBS is a condition that is hard to live with. I hope the future brings better understanding, improved facilities and more freedom for us all.

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Your Letters

What did it for me



A personal reflection by Network member, Mindi Kaine.

Since last August, I have adopted a new life style, which has left me pain free and with as near normal a gut as I have had in years!

How? Well, I went to see a naturopath last July and changed my diet, taking out sugars and alcohol and adding more protein. I also eat short grain organic brown rice twice daily - the most gut healing food I have ever had. I use castor oil packs on the liver, gut and back for pain relief. I use prescriptive enemas which really help the pain - e.g. magnesium for intestinal spasms, coffee for energy and headaches, bicarb for acidity, aloe vera for inflammation, chamomile to calm things down. After 9 months I felt more in control and relaxed and now drink my red wine again when I fancy a glass, I also eat dark chocolate because it makes me feel good.

I have no pain in my gut unless I deviate from this regime and I have been going to the loo like a normal person for the first time in years. I was going up to a dozen times on some days and not at all on others.

Even when, earlier this year, I suffered a severe life changing event and have had to move to Dorset, my diet helped me cope and I am hoping time and some new work will help to heal things. I have had time to focus on myself since losing a lot of my counselling work with young people due to social services cut backs so I am broke but it has been worth it to have Me time and heal. Now I want to share this so I am setting up a counselling room here and a new website (www.canitalkabout.me). My work will be specialising in young people and those with bowel problems too.

Nick Read comments. Naturopathy, or Naturopathic Medicine, is based on the idea that vital energy or vital force guides bodily processes such as metabolism, reproduction, growth, and adaptation. While there is no evidence to support the concept or practice, naturopathy favours a holistic approach using natural treatments and remains popular with people with IBS. We at the IBS Network would always advocate you contact a state registered dietitian for advice on nutritional balance diet and therapy, but we acknowledge that IBS is an illness

of the individual and appreciate how treats and a little of what you fancy does you good. (Trekking through the south west wilderness in Tasmania on 'iron rations', I found that an evening square of dark chocolate and tot of port sustained morale and endurance).

More Research needed

As someone whose quality of life has been decimated by ibs I often browse potential remedies. Recently I noticed that Dr Thomas Borody in Australia has started to use faecal transplants to treat patients with chronic gut complaints. At first the idea sounded repellent, but the evidence suggests that this approach can relieve some people of their chronic bowel upset gut symptoms. To my knowledge, there is currently no doctor in either Britain or Ireland who offers this procedure for IBS, though Dr McConnachie from Glasgow is using faecal transplant to treat colitis.

Would the IBS Network ever consider conducting a trial of faecal transplants for IBS? Apparently it is way more effective than probiotics? I am a member of an IBS forum and, believe me, there are many people out there who are very interested in this. If funding is an issue, I feel sure that there are many, who would be very willing to donate to see it happen.

Robert Drohan.

Nick Read comments I have followed the research on faecal transplants over many years. I remember hearing about how people with C. Difficile colitis and ulcerative colitis could be cured by faecal enemas from a spouse, though some would say there are limits to togetherness. There is a growing interest for faecal transplantation among medics, though no evidence that it is useful for IBS as yet.

The IBS Network does not directly support research, but we know the scientists conducting research in IBS and could instead of raising funds for research into novel treatments is something we should consider. How would you propose we do this? We would love to hear from you.



‘We’re all in this together!’ 21 years of the IBS Network

Dr. Val Harrington is Senior Lecturer at the Centre for the History of Science, Technology and Medicine, University of Manchester. She is currently funded by The Wellcome Trust to conduct research into the history of IBS.

In November 1990, Sue Backhouse, working in her Sheffield printshop, received a letter from Christine Dancey, a psychology lecturer in London. Sue had suffered from IBS for nearly twenty years and, like Christine, could find little information about the condition. ‘What I would really like to do’ replied Sue ‘is to start a newsletter.’ In the spring of 1991, the first issue of Gut Reaction (GR) appeared. Later that year Christine held the first meeting of the Sydenham self help group. But ‘the thing really took off’ when publicity on the Des O’Connor Show provoked 10,000 letters, delivered in sackloads. The size and depth of the response reflected just how isolated many sufferers felt. By the end of 1992 there were over 2,000 members and seventeen local groups.

In those early years, the IBS Network was little more than a loose affiliation of individuals and groups. Sue and Christine were committed to the notion of self help as an organic, grassroots movement and saw their role as a point of contact for information, advice and the publication of GR. Gradually, their network of self help groups and supportive professionals expanded to cover the country. Among their supporters was a certain Nick Read, Professor of Gastroenterology in Sheffield, who became their medical advisor and offered the use of a ‘broom cupboard’ in his department as office space for Sue’s growing band of volunteers.

In 1994, the Network became a Trust and Sue and Christine handed over responsibility for decision making to the new Board of Trustees, which was chaired by Maureen O’Hara. Their first task was to register the network as a charity, a complex process coordinated by Dorothy Mitchell, retired businesswomen, grandmother and self styled ‘Rossendale Rottweiler’, who was treasurer from 1995 to 2004. It was Dorothy, who put the Network on a professional footing – though always mindful of the need to stay true to its core ethos as a members’ organisation. Central to achieving this balance was Penny Nunn, who was appointed development officer in 1997.

Penny Nunn



**LISTEN TO
YOUR GUT**



In 1996, Sue withdrew from the Network. Her five year involvement had helped her 'take control of my life' and she was now ready to move on. Christine stayed and Shirley Smith took on the role of editor of GR, giving it a much needed visual and content makeover. The Medical Advisory Service with their team of disabled nurses no longer employed by the NHS, were recruited to operate a telephone helpline. Liz Taylor, a hypnotherapist and trustee from Rossendale, devised a very successful sixteen-week therapeutic programme, run by trained therapists and open to all Network members. This was the precursor of the web-based IBS self management programme and this years IBS Self Care Plan and health professional training.

By the millennium, The IBS Network had been transformed from a small grassroots movement into a well-respected, professionally-run charity, but if it was going to reach out to the millions of people with IBS, it needed to attract investment and grow. In 2006, Jonathan Blanchard Smith, the newly appointed Chair of Trustees, embarked on a programme of reorganisation and expansion. Central to this was a massive re-branding exercise. So in autumn 2007 the IBS Network changed its name to the Gut Trust and designed a new website. Unfortunately, the rebranding didn't attract the expected investment. Jonathan resigned and so did Penny and the rest of the trustees, and the trust was plunged into financial difficulties. Nick, who had stepped down from the Board in 2005, returned and with Kirsty, the new office manager and the support of trustees Gillian Kemp and Robert Wright, rebuilt the organisation into what it is today.

In March 2011, we once again became The IBS Network, defining our mission 'to facilitate self care of IBS by providing information, resource and training' The website was redesigned, Gut Reaction developed a new look, Relief, a lively interactive web-based newsletter was introduced and the IBS Self Care Plan was launched.

Over the years the Network has successfully adapted to changing medical, social and business environments, but has never lost sight of Sue and Christine's vision of how the power of information and assisted self help can transform the lives of people with IBS. Today, members gain information from the website and interact through new social media channels rather than through letters' pages and self-help groups, and there is much more emphasis on working with health professionals and corporate partners. Nevertheless its lifeblood is still its membership.

We can't do it without you. The IBS Network has always been 'for the patients by the patients'. At its height, dozens of volunteers played an active role. We need to recreate this active involvement and identification. So once again, we call on you to help your IBS Network work to make a real difference to the lives of everybody with IBS. Write in today, volunteer, join a focus group, be on our media list, raise funds, start a self help group, blog, write in to Relief or Gut Reaction, inform your health professional, offer your skills, time to make it work. With your help, we can do it. Valerie Harrington.

Valerie Harrington would like to thank those Network members, past and present, who have taken part in her research and helped bring the history to life. If you have any memories you'd like to share or would be willing to be interviewed about your experiences of the Network please contact me on valerie.harrington-2@manchester.ac.uk

The ibs network, the National Charity for IBS, is a company limited by guarantee.

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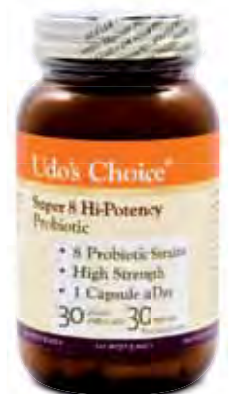
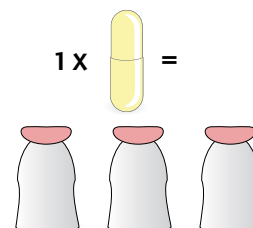
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Book Reviews

Romance, Riches and Restrooms By Tim Phelan

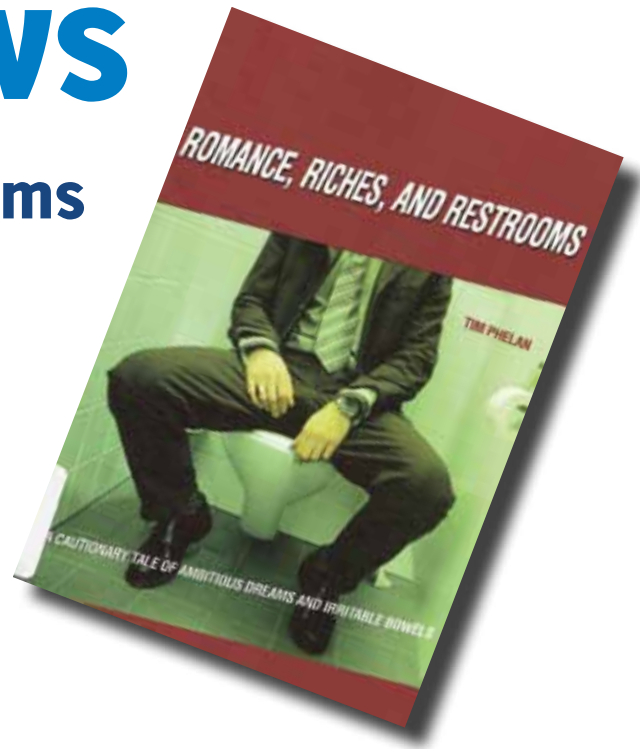
Anyone who has IBS with diarrhoea will appreciate this book! It's an autobiographical tale of a young man's battle with IBS that should also be read by those who've heard about or are associated with this debilitating condition. The story begins with Tim admitting to a new girlfriend that in spite of having majored in French he'd never been to France - a page later we learn that he had never even left his neighbourhood unless he really had to.

Does this sound familiar? Well, in this book there's more to come that might also strike a chord.

Whilst not all of us can pinpoint our original trigger, some of us can. Tim believes that his IBS started by drinking 'one surprisingly powerful cup of French Roast coffee' thirteen years previously. Since that moment his life has never been the same.

Up to that point however, Tim's emotional life had not been easy. His parents divorced when he was 9 and at 14 he was told by his English teacher that his father could not pay the school fees. Fortunately because he'd worked hard, Tim's fees were paid by a fund of which he later became an Assistant Director. It was 3 months into this role at an important dinner, that he drank the cup of coffee that changes his life.

Like many of us, Tim is caught offguard by the grumblings within – just before his boss is about to make a long speech. Unfortunately being seated so close to the speaker, Tim feels unable to escape to the toilet because 'if I excused myself to use the men's room now, how would that make me look?'. He admits that there was nothing physically to stop him leaving, except for his own embarrassment. He hopes instead, that someone else will make the first move to the loo – but they don't. A nightmare scenario encountered by many of us! Memories of soiling himself at the age of 7 when in the company of his peers flood back as the pressure inside him builds up. His description of these awful feelings is just so accurate that anyone who's had such an experience will not fail to feel for him. Thankfully he eventually makes it to the toilet in time but discovers on his return that he's missed a golden networking opportunity. From that moment he learns – like so many of us - to get a seat 'at the very back of the room, right next to the men's room.'



Tim's writing style is so very involving and the problems he encounters when his IBS kicks in are both awful and amusing. Dates with girls and travelling by public transport are events fraught with danger. His anxieties leap off the page as he tries to combat smells and access toilet rolls in intimate situations. IBS makes any thought of spontaneity in his life impossible. His life is determined by the location of toilets and understandably he feels he's missing out on life. Eventually after a variety of 'treatments' he discovers Cognitive Behavioural Therapy which gives him the courage to go on a break. During this time away and hearing a toilet flush for the umpteenth time, a friend asks if he's OK and it's then that Tim discovers he's not alone with IBS. Is he cured? No. But does he begin to get his life back? Read the book and see.

As Tim reminds us, whilst going to the toilet is a necessary and universal need, talking about it remains a taboo subject – particularly when it comes to problems with bowels. Until this taboo is broken, he says, those of us who have IBS will not only continue to suffer, but so will others who, for whatever reason, need frequent access to toilets. As Tim points out, there is a 'hierarchy of bodily functions' and bowels are there at the bottom!!!!

For me, the main message of this book is don't hide your problem. Tim has become brave enough to speak out in this excellent, down to earth tale of coping with IBS, and we should follow his example.

Romance, Riches and Restrooms by Tim Phelan, published by Universe Inc 2006 is available from books stores such as Amazon, and Abebooks

Gillian Kemp

2theloo

A concept from The Netherlands that takes toilets seriously

Have you ever chased up and down a high street desperately seeking a toilet? Would you like to have confidence that the public toilet you visit is clean and well maintained? Would you like the reassurance that there will be a family / baby changing facility and an accessible toilet available? If so then read on.

In 2010, Eric Treurniet, a marketing executive in The Netherlands, had the dilemma of where to take his 2 young daughters to the toilet – the Gents or the Ladies? Neither was suitable for a male with 2 little girls and there was no guarantee of their cleanliness either. This sparked his interest in toilets and led him to establish the first of a chain of public toilets in February 2011 in Amsterdam which he called 2theloo. Since then the concept has expanded into Belgium, Israel, Spain and Poland and there are plans to bring 2theloo into the UK. The aims of 2theloo are to provide the best service, be easy to find and make a visit to the toilet a pleasant one.



What is different about a 2theloo facility?

- 1 It looks like a shop and has clear signage
- 2 It looks attractive, inside and out
- 3 Found in shopping centres, service stations, railway stations
- 4 Cleanliness a high priority
- 5 The toilets are manned by trained staff.
- 6 Opening hours match those of the area in which they are located
- 7 An easily accessible disabled toilet
- 8 Adult and child sized toilets and, baby changing areas.
- 9 A shop, selling toilet related products.
10. A coffee area in some facilities



The advantage of 2theloo premises is that they all meet the same basic criteria wherever they are so you know what to expect - just like going to a well-known fast food outlet!



Are there any downsides?

- **Availability:** There are no 2theloo facilities currently in the UK but the opportunity is being explored
- **Charge:** There is a small charge to use the toilets (including the accessible toilet) usually €0.50. The toilet ticket can be used as a voucher against the cost of items purchased in the shop.
- **Access:** There is turnstile access to the toilet area

Could this be a way to solve the public toilet problems in the UK? The IBS Network would certainly support such an initiative.

Do let Gill gillian.kemp@ntlworld.com know your thoughts about this exciting new concept and whether you have visited a **2theloo** facility.

Gill Kemp
Management Committee Member, The British Toilet Association www.britloos.co.uk

This article has been compiled from a conversation and emails from 2theloo, information from the 2theloo website and personal impressions. Photographs are courtesy of 2theloo.

www.2theloo.com

Don't let IBS cramp your style this autumn

Stress and IBS flare-ups

September can be a stressful month of the year. Whether you have just come back from a holiday, are getting your children prepared to go back to school or are returning to work after the summer break, getting back into a routine can be a shock to the system.

Being stressed or out of your routine can trigger a flare-up. However, IBS symptoms can vary from person to person and this may be why your symptoms increase or decrease on particular days, regardless of your diet and other lifestyle factors. Some stressful situations can be controlled but it's those that can't be avoided like financial problems, being late for work due to unforeseen circumstances or arguing with a partner that are often more troublesome.

Recent consumer surveys reveal that more than half (55 per cent) of IBS sufferers suffer from abdominal cramps and pain at least once a fortnight¹ and that almost one in three suffer from flare-ups as a result of feeling stressed and overwhelmed.² However, being aware of personal triggers can help you to feel in control and to manage your condition better so it doesn't stop you doing the things you love.

If you do find yourself feeling uncomfortable, stressed or anxious you may find the following tips helpful to prevent flare-ups:

- **Exercise regularly:** You may want to participate in gentle outdoor exercise before the winter sets in. Not only can exercise help to relieve stress it can also help to stimulate normal contractions of your intestines. Exercises that can be particularly useful in helping you relax and improve your digestive health include aerobics, swimming, yoga and pilates
- **Keep a diary:** Not only can you log and identify foods that trigger symptoms, it is also useful to make a note of stressful situations that can bring on your symptoms. Try the Buscopan Abdominal Diary available at www.ibs-relief.co.uk or the IBS symptom tracker available at www.theibsnetwork.org to document your daily eating habits, stress levels and exercise routine
- **Talk things through:** If you are feeling stressed and anxious you may find talking to a friend, family member or partner helpful. Through dealing with the bigger issues, the pain may be avoided

References

1. Buscopan U&A data, April 2012
2. SOS survey. 2000 respondents. February 2011
3. National Institute for Health and Clinical Evidence (NICE). Irritable bowel syndrome in adults: Diagnosis and management of irritable bowel syndrome in primary care.

- **Relax:** Remember to take time out for yourself, whether it's reading a book or indulging in leisure activities it's worth looking into relaxation techniques to help cope with the causes of your stress

Do you feel the same? A recent consumer survey indicates that 21 per cent of IBS sufferers are embarrassed by their condition¹

Diet and IBS flare-ups

Whether it's work lunches or dining out at your favourite restaurant, choosing the right foods when you are away from home can be challenging and it's not unusual to be anxious about the onset of a food-related IBS flare-up. Some fruits and vegetables, foods that are high in fat or dairy products, and foods containing the sweetener sorbitol can irritate a sensitive bowel. You may also find it helpful to reduce intake of insoluble fibre such as wheat, wholemeal or high fibre flour and breads, cereals high in bran and whole grains such as brown rice.³

Whilst there are many foods that can cause abdominal discomfort, everybody's digestive system is different so foods that affect one person may not have an effect on others. Therefore it's important to be aware of personal triggers and work out what's best for you. Also remember that it's not just the food, if you are worried or upset, what you're eating is more likely to cause symptoms such as abdominal cramps too.

Treating your IBS

Bloating, constipation and diarrhoea can be uncomfortable at the best of times and according to a new consumer survey almost a quarter (24 per cent) of IBS sufferers say that abdominal cramps and pain are the most debilitating symptoms of their condition.⁴

If dietary and lifestyle changes are not enough to alleviate your IBS symptoms alternative options may be available to you. Current recommendations for treating abdominal cramps and pain, alongside lifestyle and dietary changes, include using antispasmodics, which work by relaxing bowel muscles to provide targeted relief from abdominal cramps and pain. Speak to your pharmacist or GP for advice.

- Available from: <http://guidance.nice.org.uk/CG61/NICEGuidance/pdf/English>
[Last accessed: 17 August 2012]
4. IBS survey. 1000 respondents. February 2012

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