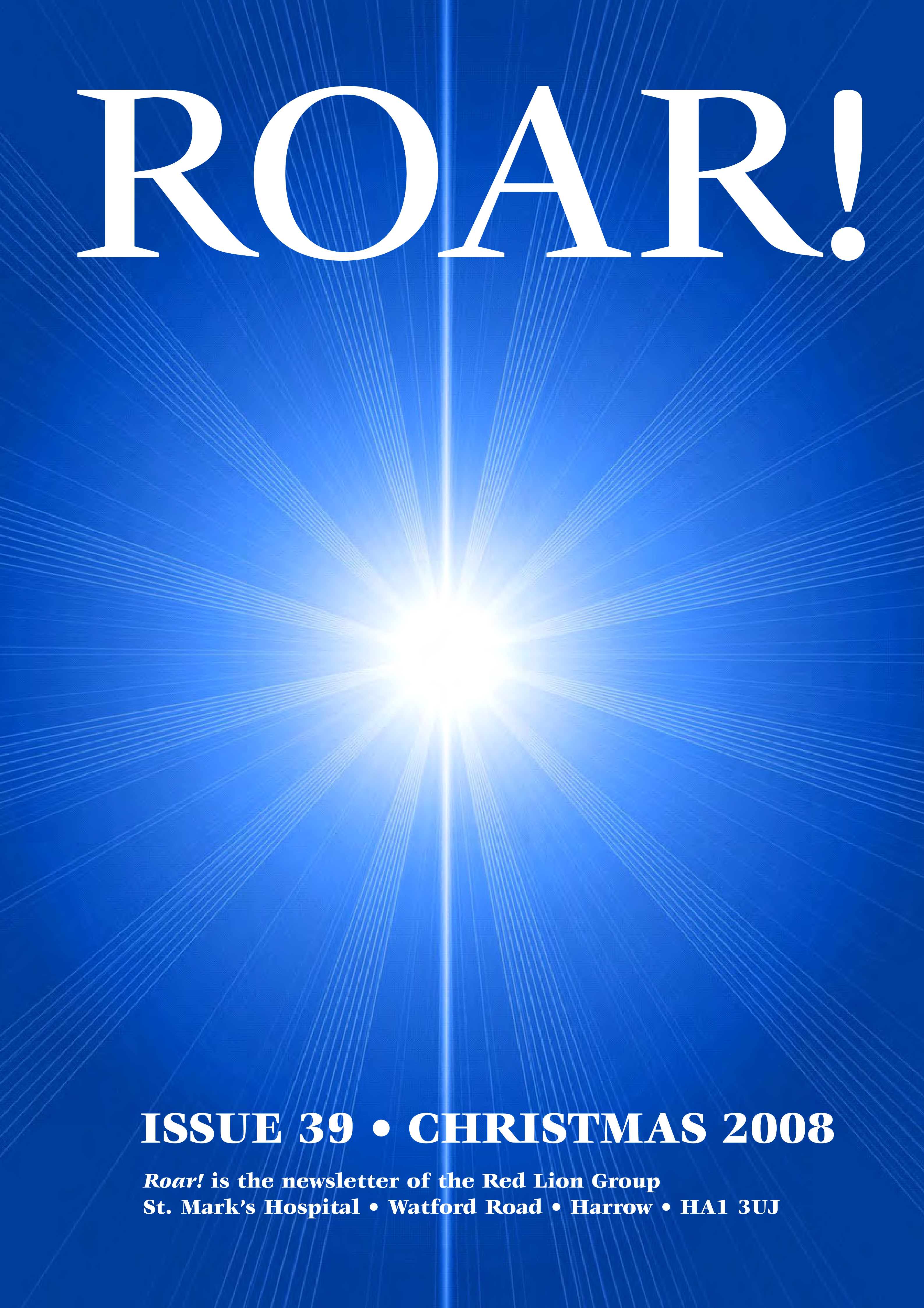


ROAR!

ISSUE 39 • CHRISTMAS 2008

Roar! is the newsletter of the Red Lion Group
St. Mark’s Hospital • Watford Road • Harrow • HA1 3UJ

Regional Reps

HERE IS our current list of regional reps with home telephone numbers — please feel free to contact your local rep and get acquainted.

If you would like to be a regional rep, please contact Inez Malek on 020 7581 4107 or liaison@redliongroup.org.

AVON		
David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
Carol George	Sandy	01767 263092
CLEVELAND & NORTH YORKSHIRE		
Christine Jackson	Saltburn by the Sea	01947 840836 chrisjacks@supanet.com
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DORSET		
Clive Brown	Bridport	01308 422281
ESSEX		
Peter Zammit	Benfleet	01702 551501
HAMPSHIRE		
Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Susan Burrows	St. Albans	01727 869709
KENT (WEST)		
Rosalyn Hiscock	Pembury	01892 823171
LANCASHIRE		
Joan Whiteley	Clitheroe	01200 422093
MERSEYSIDE		
Blanche Farley	Liverpool	0151 924 4282
Anna Morling	Newton-le-Willows	01925 229648
NORFOLK		
Sandy Hyams	King's Lynn	01485 542380

Contents

NORTHAMPTONSHIRE		
Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	07768 400406 mansfieldsmith@hotmail.com
NORTHERN IRELAND		
Sharon Hendron	Lisburn	02892 661559
SOUTH LONDON		
Jonathan English	SW12	020 8673 3092
SOUTH WEST LONDON		
Dee Odell-Athill	W10	colin@odell-athill.demon.co.uk
SUFFOLK		
Anna Morling	Leiston	01728 830574
WILTSHIRE & DORSET		
Bernadette Monks	Salisbury	01722 327388
YORKSHIRE		
Sue Appleyard	Huddersfield	01484 641227

Front cover: *Star* by Sean Gladwell

Back cover: *A Snowman Pillow* by Patrick Wormsley

Notes from the Vice-Chair

Water, water everywhere, and not a drop to drink. These words from Coleridge's *The Ancient Mariner* almost came true for Red Lion member Emma Edwards and family when their water rates rose so high that they nearly had to cancel their annual bill.

Emma's problems started when her supplier Thames Water fitted a meter to her family's household supply and they found their water bill rose by £130-a-year. She wrote to Thames Water and pointed out that she had a medical condition that meant she had to go to the loo 10-12 times in 24 hours and thus used more water than most people.

But after promising to help the Dartford mother-of-three, the company said that although they supported some types of illness they did not recognise her unusual condition – an ileo-anal pouch – and refused to lower her charges.

Months of correspondence and phone calls followed – to no avail. So Emma wrote to her local MP, Dr Howard Stoate, a member of the Commons Select Committee on Health. The Labour MP raised Emma's case in Parliament and contacted Thames Water.

A few weeks later Emma received a letter from the director of Thames Water, the UK's largest water company supplying 8.5 million homes. It said that "due to the nature of your medical conditions and personal circumstances," it would charge her a flat-rate £199-a-year instead of the £300 plus she and her husband Terry had been paying.

"I was determined to go on campaigning about my position until I got a result. After all Thames Water were asking me to pay extra for having a problem," a relieved Emma told *Roar!*.

Not all water companies take the same view. Anglian Water sends a leaflet to its eastern counties users highlighting the illnesses that qualify for lower bills. These include Crohn's disease, ulcerative colitis, abdominal stomas, incontinence and "any other medical condition which involves significant volumes of water usage" i.e. pouch problems.

If like Emma Edwards your water bills have soared in the past year or two, ask your local water company to send you a leaflet or else check the small print on the company's website. If you still get no satisfaction (whether you have a meter or not), contact the company, explain your situation and ask if they will reduce your bill. It could save you more than £100-a-year

If the company refuses to help, ask them to explain why (they may not have a policy for pouch-holders yet) and then contact me on 07939 110842 or info@christopherbrowne.co.uk and I will send you the correspondence that helped Emma win her case.

If that doesn't work then *Roar!* will launch a campaign to make the water companies see sense.

Caring for pouches can be costly in other ways too. Some of you may remember a recent *Roar!* article about free medication for pouch-holders. It was called "A prescription for success" and referred to a timely letter written by former Red Lion chair Dr Martin Peters to Essex area health authority in 2003. In it he said anyone who has an internal version of an ileostomy (i.e. a pouch) should get the same free prescriptions as ileostomy-holders.

Until then Essex, like many other health authorities, had refused to give exemptions to pouch-holders. Peters' letter changed all that and since 2003 more and more area health authorities have done the same.

So if you still pay for the creams, steroids, tablets and medication you need to cope with pain, soreness, irritation or bleeding, you could save yourself a lot of money – and we all want to do that during a global credit crisis don't we! – by getting your prescriptions free.

Just phone or email me (see contacts above) and I'll send you copies of two *Roar!* articles (including the one about Dr Peters's letter) that you can present to your GP and, if necessary, your local health authority.

Getting your doctor to change his or her mind might turn out to be the best Christmas present you've ever had.

Talking of which, it's that time of year again. Tim and I hope you enjoy this seasonal edition of *Roar!* and we and the committee wish you a very happy and healthy Christmas and New Year. And while you're planning 2009 why not jot down the date of the next Information Day. It's Saturday, 25 April. No, it's not a bank holiday and it's the Saturday before the schools go back!

Look forward to seeing you there.

News in Brief

A new support group called the Polypeople has been formed to help patients and families with Familial Adenomatous Polyposis (FAP).

It was set up at the FAP Information Day organised by St Mark's Hospital's Polyposis Registry on 15 November. It's the first time the Registry has had a support group and it will help raise funds for research and patient surveys.

A Registry spokesman told *Roar!*: "FAP is extremely rare and is not really high profile enough to attract large grants from the Government or the drug companies but we are hoping things can move forward now that a group has been formed."

Approximately 75 people attended and one of the highlights was a talk by Dr Arj Shankar, a surgeon from University College London, who showed how CT scanners and internal cameras can produce 3D images inside the body to help surgeons spot tumours, polyps and other health problems.

■ While we're on the subject of scanners and insides, Mark Davies, a 36-year-old marketing director, has just written a book titled *Saving My Arse – a Story of Cancers, Colons and Singapore Noodles.* I haven't read it but it certainly sounds like a lively read!

The book tells how Mark, who had no family history of cancer, found he had a 3.5 cm tumour at the top of his rectum. After a five-week course of chemotherapy and radiotherapy, he went on to a novel kind of treatment called Papillon radiotherapy. This shrinks tumours and makes them easier to remove.

After the treatment, Mark had an operation at Royal Liverpool University Hospital to cut out what was left of his tumour. His surgeon inserted an endoscope in Mark's anal canal forming a tunnel so surgical instruments could be used. He then cut out the tumour leaving two centimetres of healthy tissue around it before stitching up the cavity.

The young marketing director left hospital three days later. A month afterwards he was told the operation had been successful. "Although I will have to have regular check-ups for some time, I am hoping to get the all-clear after five years," he says.

You can read all about Mark Davies's experiences by ordering his book for £9.99 (plus 1.50 p&p) from www.savingmyarse.co.uk

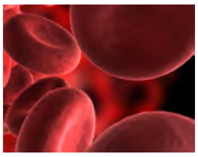
Letters

Dear Christopher

In answer to Heather Pearton's "Absorbing Stuff" (Summer *Roar!*), I had my pouch made in 1983/1984. My life dramatically improved and I lived on a normal, good home-cooked diet with almost no exclusions. After about fifteen years or so it was mentioned by one of the nurses at an Information Day that we should have an annual blood test to check adequate absorption. Anyone enjoying a "normal healthy diet" gets all the vitamins needed from their food and there is generally no need to take supplements.

The blood test is: full blood count (I don't know exactly what that checks); urea; electrolyte; folate and B12. About two years ago my test showed that my B12 was low (I didn't feel any ill-effects) but now I go to my practice nurse every three months for a B12 injection.

When nurse specialists were introduced, one or two of those at St Mark's published pamphlets on topics like this. Maybe one of them could add this information to a diet advice sheet to be given to every patient.



Remember too that our GPs have to have a wide range of knowledge about many different conditions and it's hardly surprising that sometimes we know a little bit more about some aspects of our condition than they do, so don't be too hard on them.

Best wishes
Bob Gordon
Uxbridge
Kent

Dear Roar!

A few years ago I wrote an article for *Roar!* on Uterine Artery Embolisation (UAE). I was hopeful that this procedure would, by cutting off the blood supply, rid me of a large fibroid which was at the back of the womb.

Unfortunately, as an MRI scan revealed, the first embolisation did not work at all. This was followed a couple of years later by a second UAE procedure. This time the blood supply has been stopped and the fibroid has reduced by approximately 50% in volume but is still the size of a tangerine and still causing me pain and other problems.

My gynaecologist has told me that now the blood supply has been stopped and that considerable time has passed since the operation, the fibroid will stay the size it is. For anyone who has not had extensive bowel operations the next step would be a hysterectomy.

He, however, said he would not attempt to perform this on me as I would no doubt have adhesions joining the bowel to the womb and it would be, in his words, a life-threatening operation.

At this year's Information Day I asked the question 'Is it advisable for people with pouches to have a hysterectomy?' The answer which was published in the summer edition of *Roar!* was not encouraging so it would seem wise for me not to pursue that route.

I wondered if any other readers have fibroid problems and whether they have come across any procedures other than embolisation or hysterectomy? I would really appreciate it if they could contact me either through Roar or via email sathelen@yahoo.co.uk.

Congratulations on the summer edition of *Roar!* It contained some really useful articles.

Kind regards
Sally Thelen

Funky Cold Medina

We are very pleased to announce a first – in this case the first-ever survey on Medina catheters. This is confirmed by both St Mark's Hospital and the leader of the survey Dr Simon McLaughlin who until recently was a research fellow at St Mark's. Simon is now gastroenterology specialist registrar at Guy's and St Thomas's Hospital, London. Here is his report.

Although most pouch patients experience good pouch (bowel) function following surgery, a sizeable number do not. For these patients diagnosis and treatment of the cause of poor function is vital if they are to achieve a good quality of life. Pouchitis is the most common cause of poor pouch function. However there are other causes which may give similar symptoms.

Functional outflow obstruction (FOO) is one of them. This means the pouch is difficult to empty and behaves as if there is a blockage or narrowing near the exit (anus), although it does not show up under examination. It may be caused by the link between the pouch and anus becoming kinked when the pouch is full or when the patient is straining to empty it.

FOO was quite a common problem with the early S-shaped pouches, and this led to the development of the 'W' and 'J' versions by Parks and Nicholls (the 'W' version) and Utsunomiya (the 'J' version). Because these emptied more reliably, the problem was reduced.

Diagnosis

FOO is diagnosed by a special X-ray test called a defecating pouchogram. This involves X-ray contrast dye being inserted into the pouch via a catheter placed in the anus followed. X-ray pictures are then taken as the patient empties the pouch behind a screen.

Treatment

For the vast majority of patients, the best solution is to use a Medina catheter. This is a soft rubberised plastic tube which patients are taught to insert into their pouches via the anus using lubricating anaesthetic jelly (lignocaine). Most patients will use this every time they need to empty the pouch. Others will combine it with conventional emptying. Another option is redo-pouch surgery. However this is more risky than the original pouch operation and doesn't necessarily lead to better emptying. Neither can it be converted to an end-ileostomy (stoma).

Conclusion

To our knowledge there are no medical studies on the outcome of patients using Medina catheters to empty their pouches. Although our experience suggested patients found this treatment useful we wanted to establish whether this was really the case so we could better advise future patients.

Here then are the results of the first ever Medina catheter survey:

After seeking approval from the St Mark's Hospital ethics committee, the survey team identified 31 Medina catheter users from the hospital's pouch database. We sent them a questionnaire that covered quality of life, bowel frequency and problems with using catheters.

These are our findings:

- Twenty-three people (74%) returned completed questionnaires. They were all in the 23-69 age group and 68% of them were males. Catheter use ranged from six months to 30 years.
- Of those who responded, 71% reported an improved quality of life since using a catheter.
- The average bowel frequency was six times in 24 hours with a range of two to 14 times. Half of the patient group used the catheter every time they emptied the pouch whereas others used it intermittently. Almost three-quarters of the group reported that using the catheter did not restrict their work or social life. Just under one-fifth reported occasional catheter blockage due to thickening stool and just over one-half of patients found that they needed to modify their diet to use the catheter.

The median quality of life measured using the Cleveland global quality of life score (used in many pouch studies) was 0.72.

Conclusion

The study demonstrates that using a Medina catheter can improve quality of life in patients with functional outflow obstruction. Furthermore using a Medina catheter results in good functional outcome with a pouch (bowel) frequency that is well within the normal range.

Reassuringly the majority of patients reported that using the catheter did not restrict their work or social life. The quality of life scores recorded in this study are only slightly inferior to the results of large studies of all pouch patients, which is again reassuring.

We hope that this study will help to encourage those patients who have been found to have functional outflow obstruction that using a Medina catheter should result in good pouch function, a good quality of life and minimal (if any) restriction on work and social activities.

We would suggest that there is a need for the Red Lion Group to form a Medina catheter users group. This would allow medical professionals to put patients in touch with experienced users who could help advise and reassure those who have recently been prescribed a Medina catheter.

My Catheter Conversion

Roar! co-editor Christopher Browne explains why it took him 12 years to find out how to use this popular pouch-emptying device.

I've just had to pay a large fine for wasting hospital time – or at least I should have done. That's the view of a stomacare nurse when I told her I'd started using a Medina catheter for the first time.

"Just think, you've spent twelve years hanging around in hospital waiting-rooms, going to appointments with puzzled consultants and making worried phone calls about your troublesome pouch when all you had to do was use a catheter," she told me.

And she was quite right of course. For in 1996 I was given one of these long thin plastic tubes by a nurse specialist at St Mark's to try and clear my reluctant pouch.

I went home and after eyeing this gangly-looking object a few times, decided to take the plunge. I pushed it up my backside, and waited for some action, but nothing happened. "There must be something stirring in there," I thought to myself and tried again a few days later. But once again not a drop. Niente. Nothing.

The next day I phoned the nurse specialist who'd given me the catheter and told her I couldn't get it to work. She was philosophical and said I'd have to find another way to solve my problems.

So I forgot about catheters until earlier this year when I saw Simon McClaughlin, a St Mark's research fellow, about my pouch-emptying difficulties. He tested, scanned and probed with aplomb as he sought to find the causes. All the results showed a fairly normal-looking pouch. "But I'm having all these blockage problems whenever I go to the loo," I said. The refrain I'd used with every other consultant I'd visited. He said the various post-pouch ops I'd had for ulcers and dilation had left scar tissue and lesions in parts of the anus.

I had two options. One was to use a Medina catheter. The second was more drastic. Abandon the pouch and have an ileostomy.

I booked an appointment with Beccy Slater, a pouch specialist nurse at St Mark's. On the day of the visit, Beccy asked me to lie on my side and gently inserted a catheter up my backside. A few seconds later a giant tidal wave cascaded down Harrow-on-the-Hill (at least that's what it felt like). For my pouch emptied like it had never emptied before as kilo after kilo seemed to pour into Beccy's red bucket.

"You're doing well," she said reassuringly. Then she handed me the catheter and asked me to do the same. I took the plunge and "whoosh" another outpouring. "This is turning into something like fun," I thought when I realised the catheter really worked after all. Beccy was positively glowing too and I went home a happy man.

That was six months ago. Since then my life has been transformed. I can relax, instead of mildly straining, on the train to work, I can write news stories without having to pause for a comfort – or in this case discomfort – break and I can visit friends and go to dinners, parties and social events feeling upbeat and cheerful. I even went on an eight-hour flight to Miami with no real problems recently.

Why did my catheter conversion take so long? There were two reasons. The first was ignorance. The nurse who first gave me the tube assumed I knew how to use it. However instead of pushing it seven or eight inches up my backside, I'd assumed it started about two inches from my so-called entry-point. So my weak thrusts were in vain.

The second reason was reluctance. No one exactly relishes endoscopes, surgical devices or thin plastic pipes being pushed up their backsides, however many times they might occur. But some are braver, or more determined, than others. I was one of the others.

However Mr Timid has been replaced by Mr Bold. I have used the catheter every day since June this year, visiting the loo two to four times – instead of nine to 10 times – in 24 hours. Each time I use four to six syringes of water (this depends on liquidity and some people may need less) to help ease the stools through. At first I used Lignocaine on the tip of the catheter. I now find wetting it works too.

Each visit takes 9-12 minutes which is only half-an-hour a day. Before I spent at least 90 minutes in the loo. I also find I don't need to go to the lavatory the normal way anymore. I go just after breakfast and immediately before bedtime and try to fit in at least one visit in between – although I found using a catheter at work tricky at first. My company's loos are grouped side-by-side with slim partitions between them. My solution was to use one that had been set slightly apart from the others on another floor in the building. Fortunately most offices have self-contained loos and you'll find those slightly longer visiting times are offset by only needing to go once during the working day (some may need two visits).

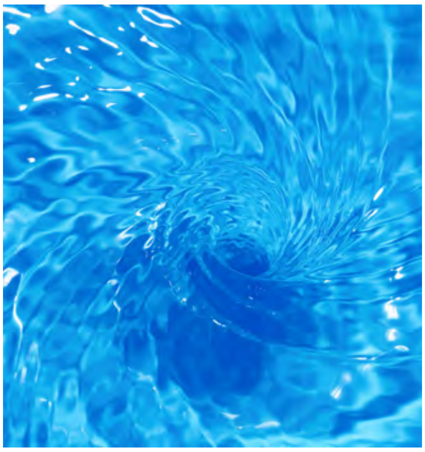
Six months later I am living a simpler, easier and more controlled life. In the day I am a buoyant, far more sociable and, I like to think, effective human-being. Just as Simon said I would be. I also sleep better as I don't have to get up in the night to go to the lavatory.

My advice is this: if you've ever had any qualms about using a catheter, persevere or make an appointment with your local pouch specialist and ask him or her to show you how it works. You may be reluctant at first but once you've succeeded, you'll never look back.

As for me, I'll always be grateful to Simon and Beccy for converting a once bashful patient into a Catheter Convert.

If you've any concerns or want to discuss using a catheter, please contact me on 07939 110842 or info@christopherbrowne.co.uk. I'll be happy to talk to you. Or for a more professional opinion speak to your hospital's stomacare department.

You can read all about Medina catheters in Simon McLaughlin's exclusive survey on page 5...



The Partner's Tale

Husbands, wives and partners are as important as pouchees during operations and post-patient care. You may remember Red Lion member Sally Jenkin's moving account of her two caesareans in the January *Roar!*. Here her husband Will tells how the other half copes.

A year ago my wife Sally wrote an article in *Roar!* about living with ulcerative colitis. She dealt with how it originally started, the various treatments she had (drugs, homeopathy, more drugs, some different drugs, an operation, a bag, drugs, a second operation .... and I think that was it); and the two caesareans that followed (I think by then she was getting a little bored with being opened up) and two wonderful children, Anna and Thomas. So when the editor of *Roar!* "wondered whether I might be interested in doing an article from the partner's point-of-view" I thought "why not".

But as I thought about this over the past month or so and pondered what I could write about, I realised I had to consider who I was writing for – 1) those of you who have suffered or are suffering from the illness and to help them understand the partner's angle and 2) for the partners of those with the illness so that they can draw on another's experiences. I have tried to direct the article at both.

There are three stages to living with UC – living with it as a disease, what happens between the two operations, and life after the operations. I first met Sally on a hockey tour in September 1993 and she developed UC shortly afterwards – but I don't think I was the cause! For the first six months or so, it was there but not invasively so – it was broadly controlled through drugs. However, she was hospitalised in the summer of 1994 as it got totally out of control; I had not realised how ill she was but then neither did her flatmate!

I am not a great one for medical details. Sally has a human biology degree and is now undertaking her PGCE to teach science at secondary level and so the inherent interest is there. However, I found myself caught up in it all and simply supporting where I could, as Sally went through the realisation of what she had and understanding the consequences of what this would mean to her and, possibly at this stage, us.

Her condition was initially contained through drugs though this didn't always stop the urge or actual need to "go" and she was always plotting the next loo stop whether we were shopping, travelling or doing whatever. For someone who likes to complete a certain activity (leave home when I want to, buy what I need and go home, get to wherever I'm going) as quickly as possible, this could have become frustrating for me. However, I was able to summon the necessary levels of patience to stop, wait, and then carry on time and time again. "How selfish" I hear you say; maybe, but I am who I am and I never left her behind!

Will and Sally Jenkin and their two young children, Anna and Thomas

In addition to this, the impact was a cycle of options: consideration of different drugs or a different approach (e.g. homeopathy and acupuncture), have an operation or not and so on; while most of these decisions were solely Sally's, some of them might have had a significant and possibly life-changing impact on me. Before we were married, I knew that a bag was a possibility – could I live with that (bearing in mind it could have been permanent), how would I feel about it, how would it affect our sex life, would it get in the way etc? For those of you who have read up on this, it was very much the usual questions but not something I had ever expected to have to answer myself ... but more on bags later.

Despite all of these considerations, I decided none were significant enough. We were married in May 1996 with Sally keeping things under control with steroids and Mesazaline and then honeymooned in Belize without too much upset or disruption. She supplemented the drugs with other things that helped reduce loo trips, rather necessary as we spent three days trekking inland.

Of course, of top priority was Sally's health but the impact was also on me. I clearly remember her meeting me at King's Cross Station in London having had her latest check-up at Charing Cross Hospital. She said that the pouch operation may remove her ability to have children as a result of scarring on her fallopian tubes. While a bit of a shock at the time, my view was quickly one of "So we'll be the wild uncle and aunt who turn up in the convertible sports car, treat all their nephews and nieces to mad days out, spoil them rotten and then drop them off, exhausted, back on their parents"; simply a case of seeing how we could make the most of a bad situation. As things turned out, this was one of the cards we were not dealt but having not had children at the time, I didn't know what I was missing; now I wouldn't swap it for the world – well, most of the time.

So then came the agreement to have the operation, or rather the first, and the imposition of a bag; the second, reversing it was expected but not planned for some months. The operation was successful and I did what any husband would do looking after a patient – fetching, carrying, getting cups of tea, taking up visitors and so on. The bag was, well, the bag; you get used to it and its contents though to be honest, I never got that close to the emptying process; sorry, just not me and on the basis it was temporary, there wasn't really a need. And it only ever came off once in bed, while we were asleep I hasten to add! Not the greatest of things to happen at the best of times but we were staying with the mother of one of our friends! A little bit embarrassing but we were all just very practical about it; after all, it's not really a lot different to cleaning up after a baby's nappies have leaked in their cot and I would like to think that my straightforward, practical approach to this sort of thing helps.

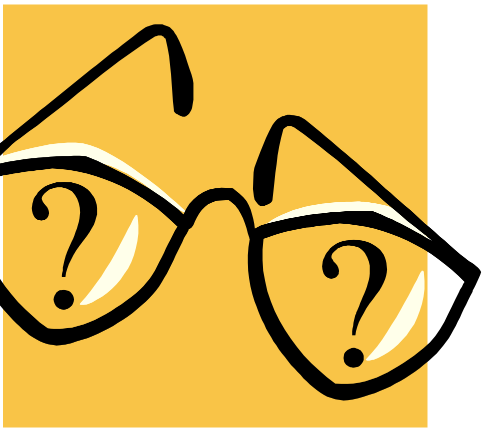
And then Sally had the second operation. I have no idea how the impact of a proctocolectomy affects people; is Sally abnormally stoic about it? Has she had minimal adverse effects? Am I supportive and flexible or is she merely tolerant of any inadequacies? Have we just been relatively lucky with the whole caboodle? One major autoimmune reaction left her with *erythema nodosum* inflammation of the fat cells just under the skin) and enormous blisters on her legs and she was unable to walk during one holiday and for a few weeks afterwards. Of course there was the concern over Sally's health and well-being but I did what I could to make it more bearable. Most of the time I know little about it other than when she wakes me in the night going to the loo. If she lets me know she is suffering from some aspect, I know it is affecting her more than normal.

So where does this leave us, or rather me and my interaction with my better half's situation? The need to be very supportive and understanding if things are not going well, e.g. if there is a flare up making life uncomfortable, go without saying; the need to be patient when we need to plan in a little bit more detail if we are going for a long walk in the glens of Scotland, miles from civilisation where public loos are somewhat non-existent; the need to ignore the times when "her bottom leaks"(!) in bed; get over it, she's the one living with it – there are a million other things that could be worse.

If circumstances change – she may yet need a bag but hopefully not for some years to come - we'll deal with it. She'll need an op in the next year or so to reduce scarring material which occasionally causes a blockage; having already deferred it so she can work it into her PGCE schedule, we'll plan it in – that's what we do. To be honest here, we have a very normal life; I am not aware of anything we do or don't do because of the fact Sally has an internal pouch. We are very lucky and count our blessings – long may it last.

The 2008 Brains Trust

The Brains Trust has been one of the highlights of the last two Information Days. It gives us a chance to ask questions about specialist – and sometimes very personal – concerns we couldn't normally discuss during our everyday lives. Although we had a panel of four last year, we thought it would be simpler to have a smaller group this time. So our panel of experts were St Mark's colorectal surgeon Sue Clark and Simon McLaughlin, a St Mark's research fellow until his recent appointment as gastroenterology specialist registrar at London's Guy's and St Thomas's Hospitals. Once again Red Lion secretary Margaret Dean took notes.



What is the advantage of having a pouch?

The main reason for having surgery is to eliminate ulcerative colitis and with FAP (an inherited condition with a high risk of cancer) the colon is removed to prevent the development of cancer, often in teenagers. To say "if you do not have this operation you will have bowel cancer" to a well person is devastating and being able to offer a pouch makes it more acceptable than the alternative, which is a permanent ileostomy. This is especially so for the young as body image is important and, for some people, a good lifestyle is paramount.

What are the problems associated with removal of the rectum and anus?

The rectum and anus are usually removed together as there is more of a problem if you just leave the anus. There can be a risk to bladder function when you take out the rectum. Pelvic nerves can also be a problem depending on how close they are to the cut as they can cause difficulties with erections and ejaculations.

My pouch is not working. I have been told that there is no infection but that I may have an obstruction and also IBS.

Having the colon removed is a big operation and can cause adhesions, membranes that are stuck together and kinking of the bowel. These obstructions usually settle down with rest and can often go away. There are of course some patients who may be particularly prone to adhesions and if they have inflammation too, particularly where the joining of the pouch causes a scar that can shrink, this can cause an obstruction. There is no easy answer for this but one may have to use a catheter so that the pouch can empty properly.

Can adhesions be seen better by an MRI scan?

Not really – a CT (Computerised Tomography) scan can be of better use. The CT scan cannot see adhesions but it can see the configuration of the bowel thus enabling the consultant or consultants to see where the problem is.

Is there anything you can do before surgery to reduce the amount of adhesions?

No. Adhesions are a huge problem. There are some people with genetic differences in enzymes which may be a contributory cause.

How many people in the UK and worldwide have had pouches? Is there any data on this?

There is no international data on this but St Marks have carried out about 1,800 operations

When I had my pouch I was really ill for a long time and one of my problems was salt deficiency. I was here in St Mark's and insisted on having my bloods tested because it felt like anaemia. It was then found that I was deficient in salt.

This does not happen very often. It happens when people are on steroids particularly in the early stages. We also need to check patients for magnesium deficiency. You will need to have your bloods checked every year once you are on an even keel.

What is the difference between pouchitis and having an infection?

Pouchitis is not really an infection *per se*. It is very like ulcerative colitis. However, there are bugs like clostridium that can mimic pouchitis, and we advise you to send off a stool sample to get it tested.

When a patient comes into hospital and says he or she has pouchitis should a stool test be made?

The chances of it being an infection rather than pouchitis is very small. A stool will be tested for bugs.

What is the outlook for long-term pouch function?

This is different for different people. It partly depends on what your bowel function was like before your operation and partly on the type of pouch you have.

We now have results going back 20 years. In most cases the pouch becomes stable over time – as does the frequency. There will be a slight increase in leakage. We have also been asked about pouch failure. The highest rate of failure is in the first year. This is also when we find patients whose pouches are never going to work. This may be due to pelvic sepsis. A lot of people lose their pouches in the first 10 years and about 15% within 20 years, however, the numbers do go up in time. These are people who have had problems for some time; they are not people who are doing well.

What in your opinion is normal pouch function?

Going to the toilet about five to six times a day and once or twice at night and also being able to hold on for over an hour. This is the kind of standard we are trying to achieve. There are of course some people who will go more than that and, conversely, those who will go less than six times a day. Sometimes there are pouch problems, pouch frequency, urgency, bleeding, abdominal pain, difficulty with defecation, symptoms of fistula, incontinence and seepage. The majority of people will have had at least one episode of these in their lives.

Is pouchitis just an inflammation and what are the symptoms?

Yes. You go to the toilet with urgency more than normal and also experience abdominal cramps. Bleeding is very common. Most people feel tired and washed out and have low energy levels. The biggest factor here is urgency. The consistency of the stools tends to go down and there could well be a change in the stool odour as well, which probably indicates a change in bacterial composition.

When I had my pouch 11 years ago I was told not to take any anti-inflammatory drugs as they could potentially cause pouchitis. Is this correct?

Yes that was very good advice.

Is it the ingredients of anti-inflammatory drugs that can cause problems?

Anti-inflammatory drugs, which are prescribed for colon problems and for people with joint inflammation, can make your stomach bleed or cause inflammation in part of the small bowel. Those taken for your joints are pretty harsh on your gut as well.

What is pre-pouch ileitis?

It is very similar to pouchitis. It only occurs in people who have had pouchitis. The pouch is inflamed and the segment outside the pouch is also inflamed.

I have quite severe pouchitis and an ulcer in the pouch. Will this clear up and will I continue to get pouchitis?

Many people that have pouch inflammation do not have the symptoms of pouchitis and could have the condition for many years. If you have symptoms you will need low doses of antibiotics. An ulcer in the pouch is not the real cause of pouchitis. Generally if you have a course of antibiotics the symptoms will go. It does not matter what the pouch looks like – it is more important to look at the symptoms. The small bowel was not made to take faeces and the delicate tissue was not designed to take them either and therefore there is a predisposition to inflammation.

The pouch is amazing at what it is doing. Think of the things we put down it, with vast amounts of bacteria passing through us and out again. There may be a connection between people who have a predisposition to good and bad bacteria; it may only need one thing to tip it over the edge.

Do pouches wear out? Why can't the rectum stay and why can't we wait and see whether the rectum becomes cancerous first?

Professor John Nicholls has been performing pouch operations for more than 30 years and there are many people who have had them for over 20 years. Those people who have had them excised will have had problems for a number of years. You could take out the rectum at a later date but you get a problem with it not taking up nutrients. It is not worth taking the cancer risk with the rectum. With age the rectum can get distorted and we are unable to see all the way up. It would, say, be less worrying to have it done early when the patient is fit rather than when he or she is old.

Please support the Red Lion Group

Registered Charity number 1068124

All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**

Contact the Red Lion Group

CHAIR
Michael Dean
9 Mornington Crescent
Hadleigh
Benfleet
Essex SS7 2HW
Tel: 01702 552500
chair@redliongroup.org

VICE-CHAIR AND NEWSLETTER EDITOR (CONTENT)
Christopher Browne
89 Fulwell Park Avenue
Twickenham TW2 5HG
Tel: 020 8894 1598
vice-chair@redliongroup.org

SECRETARY
Margaret Dean
Address, and home telephone number as for Chair.
secretary@redliongroup.org

NOTES SECRETARY
Christine Lawton
19 Nathans Road
North Wembley
Middlesex
HA0 3RY
Tel: 020 8904 7851
notessecretary@redliongroup.org

TREASURER
Marjorie Watts
11 Meadow Way
Upminster
Essex
RM14 3AA
Tel: 01708 445199
treasurer@redliongroup.org

LIAISON OFFICER
Inez Malek
33 Trevor Square
London
SW7 1DY
Tel (home): 020 7581 4107
liaison@redliongroup.org

CLINICAL NURSE SPECIALIST
Zarah Perry-Woodford
St Mark's Hospital
Northwick Park
Watford Road
Harrow HA1 3UJ
Tel (work): 020 8235 4126
pouch@redliongroup.org

NEWSLETTER EDITOR (LAYOUT)
Tim Rogers
30 Amberley Gardens
Epsom KT19 0NH
Tel: 020 8393 6968
newsletter@redliongroup.org

PRESS OFFICER
Stephanie Zinser
Tel: 01932 867474
Fax: 01932 867444
pr@redliongroup.org

EX-OFFICIO
John White
44 France Hill Drive
Camberley GU15 3QE
Tel: 01276 24886
john@redliongroup.com

Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW
Tel: 01622 739034
Fax: 020 7691 9527
morag@redliongroup.org

Lorraine Howell
125b Welldon Crescent
Harrow HA1 1QJ
Tel: 020 8723 4801
lorraine@redliongroup.org

PRESIDENT
Sue Clarke

PATRON
Claire Rayner

Join the Red Lion Group

- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

Visit Our Website

www.redliongroup.org

Write for *Roar!*

Ideas, Ideas, Ideas and More Ideas

Yes Tim Rogers and I thrive on them for it's ideas that make *Roar!* the readable package we like it to be.

Whether it's something that happened to you on the way to work, an interesting holiday or personal experience, an insight into your life with a pouch or a lively letter, please don't hesitate to send it in.

But then if writing articles isn't exactly your favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

That way we can keep your newsletter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

Christopher Browne
***Roar!* Content Editor**
89 Fulwell Park Avenue
Twickenham
Middlesex
TW2 5HG

or
cbrowne@brownemedia.co.uk