

ROAR!



ISSUE 40 • SUMMER 2009

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.



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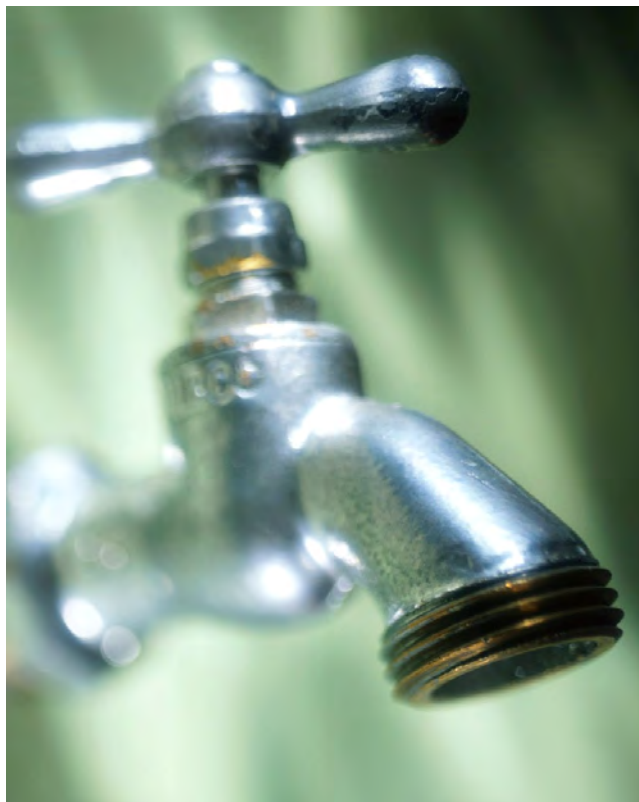
Harrow's got talent. It really has. As anyone who went to this year's Information Day at St Mark's Hospital would agree. More than 90 Red Lion members, partners, families and friends – from as far afield as Italy, Ireland and Scotland – heard three lively and thought-provoking talks with snatches of funky music, unexpected audience participation and feisty comments from the floor.

Then, in one of the more serious bits, Drs Simon McLaughlin and Parth Paskaran and pouch support specialist Zarah Perry-Woodford answered your questions on such topics as coping in a post-op crisis, whether pouches affect fertility, if uc is hereditary and why Europe has far more gut problems than any other continent. It got so intense that at one stage chairman Mike Dean and I were doing a St Mark's quick-step – or side-step might be more apt – as we juggled the two hand-mikes from one questioner to the next. The Q&A session was called The Brain's Trust, although we could have renamed it The Himsworth Hall Shuffle.

But the real cabaret was in the afternoon. First there was the raffle which raised an impressive £100. Then Ellie Bradshaw showed us what Biofeedback really means. I imagine quite a few of us have pondered this curious-sounding word from time to time. I certainly have and it only took a few pithy phrases from Ellie to reveal the truth. It means going to the loo elegantly. Backed by some modish music, Ellie got us all going like a colony

of performing seals. From pelvic floor exercises to the less strenuous “putting your feet on a box as you go” ones – Ellie and the Feet-Warmers could have kept us entertained for hours.

But if you want to see a red lion in his or her den, go to the annual workshops. All inhibitions are cast aside and the talk is raw (pardon the pun) as problems and experiences are aired and suddenly you realise you've got 15 to 20 new friends (at least I did). This year there was a choice of six: Problem pouches and diet led by Zarah Perry-Woodford; Medina catheterisation – a personal experience which I took; and Investigations into pouch dysfunction by Dr Simon McLaughlin (you can read a summary



of his talk on page 9). There were also open forums for female pouch-owners (Lorraine Howell), male pouch-owners (myself) and pouch partners (Mike Dean).

The day's only glitch was a building refurb in the canteen which meant many of us had to resort to pretty basic snacks or slot machine sandwiches for our lunch. Happily the day's general good humour and Ellie and the Feet-Warmers managed to sustain us for the rest of the afternoon.

Catheter corner

Well, well, well. Tim and I never expected the large number of emails, letters and phone calls we received after the Medina catheter and water bills articles in last December's Roar. Ten maybe; 15 possibly. But the 50 or 60 you actually sent was completely unexpected – and I am still getting up to five phone calls and emails a week from you. It just shows how we all react to articles that affect us personally.

I've had many a long dialogue and chat with members over the past six months. Though no one's actually referred to me as Catheter Chris – yet. Most people wanted to know how and when to use them, the best ways to carry and store them, how often you should use them, where to discard them and, crucially, how to get hold of these unique plastic tubes.

Like all other pouch aids and medications, you can get them on prescription from your GP (I recommend you see your hospital's clinical pouch specialist first and ask him or her to explain how catheters work and to give you a trial run – that's how I first picked it up). Its official title is Medina catheter, the serial number is M8730, you can get them on prescription from your GP, they come in packs of five and are made by the Swedish company Astra Tech.

I am delighted to say that at least 10 of you have already become catheter converts with such comments as “it has changed my life” and “my quality of life improved straightaway”. Another 10 to 20 members said they would be contacting their hospital's pouch or stomacare nurse to find out more.

A few of you said you didn't like the idea of pushing a plastic tube into your pouch – neither did I when I was first used one. I know it's a bit off-putting but so are some of the other tests and examinations we pouch-owners have to go through. So, unless you have a genuine problem with the catheter, I advise you to keep on trying. You won't regret it. One or two members also had problems with lubricating

the tip. As I told them, I find water, Vaseline and Lacrilube work best.

Talking of tubes and plastic pipes, the article about Emma Edwards's experiences with Thames Water Authority provoked almost as many emails and phone calls as the catheter one. I even had an email from Chris Betteridge, Thames Water's Customer Diversity Manager. He said he had spoken to at least two of you about your bills. He also sent Roar details of the company's extra care services (you can find out about these on the Letters pages).

Almost half of you wrote and asked whether you need to claim benefit to get a water discount. The answer

is "yes" as all seven of the water authorities – there are 24 in the UK and Ireland – you wrote about confirmed.

However one member who lives in a three-bedroom house in Plymouth is paying more than £1,000-a-year to South West Water, the highest-charging water authority in the UK apparently (see letter), while another Lion in Rainham, Kent, pays £200 to Southern Water, which is one of the UK's lowest-levying authorities. The sheer size of some of your water bills is an issue I aim to cover in another *Roar!*

Another topic I will cover is the Medina catheter. Using one has transformed my life and, by the sound of it, quite a number of yours too. So I

intend to start a section called the Catheter Converts Club for new and more experienced users to ask questions about anything they are not sure of or to get tips and advice (anonymously or otherwise) from other members. If we don't know the answer we'll ask a professional. Just email or write to me at cbrowne@brownemedia.co.uk or 89 Fulwell Park Avenue, Twickenham TW2 5HG.

We are giving a £20 Marks & Spencer voucher for the member who sends the best letter to the Winter *Roar!* Call it an early Christmas present from the editors. Meanwhile, catheter or no catheter, Tim and I wish you a very, very happy summer.

Chairman's annual report

At the start of this year, with the economic situation being reported so bleak, I was a bit concerned that our charity might experience a downturn in line with all the other charities. But I am pleased to say that we have managed to escape it and our Treasurer will give more details in her report.

I would like to take this opportunity to thank Chris Browne for his work in the production of the Roar magazine and in particular for his article on Medina catheters which drew

a large response from the membership. It is heartening to know that people actually read the magazine!

In the latter part of last year it was also good to see Zarah back from maternity leave and as always she is very supportive.

On a sadder note Margaret Dean will be standing down as Secretary and I would like to thank her for her hard work and support over the last six years. However, I am pleased to report that John White will be continuing on

the committee and we will, therefore, retain his invaluable knowledge of the Red Lion Group

For this Group to function it is essential we have a new Secretary and Chris Browne will cover this in the nominations section.

I would also like to take this opportunity to thank Dansac and Ostomart for their continued support of the Red Lion Group.

Mike Dean
Red Lion Group Chair



Jim was not happy that someone had redacted the loo paper

What is biofeedback?

A guide to pouch-emptying by Ellie Bradshaw, St Mark's clinical nurse specialist, at April's Information Day.



Biofeedback is a technique used to help patients and individuals with pouch evacuation problems, constipation and faecal incontinence. Put simply, it is an “alternative” way of going to the lavatory using unfamiliar muscles and bowel control, said Ellie Bradshaw.

Anyone who uses the alternative method needs to exercise their pelvic floor muscles and improve their anal sphincter control to ease evacuation whenever they go. Biofeedback also involves using mind over matter – or behavioural therapy, said Ellie.

Two other well-known aids to pouch evacuation and faecal/mucus constipation relief are Medina catheters and water irrigation, she said.

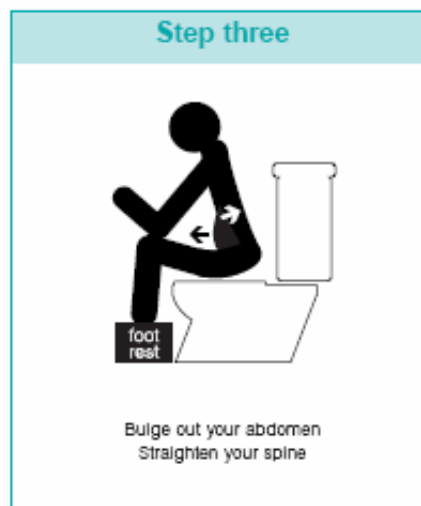
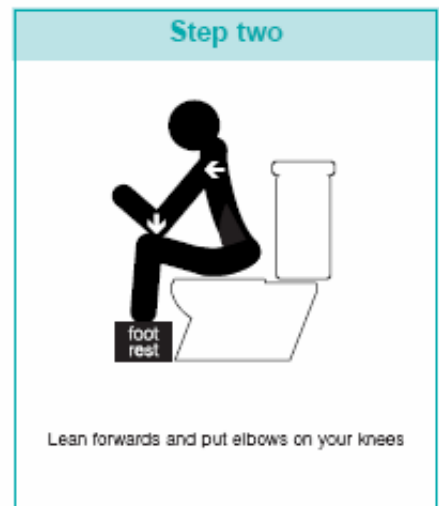
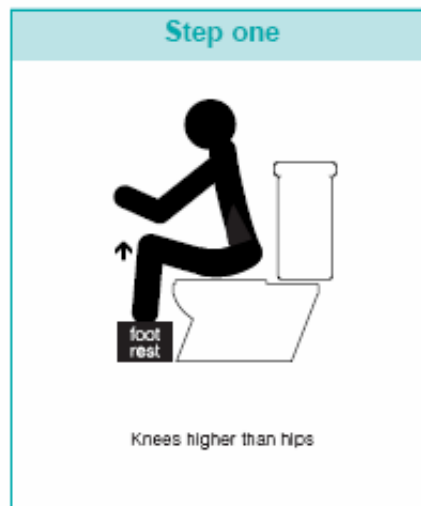
In 2007, the National Institute for Health and Clinical Excellence (NICE), the UK body that promotes good health, referred to biofeedback as “widely advocated as a first line non-invasive treatment”.

If you go to the lavatory the biofeedback way, you squat over the bowl – often using a low footstool – resting your elbows on your knees and keeping your back straight to make complete evacuation both “anatomically and gravitationally” easier, said Ellie.

Ellie advised patients who use biofeedback to follow a regular exercise regime. “If NICE has tentatively pointed the way towards the positive effect of biofeedback for IBS, as well as for constipation, evacuatory dysfunction and faecal incontinence (for which we have an 80 per cent improvement rate), it may well work for pouch patients,” she said.

Ellie ended her talk with a flourish, asking pouch-holders to join her in a musical demonstration of the key biofeedback exercises.

Correct position for opening your bowels



Reproduced by kind permission of Ray Addison, Nurse Consultant in Bladder and Bowel Disfunction, Wendy Noss, Colorectal Nurse Specialist.

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Taking the “ouch” out of the pouch

A summary of the latest research on pouchitis by Parth Paskaran, a St Mark’s research fellow, at Information Day.

Pouchitis is a type of inflammatory bowel disease (IBD) similar to UC or Crohn’s Disease, said Parth Paskaran. More technically it is “an inflammatory condition affecting the ileal reservoir in patients having undergone pouch surgery with endoscopic and histological findings accompanied by clinical symptoms of frequency, urgency and abdominal cramping,” he said.

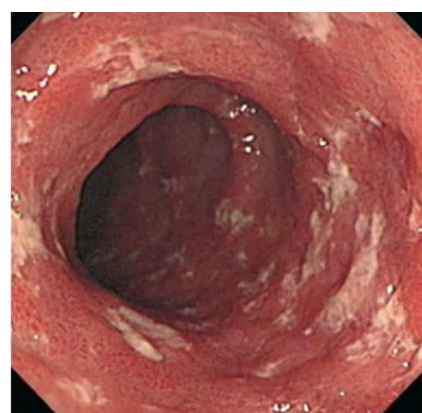
Parth said figures show the number of pouch-owners who suffer from post-op pouchitis varies from seven to 50 per cent.

He said a St Mark’s research team had been testing four groups of people with pouchitis – some had suffered ulcerative colitis (UC); others familial adenomatous polyposis (FAP) – to

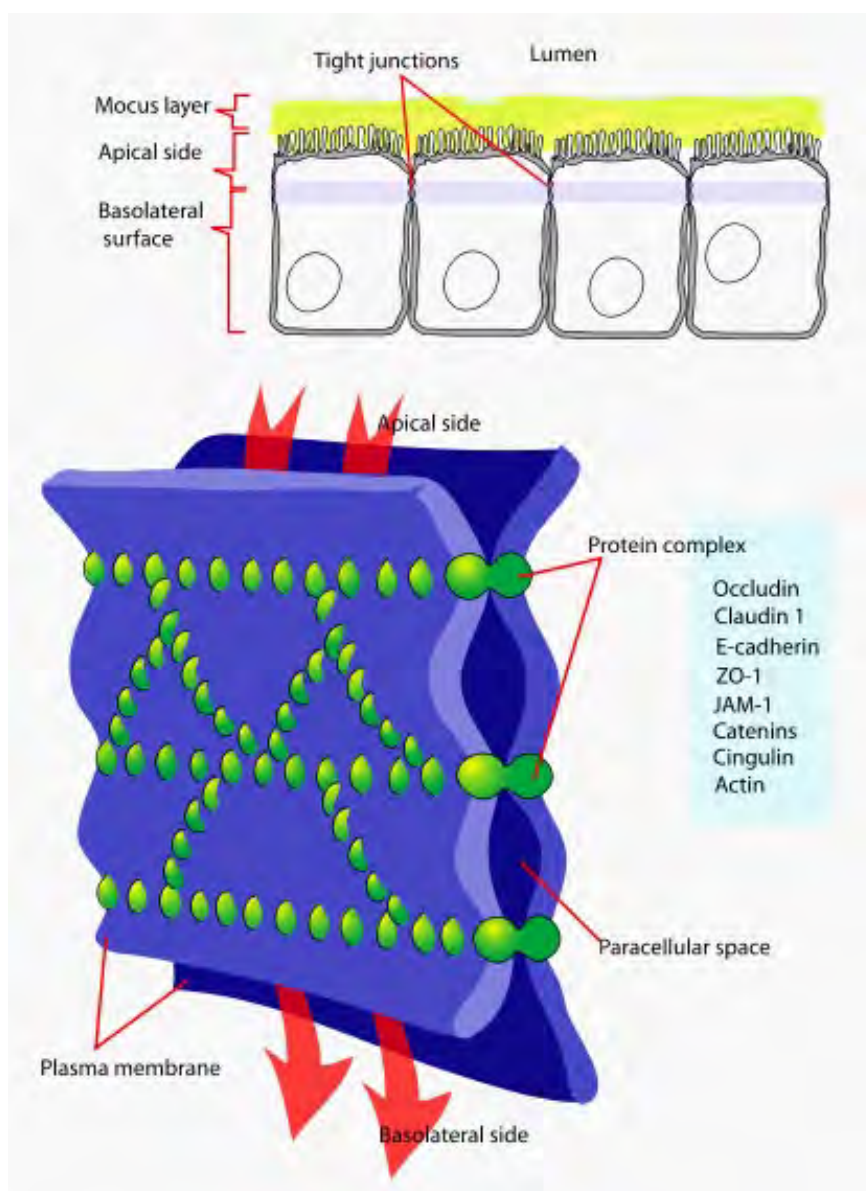
identify the bacteria they carried in their systems. After four weeks’ of antibiotics the groups were assessed to find out whether the drugs had affected their specific bacteria or reduced the total load, he said.

Explaining how the large and small colons work, he said everybody had spaces between cells – or tight junctions – which are filled with a complex framework of proteins regulating the passage of molecules in and out of the wall of the gut. The proteins were “modified and differentially expressed in inflammatory states”, he said.

He said researchers were currently comparing the way tight junction proteins work in pouchitis and non-pouchitis groups.



Above: This is what pouchitis looks like through an endoscope. Right: A diagram showing tight junctions



Investigation of pouch function

Roar! reports on an Information Day workshop led by Dr Simon McLaughlin, research fellow of Imperial College London.

Patients with normal pouches need to go to the lavatory four to eight times in 24 hours and should be able to “hold on” for more than an hour. Half need to evacuate in the night and a third take codeine or Imodium to help them control their pouch activity, said Simon McLaughlin.

If a patient’s pouch failed he or she would normally have an ileostomy, either removing the pouch or keeping it so it could be re-used at a later date. Approximately 10-15% of patients’ pouches failed in the first 20 years. The main causes were pelvic sepsis (50%), poor function (30%) and chronic pouchitis (10%), said Simon.

The symptoms of a poorly-functioning pouch were frequency, urgency, bleeding, abdominal pain, fever, low energy, defaecation difficulties, fistula symptoms and incontinence.

While inflammatory problems ranged from pouchitis, pre-pouch ileitis and cuffitis, non-inflammatory ones included strictures (small bowel adhesions), pouch-anastomotic leaks or pelvic sepsis, fistulas, irritable pouch syndrome and bacterial overgrowth among others.

The usual pouch investigation methods ranged from anal examinations to rigid pouchoscopies and blood tests. Consultants also used a flexible pouchoscopy to exclude or confirm whether a patient had a range of problems including pouchitis, cuffitis, neoplasia and Crohn’s disease, said Simon.

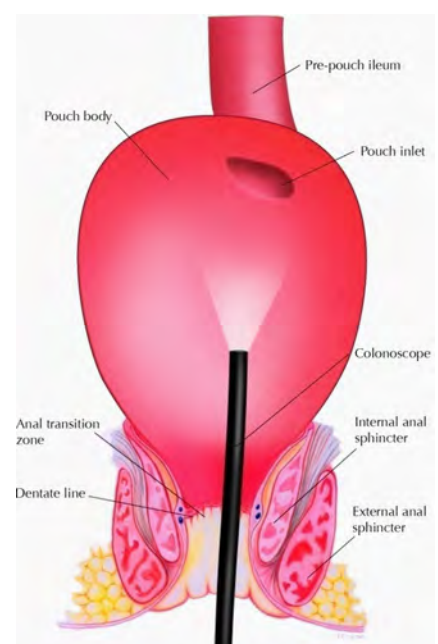
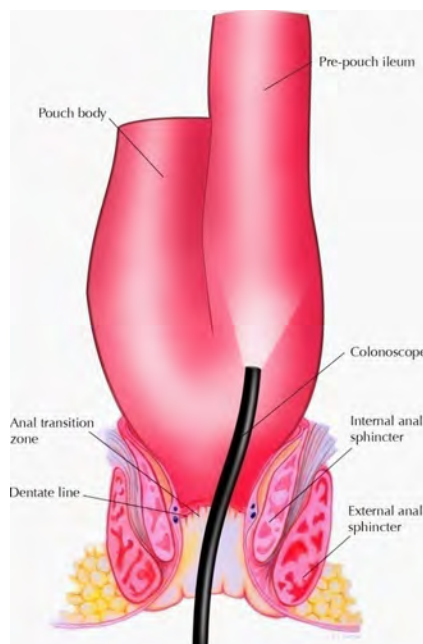
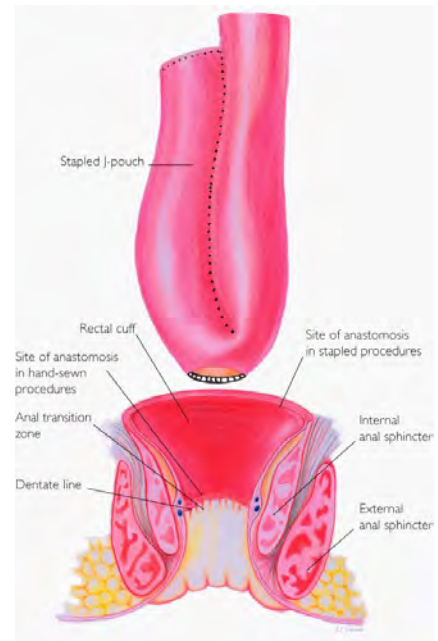
Research showed that pouchitis occurs in 20-50% of patients with UC and 2-5% of those with FAP and that it is the most common long-term pouch complication, he said. Patients with pouchitis tended to be treated with antibiotics.

Another problem that occurs in pouches is strictures. These tend to recur and one of the key treatments was endoscopic balloon dilatation. Simon said surgery was the main treatment for patients with pelvic sepsis, while

fistulas could be surgically drained or the patient could have a temporary loop ileostomy.

Patients who had long-term emptying problems could be treated with Medina catheters, biofeedback or revisional pouch surgery, he said.

A recent St Mark’s survey of 31 Medina catheter users (published in the December 2008 *Roar!*) revealed that they average four visits to the lavatory every 24 hours. Half reported dietary restrictions while almost 50% used a catheter every time they evacuated. The average length of usage was nine years, 71% of those surveyed said their quality of life had improved, and 26% said using a catheter had limited their social and work lives.



Right: A J pouch.
Far right: A W pouch.

Photos from Information Day



Pleased or relieved? A happy Ellie Bradshaw, St Mark's clinical nurse specialist, relaxes after her entertaining talk on biofeedback



Dr Parth Paskaran (left), research fellow at St Mark's, and Dr Simon McClaughlin, research fellow at St Thomas's Hospital, discuss a point during the Brain's Trust



Chairman Mike Dean welcomes Red Lion members at the start of Information Day



Pouch nurse specialist Zarah Perry-Woodford answers a member's question during the Brain's Trust

Happy anniversary

Red Lion member Irene Hardacre from Crosby, Merseyside, celebrates 20 life-changing years as a pouch owner.

It occurred to me recently that the 20th anniversary of my pouch surgery had passed unnoticed. This was largely as a result of living a “normal” almost trouble-free life as far as my pouch was concerned. Prior to that, my colitis had become so debilitating that any kind of normal home life had become almost impossible.

I was 23 when I first developed uc. I had a 10-month-old baby, and after hospitalisation and steroid treatment, my condition improved. I had periods of remission in between during which I had two more children.

However in my thirties, my condition returned with a vengeance and periods of remission became less and less. So I had to take stock. I had three young children, a husband in a busy full-time job, but had lost control of my life, my ability to make decisions, and carry out the day-to-day tasks I’d grown to know and love; colitis was now ruling my life.

I had been reduced to a six stone, exhausted young woman who had grown tired of feeling so ill. I had been admitted to our local hospital six times in a year, each time with an exacerbation of my condition. Enough was enough.

I’d heard of St Mark’s through my gastroenterologist and after some discussion and debate, an appointment was made for me to see Mr Hawley (now retired from St Mark’s) in London, resulting in an exhausting journey from Merseyside where we live. It was well worth it however and the decision to have surgery in the end, for me anyway, was easy; I simply could not continue the way I was. I’d had enough of steroids as they simply were not working any more. And with this new hope, I became optimistic and had faith in the skill and dedication of the surgeons and staff there who completed my operation in two stages; I was not to be disappointed.

I had inherited colitis from my father whom I was never to meet as he died just before I was born. In the 1950s there was little that could be done with the disease and he eventually succumbed to it.

I was determined it was not going to happen to me. I had built a little

family and was so happy and desperately wanted to see my children grow and flourish. And I have. My eldest son Stephen is now teaching in Vienna,



my middle son Peter works as a mentor and counsellor in a school and my daughter Corrina has blessed us with

two wonderful grandchildren, Eve and George.

Over the years I’ve had little problem with diet and I can more or less eat what I like. I love Indian food, fruit and a whole range of dairy products and have very rarely suffered any adverse reaction. I enjoy walking and cycling and on my 55th birthday, my husband, who is a keen Fell walker, “dragged” me up Skiddaw, over 3,000 feet of mountain in the Lake District. We also have regular foreign holidays and the flights and travel have been fine.

On only two occasions in 20 years have I needed advice regarding “pouchitis”. I found St Mark’s most helpful about treatment and I was very quickly sorted out.

I returned to my profession as a nurse in the hectic atmosphere of a busy teaching hospital within a year of my operation and still thrive on the challenges my work offers.

Having the pouch operation changed my life, not because it gave me something extra or something different or better; it quite simply gave back my ability to be “normal” again.

Secretary alert!

If you were asked to name the first person you meet at Information Day, the answer would invariably be Margaret Dean. For it is Margaret and husband-chairman Mike who run the reception desk, greet members and guests as they arrive and hand out welcome packs of the day’s events.

What most members don’t realise however is that Mike and Margaret also put the packs together and do most of the day’s organisation as well as acting as chairman and secretary of the group. Pretty impressive, eh!

Sadly one half of this unique double act is retiring. After six years as secretary, Margaret Dean announced her retirement at the April AGM. Irreplaceable. Hard act to follow. I know, but we still need a new secretary. The good news is Mike and

Margaret were a unique double-act and the new secretary will need to do less than half of Margaret’s workload. The role will involve liaising with the chairperson and drafting the agenda of three or four telephone conference meetings a year; sending out letters as and when required, taking the minutes of meetings including the AGM, and dealing with general correspondence and emails.

It might well suit a job-share between two friends, partners or a husband-and-wife team. If you’re interested or know someone who is we’d very much like to hear from you. Please contact Mike Dean on 01702 552500.

Meanwhile. Goodbye Margaret. We’ll miss your efficiency, eye-for-detail and good humour.

Letters

We've had such a bulging post-bag of emails, letters and phone calls in response to the catheter and water rate pieces in the Christmas Roar that we've decided to print a selection of your replies. But we'll start with a pair of letters on other topics first. So here goes...

A sore time with sesame seeds

Dear Roar!

I recently had a bone density scan and was told that I had osteopenia in my left hip, which if left unchecked could develop into osteoporosis within five years.



The radiologist who carried out the scan gave me a list of calcium enriched foods. Although I already eat quite healthily I decided to really try and up my calcium intake through food as well as with calcium tablets. One of the foods which are supposed to be very good are sesame seeds and almonds. My problem is that the sesame seeds reappear and also I have been getting very sore and a real scratchy feeling when I go to the toilet. I wonder if any readers could answer the following questions:

1. Is it worth adding sesame seeds to my food if they reappear, ie am I

likely to be absorbing any calcium from them?

2. Could it be the seeds and almonds that are causing the uncomfortable scratchy feeling?

I have not yet seen my GP about this so I thought I would turn to *Roar!* readers first. I would imagine there are others who have problems with osteopenia/osteoporosis as I understand taking steroids makes us more vulnerable to this disease.

May I take this opportunity to say how much I value the Red Lion magazine. It really helps to read about other people's experiences. Also I would like to pass on my thanks to the lady who took the trouble to reply to my letter about having a hysterectomy [Jane Humphries in the Summer 2008 *Roar!*].

Although I have decided at this stage not to have the operation, it is good to know of success stories in the event that it becomes essential for me to go ahead after all.

Kind regards

Sally Thelen

I take calcium tablets for osteopenia after the steroids I took before my pouch op. They certainly seem to be working!

Co-editor Christopher Browne

Prescription for success

Hi Christopher Browne

Success! I just filled in the medical exemption form [for pouch-holders], added a short covering letter (copy available to anyone on request – and this was a bit easier for me to word as I am a state registered nurse), saw my GP who supported it and, almost by return of post, got my exemption certificate.

It's happened 10 years after my pouch closure but, hey, better late than never!

Anyone can contact me who wants help with the covering letter to your GP. The help would involve the interpretation needed for "abnormal fistula".

I also meant to thank you again for the medina [catheter] article. I am now a happy convert and my quality of life improved straight away.

Best wishes

Helen Bradshaw

Congratulations on both counts
– Eds



Here are some of your responses to the catheter article...

An email from Red Lion member **Matthew Williams** was typical. Matthew said that after years of indecision about whether to use a Medina catheter or not, the "Catheter Conversion" piece convinced him to try it out.

He has been suffering from an emptying problem caused by cuffitis and a kink in his pouch, he said. But when he discussed using a catheter with several doctors, they told him it could only be used with an S-pouch – not the J or W versions.

He said he was also put off by the "great amount of confusion and mixed messages" about these transparent plastic tubes and "lack of bravery to try something that could potentially be uncomfortable".

Matthew has since asked for a trial at St Mark's Hospital (just as I did - CB).

Red Lion member **Philippa French** said that when she has spells of pouchitis she has to make hourly visits to the loo. She also has to adopt a skiing position and press down on her tummy and pouch when she goes to the loo to get any results.

Although Philippa said she once tried to use a catheter in hospital, it got stuck mid-pouch which frightened her enough to throw it away.

However she has decided to try using a catheter once again, she said.

Helen Bradshaw, who wrote the prescriptions letter above, also contacted us about catheters. Her first letter in December said: "It sounds like a Medina catheter may help me as no one has ever been able to find out why I have poor pouch function. There are phases of about two to six hours either

at night or in the day time when it gives me hell so I wonder whether it is the emptying problem you describe.

"Do you find disposal of the used catheters any sort of problem when you are out? [put it back in its plastic bag]. I will contact the local stoma care department."

A month later Helen wrote:

"I am now a happy convert and my quality of life improved straight away... I now even feel a bit more confident about public transport provided I plan a bit in advance on meal timing etc."

Another **Red Lion member** said she had difficulty extracting the catheter after use. Her solution was to lie on her side as it made her feel more relaxed and thus eased the whole process.

Some of you will remember when water was free and we all took baths, showers, unlimited drinks and plant-watering for granted. How times have changed! As water and sewerage charges soar up into the hundreds, we



might be forgiven for thinking water was a luxury not a daily necessity... Here are some of your experiences and emails.

Pouch-owner **Graham Livingston** and his wife who own a three-bedroom house in Plympton near Plymouth, Devon, paid a staggering £1,067 for their 2008-2009 water bill and have been told their charges are likely to be higher this year.

"Living in the South West we are at the mercy of South West Water and pay the highest charges in the

country... We did try a meter a few years back, but found the amount we were using was about the same as being un-metered, but with the added stress of not knowing what the next bill would be. So we switched back to un-metered," he said.

When Graham asked South West Water for a concession, the company said that as neither he nor his wife claim benefit they did not qualify. Although Graham is asking the authority for help once more, his efforts will prove fruitless I'm afraid as the companies can only legally help benefit claimants.

Any pouch-holder who claims benefits will be able to get a discount from all the water companies I've contacted with a doctor's letter and a concession form from the water company. Others can save with a meter. Take **Graham Ladkin**. Last year the Birmingham-based Red Lion paid Severn Trent Water Authority £379 for his water usage. This year Graham, who has recently had a pouch operation, asked the company to fit a meter at his council house. Which they did. And this year his bill is £246 – or £133 less than last year's which was £379.

"When I tried to get a meter fitted a few years ago, Birmingham City council's housing department said they didn't want meters in their council homes. Happily they have changed their minds and allowed council house tenants to use meters. Severn Trent have even giving me a rebate on some of last year's water bill," he told us.

But why can meters cut water bills?

Because they give precise readings of your annual usage. If you don't have one, your water charges are based on the rateable value of your house or flat – not the amount of water you use.

This means that if you have a relatively small home or live in an area of medium to high rateable values, it could save money to have a meter fitted.

Another satisfied **Red Lion** lives in the South East and pays his bills to Southern Water. After reading the Roar article, the pouch-holder who says he has a bath twice a day asked his water company to fit a meter. "The company told me that if it showed I exceeded the area's normal usage, it would put me on to a lower tariff because of my pouch," said the Red Lion member who prefers to remain anonymous.

So some water companies are willing to listen after all.

We also received an email from **Chris Betteridge**, **Thames Water's Customer Diversity Manager** after he had seen our story about Emma Edwards and her tussles with his company.

He wrote: "In the unlikely event that the water supply is interrupted we offer additional help and support for customers with medical problems." Customers can do this by joining a Special Assistance Register. Another Thames scheme called WaterSure caters for customers with metered water supplies. They must be on means-tested benefits, have a medical condition needing extra water or have three or more children aged under 19, he told us.

Betteridge who said he had spoken to two Red Lion members since the article asks anyone with problems or queries to contact him on 01793-476051 (Ext 62051) or 07747 645497 (Ext 45497).



Crossword

Contributed by Red Lion member Andrew Millis



The following cross-number puzzle was given to me recently by a secretary. I don't know where she got it from but it is obviously English and around 40 years old.

It is a marvellous problem. Solving it requires a well-balanced combination

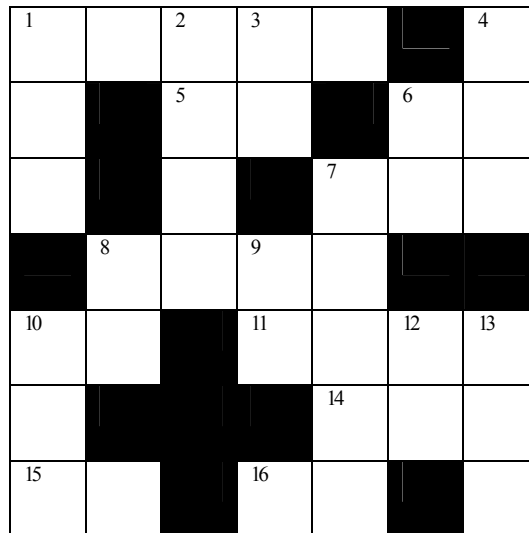
of logic, calculation and trial-and-error. The numbers are so interlocked that practically every one of them must be employed in reaching the final entry (2 down).

The puzzle concerns a farm that has been in the Dunk family for some

years. Apart of the farm is a rectangular piece of ground known as Dog's Mead.

Additional background information:

- the year is 1939
- 4,840 square yards = 1 acre
- 4 roods = one acre.



Across

- Area in square yards of Dog's Mead
- Age of Martha, Father Dunk's Aunt
- Difference in yards between length and breadth of Dog's Mead
- Number of roods in Dog's Mead times 8 down
- The year the Dunks acquired Dog's Mead
- Father Dunk's age
- Year of Mary's birth
- Perimeter in yards of Dog's Mead
- Cube of Father Dunk's walking speed in mph
- 15 across minus 9 down

Down

- Value in shillings per rood of Dog's Mead
- Square of the age of Father Dunk's mother-in-law
- Age of Mary, Father Dunk's other daughter
- Value in pounds of Dog's Mead
- Age of Ted, Father Dunk's son, who is twice the age of his sister Mary in 1945
- Square of the breadth of Dog's Mead
- Time in minutes it takes Father Dunk to walk $1\frac{1}{3}$ times round Dog's Mead
- The number which, multiplied by 10 across, gives 10 down
- See 9 down
- Addition of the digits of 10 down plus 1
- Number of years Dog's Mead has been in the Dunk family



Diet quiz for pouch patients

Are the following TRUE or FALSE?

1. Pouch patients need fatty foods for extra energy
2. Small meals are better than large meals
3. You must have five portions of fruit and vegetables a day
4. You need extra salt in hot weather or if your pouch function increases
5. Fibre increases frequency
6. Carbohydrates such as bread and pasta thicken your output
7. You should not drink plain water
8. A good pouch function depends totally on a good diet
9. A diet rich in iron may make you feel less tired especially if you have pouchitis
10. You need to take multi-vitamins with a pouch.



Longer answer questions

- What foods give you anal irritation?
- How much fluid should you drink daily?
- Name three things that you could do to prevent wind?
- Name two foods that can increase the odour of your stool?
- Mc Donalds or Burger King, which is better?



Answers

1. FALSE – Too much fat is not healthy for any diet and is not an energy supply
 2. TRUE – This will aid digestion and prevent wind accumulation
 3. TRUE – For general well being but cooked, peeled or tinned fruit or veg may be better
 4. TRUE – To prevent dehydration pouch patients need about a teaspoon of salt daily
 5. TRUE – Insoluble fibre bulks the stool making it move quicker in the gut
 6. TRUE – White rice and bread, pasta and potatoes thicken stool
 7. FALSE – Water is necessary for health however should be added to salty drinks if dehydrated – for example Dioralyte solution.
 8. FALSE – Pouch function can be affected by stress, general illness or infection, pregnancy or hormone changes as well as diet
 9. TRUE – Iron stores may be depleted in pouch patients if they do not eat enough iron rich foods such as cereals, green leafy veg or red meat. Pregnant or menstruating women may also have low levels. If you have pouchitis this can cause further blood loss.
 10. FALSE – All your nutrition should be absorbed in the small bowel above your pouch with the exception of vitamin B12 therefore you do not need multivitamins unless required by your GP. You can take vitamin B12 supplement if needed but must see your GP for a blood test first.
- **Anal irritation** is caused by spicy foods, raw fruit and veg, red wine, coconut and fibrous foods.
 - **You should aim to drink** 1.5-2 litres of fluid a day or 8-10 cups.
 - **To avoid wind** don't eat and drink, don't talk and eat, chew with mouth closed, avoid drinking through straw, smoking or chewing gum, sit up at table for meals, eat regularly, avoid foods that cause wind such as leafy green veg or onions.
 - **Foods that increase odour** are spicy food, onions, fish, eggs and garlic.
 - **Neither! Fast food is not generally healthy** but you can go for the healthier options they serve.



Treasurer's report

I would like to thank Brian Withers for auditing the accounts again this year, it is very much appreciated. I also thank John White, the previous Treasurer, for his help and time when I have any questions. Sorry John you are not too well and unable to be here with us today. I hope you will be feeling better soon.

Income

Subscription income is £155 less this year, caused by an increase in the number of retired members and a small reduction in membership which was 285 compared with 291 at the end of 2007. Thank you to the 168 members who pay by standing order, this is very helpful.

Donations as a whole have reduced this year but we are most grateful for the members and a company who have been able to help in this difficult year and support the work of the Red Lion Group. Sale of Red Lion merchandise including books more than doubled from the previous year. Please everyone remember to visit the table today to browse and donate – there are some useful items to be had!

Income from interest has reduced due to the smaller balance in 2008 and the start of falling interest rates. The Gift Aid amount is also down back to our more normal amount, but I would like to encourage you to complete a Gift Aid form, if you have not already done so, if you are a UK taxpayer. This will assist the Red Lion Group and does not cost you anything.

AGM registration and raffle income in 2008 was slightly down on the previous year.

Expenditure

The cost of the AGM and telephone meetings shows a reduction for 2008 as fewer committee meetings were held.

The increased figure for the printing and postage of Roar reflects the cost of three magazines produced in 2008, compared to one magazine the previous year. The magazines were produced in February, July and December and the July edition was larger than normal.

Postage and stationery shows a reduction as membership renewal and AGM Information Day details were

sent out with the magazines.

The website revitalised by committee member Tim Rogers was without cost this year, but it is of great value. Please see for yourselves and visit www.redliongroup.org.

The excess of income over expenditure for 2008 is £1,389 and your committee decided to donate £2,000 this year to St Mark's Foundation for use in pouch research.

The year's deficit of £610 after donation payments, together with the balance brought forward at the start of 2008, results in a final balance of £8,528 for the Red Lion Group.

Marjorie Watts



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**

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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

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 news-

letter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

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