

ROAR!

ISSUE 53 • SUMMER 2017

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 David Skinner on 01708 455194 or by email at liaison@redliongroup.org.

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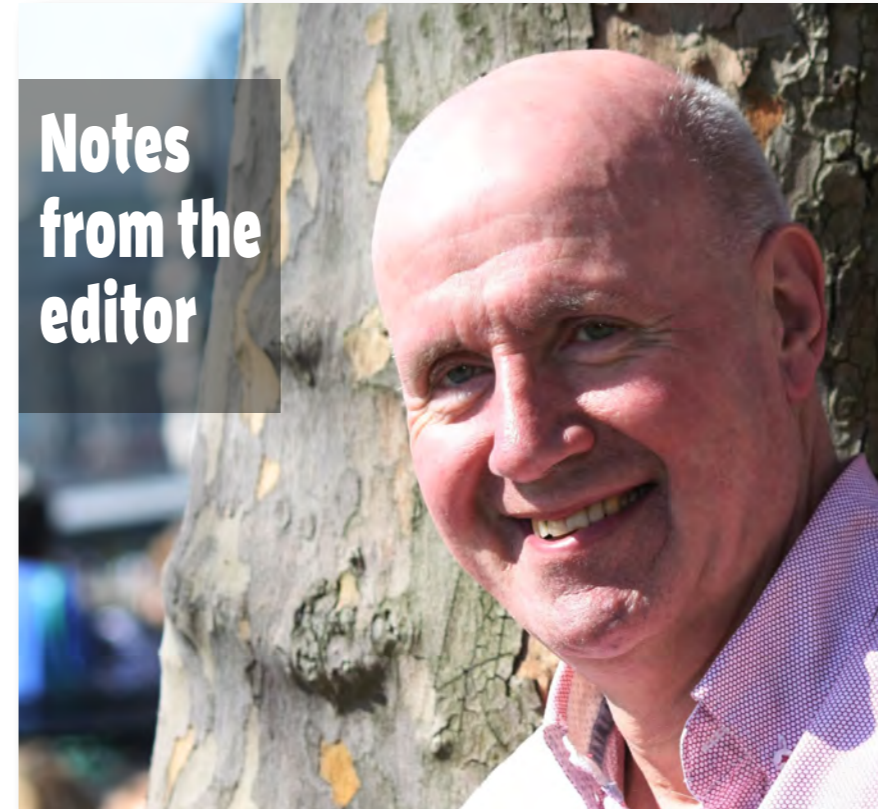
Please support the Red Lion Group

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, Paul Mulot, 103 Whitehill Road, Hitchin, SG4 9HT.**

Notes from the editor



How big a role does psychology play in problems of the gut. "A considerable one" would be my untrained and unscientific view. Which is why I found the Information Day talk on the gut-psychological link by Dr Yoram Inspector, consultant psychiatrist at St Mark's Hospital, particularly fascinating.

I liked Dr Inspector's gentle and relaxed approach to his gastroenterological role. A typical example of his humour was a saying he had heard during his early medical training: "A medical doctor knows everything and does nothing; a surgeon does everything and knows nothing; and a psychiatrist knows nothing and does nothing!"

On a more serious note he explained: "We [psychiatrists] are strange creatures. We are partly shamans, partly mysterious because we deal with the psyche and we do not have knives or a lot of medicines to help [us]." He said the psychiatrist's role at St Mark's was holistic - "we treat the person; not the disease." A view that I found both honest and very refreshing.

Like bowel issues, talking about the mind is often a taboo subject. Yet as many of us would freely admit, stress, personal problems, fears and anxieties have sometimes played a

significant role in our condition. We wouldn't be human if they didn't, yet we sometimes find it hard to admit the ways our minds affect us.

And what about the Day's other talks? If pouch owners were asked to name their top five subjects of interest they would invariably choose the

"We psychiatrists are strange creatures. We are partly shamans, partly mysterious"

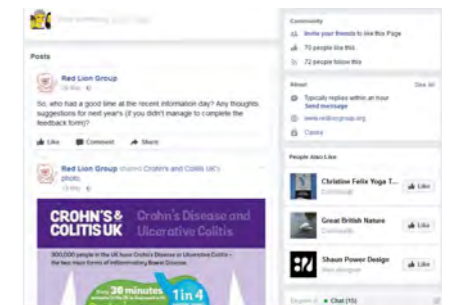
ones we heard about at Information Day - all expertly chosen and coordinated by committee member and St Mark's clinical nurse specialist Lisa Allison. St Mark's research fellow Pramodh Chandrasinghe gave us interesting insights into laparoscopic pouch surgery; St Mark's dietician Evi Kiriakidou spoke about diet and pouches (see page 12 of this issue); Ms Uchu Meade, lead pharmacist at St Mark's, talked about drugs and pouches (see page 9); Guy Worley, a

St Mark's surgical research fellow, gave us an update on the latest pouch research (his appeal for volunteers for a study on good working pouches [of which there are many!] appears on page 11); and Lisa Allison's advice on post-op follow-up for those with pouches (see page 9).

Then there were our own contributions with some typically lively and feisty male, female and family-based workshops that provided a fitting climax to the day (you can read about one key issue, skincare, on page 7).

Finally, please join me in thanking David Davies who passed his initiation as chairman of his first Information Day with flying colours and wish our treasurer Paul Mulot a prompt and full recovery from a long spell of illness.

Enjoy the rest of the summer!



Find us on Facebook

www.facebook.com/theredliongroup/

Visit our website

redliongroup.org

Browse nearly every copy of Roar! that has ever been published (including issue 1 from 1994) at

redliongroup.org/roar

For online support and advice from other members or to share your views about any aspect of life with a pouch, please visit our online discussion forum at:

redliongroup.org/talk

David Davies's 2017 chair's report



RLG exists as a forum for sharing information – indeed three of the five goals enshrined in our Constitution are:

- “To give help and advice to anyone who has an internal pouch or...is considering having an internal pouch”
- “To keep internal pouch patients informed of all relevant matters of interest to them by way of a newsletter” (aka “Roar!”)
- “To give help and advice to anyone who is a friend, a relative, or has an interest in the welfare of people who have, or are considering having, an internal pouch”

There are two main ways in which the committee deliver against these goals on your behalf. The first is through the publication of *Roar!* at least twice a year and the second is through Information Day, when members and potential members are welcomed by the committee to St Mark's Hospital, Harrow to hear talks on various topics that are

highly pertinent to pouchees and potential pouchees. They also have the chance to meet with other pouchees within this small and friendly community, to learn about tips to manage our condition and hopefully to be uplifted by the fact that you are special and not alone.

This year's Information Day was held on 13 May and was a rip-roaring success! We had a total of 55 attendees compared to 42 the previous year – an increase of 24 per cent – and some fantastic talks on topics as diverse as the psychology of coping with a pouch, dietary considerations, long-term health screening for pouchees, the latest research topics into pouches, the latest surgical techniques and drugs that are useful for pouch patients.

But the proof of the pudding is the feedback we get from attendees ...and the feedback this year was exceptionally good. There were 32 people who handed in their forms and the scores were very high with an average of more than 4.5 out of

5 (5 being “excellent”) across all of the presentations. Delegates felt strongly that they learnt something new and were very glad they came (both questions came out with average scores of 4.8 out of 5). In addition, there were some individual quotes that were most gratifying:

- “Absolutely great to talk to other people with pouches”
- “The whole day was most insightful and the RLG volunteers were so friendly and welcoming. I feel foolish for being nervous attending. Many thanks for all who organised this”
- “Excellent day”
- “Great day – well done! Xxx”
- “Useful, down to earth information”
- “Excellent presentations”
- “All aspects – very well covered”
- “Whole day was very informative”
- “Workshop – great to chat with those with pouch experience”
- “Very useful day to help make decision to have pouch surgery”

- “All very informative”

All in all, I think we well and truly fulfilled our remit to inform our members. I'd like to thank the committee for their dedication and hard work in organising the day, especially Lisa Allison who persuaded the excellent speakers to come to talk to the RLG members. In addition, I'd like to thank Susan Burrows for all her work in organising the refreshments and the lunch, Paul Mulot for arranging free parking within

the best health outcomes in patients having pouch operations were obtained by experienced surgeons in hospitals where many such operations had been performed

the hospital for members attending the event and the workshop leaders Lisa, Chris and new participant Jill White, who did such a great job in facilitating the discussions. I hope we'll be welcoming 70 attendees next year so please encourage other members to come along and join the party!

One of the speakers was Guy Worley, a research fellow at St Mark's. He is conducting a clinical trial and looking to recruit volunteers to participate in the study. The details are provided on page 11 and I urge you to consider volunteering so Guy can complete his work.

Guy presented some excellent data to show that the best health outcomes in patients having pouch operations were obtained by experienced surgeons in hospitals where many such operations had been performed. The message was clear to anyone with recalcitrant

pouch problems or indeed people considering the pouch operation at some time in the future and who were being seen in a hospital with very little experience of conducting pouch surgery. I would urge you to get referred to a centre of excellence such as St Mark's or the John Radcliffe Hospital in Oxford if you want the best chances of a good outcome.

There have been approximately 5,000 pouch operations conducted in the UK in the last 30 or so years (though no one knows the exact number). RLG membership stands at only 306, so there are an awful lot of pouchees out there who are not members or who might not have heard of the Red Lion Group, let alone had the chance to benefit from interactions with other members and understanding more about their condition.

Some pouch patients have their operations and sail off into the sun, lost to follow-up and happy to crack on with their lives. But I'm sure many others do not know of our existence and might benefit from the forum that RLG provides. With this in mind the committee set out to contact a total of 28 new centres in the UK that we know are conducting pouch operations. Our goal was to raise awareness among patients and healthcare workers who might welcome the opportunity of joining RLG.

As a result, we received warm expressions of interest and a further six clinical members signed up since we contacted these new centres. Looking to the future I'd like us to understand where these pouch patients are and how we might make them aware of RLG's existence. I'd like to think there are many people out there like us who would welcome the chance to come along to the Information Days in the future and share the warmth and the knowledge of being with other pouchees and exchanging common experiences.

I wish you a happy summer, wherever your holidays take you. I have just taken up sailing with my partner Bev and can safely say the pouch is the very least of my problems. Learning to tie a sheet bend or a bowline hitch knot is another degree of pain (as any sailors out there might be able to confirm).

LETTER TO THE EDITOR

Dear Editor

As far as I can tell, it is not uncommon for pouchees to have difficulty sleeping through the night, and understandably we normally look at resolving issues directly related to the pouch – such as what we eat in the evening and ensuring the pouch is completely empty before we go to bed. So I noted with interest Dr Michael Mosley's BBC1 documentary, “The Truth about Sleep”, which looked at sleep generally and some of the reasons for insomnia.

Well-known issues and solutions involve avoiding blue light, caffeine and alcohol before going to bed, doing exercise (but not before bed) and sticking to a routine. In this programme Dr Mosley, a chronic insomniac, looked at some less investigated, but possible, solutions such as:

- (1) Mindfulness;
- (2) having a hot bath/shower an hour before bed and then cooling down before going to bed;
- (3) eating two Kiwi fruit an hour before bed, and



- (4) taking dietary prebiotics before bed.

The prebiotics are a fibre supplement which the American University of Colorado Boulder have tested and found effective with rats. The prebiotics are food for the gut's good bacteria which breaks down fibre to produce short-chain fatty acids (such as acetate, butyrate and propionate acid). These apparently help synthesise vitamins and have other benefits for the gut and brain.

As these short-chain fatty acids are normally produced when dietary fibre is fermented in the colon, it would be interesting to know if it works for pouchees.

<http://www.bbc.co.uk/programmes/b08q8p13>

Yours

Peter White

RLG committee member

RLG committee member celebrates 30th anniversary of his near problem-free pouch



Gary Bronziet teeing up at the famous Pebble Beach golf course

Red Lion Group committee member Gary Bronziet this year celebrates the 30th anniversary of his pouch. Gary's pouch surgery was performed by Professor John Nicholls at the original St Mark's Hospital in City Road, London E1 in 1987 when he was 32. For the record, it is a hand-sewn W pouch and, says Gary, has "performed remarkably well".

Gary's pouch has clocked up a vast number of air miles over the years. Fortunately, Gary's travels have also taken him to some of the greatest and most famous golf courses in the world. The picture shows him playing at Pebble Beach in Monterey, California, which has hosted five US Opens and the 1977 PGA Championship.

Gary says he cannot blame his pouch for his standard of golf. However, he says it means he really gets his money's worth when he is playing on top-notch courses.

"I am looking forward to the next 30 years," he says.

Gorgeous Georgina

Congratulations to our intrepid secretary, Sarah Bowes-Phipps, who continues to defy orthodox medical thinking with the birth of her third child in March this year.

Sarah's daughter, Georgina, was not only the third of a trio born after pouch surgery but also follows her struggles with post-op pouch problems and fertility including several courses of IVF treatment. (Sarah will write an article about her IVF experiences in the December 2017 issue of *Roar!*).

For the record: Georgina weighed a very bonny 8lbs 4ozs and has two brothers, Albert, aged 4, and two-year-old Lawrence.



The ROAR! guide to the top ten barrier creams

Anal soreness and irritation are two of the most unpleasant after-effects of a pouch op. So here is our user-friendly guide to the top 10 products to help you banish those bedtime blues!

How many of you have suffered from soreness, irritation and rashes? Quite a few I should think from the number of times these daily discomforts are mentioned at the Information Day workshops. They can affect both men and women. But what products can we use to help clear them up and where can we buy them?

Here is our top ten guide to the most highly-rated creams and lotions based on your own experiences and some authentic medical evidence.

We'll start with **Calmoseptine** ointment which Red Lion member Tracey Sheldon says she depends on and refers to as "a bit like a very thick calamine lotion and a product that I have found both very gentle and effective". Log on to its US-based website www.calmoseptine-ointment.com or buy it from your local Costco or www.amazon.co.uk.

Adds Tracey: "The other cream I use when my skin is at its most sore is **Ilex Skin Protectant**. It really does the job in terms of protection... It's very gluey and can stick your bottom together a bit but the instructions suggest you use a top layer of Vaseline to avoid this and it really does the trick!" Order it from www.illexhealthproducts.com.

One of the most highly recommended creams at the female workshop at this year's Information Day was **Sudocrem**, a nappy rash treatment (www.sudocrem.co.uk) which you can buy over the counter at most supermarkets and chemists. Equally effective, Red Lion members agree, is the award-winning Cation barrier cream. You can buy this product on prescription as a pump spray or cream – though the latter is easier to apply apparently. To find out more, go to www.solutions.3m.co.uk.

The brand name Clinell covers a group of hand and skin care products which their manufacturer Gama Healthcare describes as "antimicrobial disinfectants". The **Clinell** spray or wipes are used for anal soreness and rashes and can be ordered from www.clinell.com. While **Vaseline**, which many of us use as back-up to other products or as a regular ointment can be bought over the counter at all main UK chemists. **Hydromol** is another ointment that is recommended by several of you. It helps treat dry skin and eczema-related conditions and can be bought on prescription or ordered from www.hydromol.co.uk.



St Mark's Hospital recommends sufferers try small doses of **Metanium**. This ointment is usually used to treat nappy rash but can be used by adults as well. It is sold by all the main UK chemists.

An oft-mentioned lubricating gel for catheter users – both male and female – which eases catheter insertion and helps guard against infection is **Instillagel** or lidocaine. The gel is recommended by St Mark's Hospital and sold at high-street branches of Lloyds Pharmacy or www.lloydspharmacy.com. To find out more speak to your hospital pouch care nurse.

Paula Rowlands, who plans to have a pouch this year (she currently has an ileostomy) and came to the 2017 Information Day, uses **Aloe**

Vera gel to help with skin irritation. She also drinks liquid aloe vera – a natural tropical plant – which she says acts as an anti-inflammatory and digestive aid. She uses the Forever Living brand, which is said to be the purest source of the gel, and you can buy it from her website www.aloepaula.myforever.biz.

Red Lion membership secretary, Susan Burrows, says: "At the Information Day workshops most people agree that certain drinks and food can increase anal irritation and there is some consensus that the condition does improve as the skin in that area adapts. Everyone – both male

and female – finds using creams and lotions an excellent way to relieve irritation – and if you are lucky enough to have a bidet that can really help application too."

A leaflet on skin care from St Mark's Hospital advises: "If you are leaking pouch contents onto your skin, there is a possibility that you will become sore. This is more so than with ordinary stool as pouch contents contain digestive enzymes and can

be quite corrosive. The best way to prevent soreness is by cleaning as soon as you can, and meticulous attention to removing all trace of stool.

"There are also many different creams that can help with sore skin, or used as a barrier. The success of different creams seems to be very individual – it is worth experimenting to find the best one for your skin. It may be worth contacting your GP or stoma nurse for advice on available products."

So, dear readers, if you know of any other creams, ointments, lotions or sprays that are recommended by healthcare professionals and have worked for you, please contact Susan Burrows on membership@redliongroup.org.

CHRISTOPHER BROWNE

Have you heard the one about the squatty potty?

And talking of stools, there is an unusual type of stool that you might not have heard about! It's called the 'squatty potty' and helps you go to the loo.

You prop your feet on this neat little product to make you squat while you are sitting on the toilet bowl and by doing so makes it easier to pass the other sort of stool! I've tried it and it certainly worked for me!

You can buy this sturdy little prop for £20.87 from www.bed-bathandbeyond.com. There's also a folding one for work, visiting friends or going on trips which is a little more expensive.




And what about a designer bag?

The Red Lion Group's eagle-eyed secretary Sarah Bowes-Phipps spotted a real fashion item on Facebook the other day. It's a bespoke stoma bag cover (see picture right) and you can buy one for £4 which includes a £1.50 donation to the famous children's hospital, Great Ormond Street Hospital (GOSH).

"A bespoke cover could have made all the difference to me emotionally when I was struggling with having a stoma bag. I think Facebook may get inundated with orders!"

You can buy them from @MiniBo Kidswear on Facebook (see right).





 **MiniBo Kidswear**
Wednesday at 14:55 · 🌐

💕💙 I made this stoma bag cover for a lovely little boy, please could I ask you to share, more than happy to make these for other children or even adults who need them

These are £4 each and £1.50 of each one ordered will be going towards Great Ormond Street children's hospital



 Write a comment...  Post

INFORMATION DAY 2017

How soon after your operation do you need to be seen by a pouchcare nurse?

If you've recently - or not-so-recently - had pouch surgery, St Mark's clinical nurse specialist Lisa Allison gave us a step-by-step guide on Information Day to that vital post-operative follow-up period

Pouch patients are reviewed by pouchcare nurses at St Mark's Hospital six weeks, three months, six months and 12 months after their final stoma closure. Sometimes they need to be reviewed by their surgical teams as well but usually their post-op care is nurse-led, Lisa told her audience at the May 13 Information Day.

While pouch patients are encouraged to go to the clinic after six weeks and a year, the other key reviews can be carried out by phone. "We look at diet, lifestyle and routine and discuss any concerns that may arise. If the patient is in clinic we may do a digital examination of the pouch anal anastomosis [pouch operation]. The pouch nurses act as a point of contact between clinic appointments," said Lisa.

If the pouch patient is well, routine blood tests are carried out annually. These include full blood count, urea and electrolytes, liver function tests, calcium, vitamin D, vitamin B12, folate and ferritin.

"If any of the bloods are below the normal range they may need correcting with supplements and medication. This should be arranged by the patient's GP. Liquid iron is

tolerated better by patients with pouches than iron tablets and if no supplements are tolerated then an iron infusion will be required. These can be requested by the GP to be given at the local hospital or, if the patient is under the care of a gastroenterologist, it will be organised at the hospital. Vitamin B12 needs to be given as an intra muscular injection every three months," said Lisa.

If there are signs of cancer or dysplasia when the colon is removed, patients will require annual pouchoscopies [examinations of the pouch using an endoscopy] and will never be discharged from hospital. Biopsies will be taken from different areas in the pouch and from the cuff [post-operative remains of the rectum]. The results take 14 days and can be obtained from the pouch nurse by phone or by attending the hospital clinic.

Pouch patients who have the liver condition Primary Sclerosing Cholangitis (PSC) or else chronic pouchitis are reviewed by pouchcare nurses annually.

Normal pouch function is four to six times in 24 hours but varies significantly from individual to individual depending on your eating and

drinking habits, lifestyle, routine and stress levels etc. "If people are experiencing increased frequency for a few days, urgency which is not normal for them, loose stool that require additional or increased doses of Loperamide, bleeding that does not cease, abdominal cramping, incontinence and leaking, ineffective emptying, anal pain, fever or nights sweats, then they need to seek advice," said Lisa.

Among the potential complications pouch patients may face are narrowing of the pouch anal anastomosis, pouchitis (as mentioned above), cuffitis and pouch dysfunction.

Initial examinations for these conditions include abdominal examination, digital examination of the pouch anal anastomosis, a rigid pouchoscopy, blood tests, a pouchogram or a defecating pouchogram, an MRI scan, a stool specimen for pouchitis screening, a CT enterography [imaging test] when patients have obstructive symptoms, anorectal physiology and a SeHCAT scan to check if there is bile salt malabsorption," said Lisa.

The whys and wherefores of tablets and medication

Codeine Phosphate or Loperamide? Metronidazole or Ciprofloxacin? Which drugs work best for pouch patients. St Mark's lead pharmacist Ms Uchu Meade explains

Many of us will need medication to help thicken the output of our pouches, Uchu told her audience of Red Lion members, relatives and hospital professionals at the 13 May 2017 Information Day.

The two recommended drugs are Loperamide and Codeine Phosphate. These cause the bowel to slow down and allow you more time for absorption of water and any nutrients you may have taken, said Uchu.

The first-line treatment for bowel control is Loperamide. This can be taken up to four times a day and in doses of up to 16mg in total strength. "Loperamide is more favourable than Codeine as, even though acting on the same receptors, the drug does not cross the blood brain barrier so there are not the side effects of the central nervous system [as in Codeine] such as drowsiness and sedation.

"Loperamide is a more gut-specific drug," advised Uchu. It can be taken in capsule or liquid form and there have been recent studies into taking them as melts.

Codeine can be taken in strengths of 60mg-a-time up to four times a day. You can also mix it with Loperamide to meet your individual needs. Codeine can also be used for pain relief and, when combined with Paracetamol, is known as Co-Codamol.



However you need a prescription to take Codeine, said Uchu.

Both drugs should be taken 30 minutes to an hour before meals to allow time for them to work before eating.

Ways to treat pouchitis

Pouchitis is one of the most unpleasant conditions suffered by pouch holders. The two preferred – or front-line – treatments are 500mg of Ciprofloxacin twice a day for 14 days or the same doses and frequency of Metronizadole. Both antibiotics either kill or slow down the growth of the most common kinds of bacteria found in the pouch. “A long period of time is needed to clear the bacteria,” said Uchu.

If a pouch patient has more than three episodes of pouchitis in a year, they may need a 28-day course of Ciprofloxacin and Metronizadole combined and some patients may need to take a maintenance dose of antibiotics “usually Ciprofloxacin”.

The main side effects of Metronizadole are a metallic taste and long courses can cause damage to the hands and feet, weakness, pain, cramps and spasms. While Ciprofloxacin can cause dizziness, arthropathy (for those aged under 18) and tendonitis in the over-60s who are taking steroids.

Another option is the probiotic VSL#3 (four sachets a day). “There has been some evidence to show that this can help patients who have

achieved remission from pouchitis after a course of antibiotics,” said Uchu. VSL#3, which can be prescribed or bought from pharmacies or health food stores, contains eight strains of live, freeze-dried lactic acid bacteria and traces of soya, gluten and lactose.

Patients who are taking antibiotics need to take VSL#3 regularly and at the same time each day.

“The timing needs to fit in with your lifestyle, doses must not be missed – even if you are feeling better – and the course must be completed.

This all helps prevent antimicrobial resistance and relapse which could lead to treatment escalation,” Uchu advised.

Pregnancy and breastfeeding

Patients who are pregnant or breast-feeding need to have their medications reviewed. While Loperamide and the antibiotic Co-amoxiclav are considered safe for those who are pregnant or breastfeeding, Metronizadole, Ciprofloxacin and Codeine are considered unsafe.

Other medications that can be used with pouches

Amitriptyline can slow down gut transit and help relieve neuropathic pain; Mesalazine is used to treat the rectal cuff; Glyceryl Trinitrate and Diltiazem treat fissures in the anal canal; Paracetamol and Buscopan can help with pain and abdominal spasms; and Dioralyte and St Mark’s Hospital’s own electrolyte mix are used to help rectify dehydration caused by high pouch output; Colestyramine sachets and Colesevelam tablets are used to treat bile salt absorption.



Uchu Meade (left) and Lisa Allison

Prescription charges

From 1 April, 2017, we have been paying £8.60 for each prescription item.

If you have a specified medical condition you qualify for a medical exemption certificate (MedEx). You can apply for this from a website (see end of article) or from your GP.

If you do not qualify for a MedEx, you can apply for a Prescription Prepayment Certificate (PPC) card. You pay £29.10 for a three-month card (you save money if you need four items or more) and £104 for 12-month card (you save money on 13 plus items a year).

You can apply for your PPC card at your local community pharmacy, GP’s surgery or from the website (below). You can also pay for a 12-month card by 10 monthly instalments.

<http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx>

Have you got a good pouch? If you have, Guy Worley would like to hear from you

Dear Red Lion Group Members, It was a pleasure to be given the opportunity to speak to you for the second time at your Information Day on 13 May – thank you for the invitation. I am a training colorectal surgeon undertaking three years of research at St Mark’s focusing on the surgical management of ulcerative colitis and the complications of pouch surgery. The pouch is a fantastic option for the majority of patients but a significant number suffer complications that require imaging [MRI scans] to help with the diagnosis.

On behalf of my co-investigators I would like to ask for your help re-

garding a study aiming to improve the diagnosis of pouch complications using new MRI techniques. Now and again we are reliant on the good nature of people like yourselves to volunteer as participants for research and I am very grateful to those who have already come forward after reading the study leaflet at the Information Day.

We would like to hear from anyone who has good pouch function and has not previously been diagnosed with infection or inflammation of the pouch. The study involves one visit to St Mark’s and one to 9 Harley Street, London W1G 9QY for the MRI (as there is no spare capacity

at St Mark’s for research MRI scans). We are able to pay £30 per visit for travel expenses.

Please contact me via the email address or phone number below if you think you might be interested and I can send you the full study information leaflet and answer any questions.

Thank you for your consideration.

Guy Worley and the St Mark’s research team
guy.worley@nhs.net
07984 680155



How to be a healthy pouch owner

St Mark's specialist dietician Evi Kyriakidou shows how eating and drinking sensibly can markedly improve your life. Here is her Information Day report

If you have just had a pouch operation, you need to have a soft, low-fibre diet with easy-to-digest foods. Then reintroduce foods slowly ensuring fibrous foods are chewed well, said Evi.

After the first two to four weeks, you can begin eating high energy and protein foods to promote healing and prevent weight loss. If your appetite is limited, eat little and often throughout the day, advised Evi. She also advised recovering patients to eat high energy snacks between meals and drink milky drinks and smoothies rather than tea or coffee.

She said you should aim to drink 1.5 to 2 litres a day and add extra salt

and repair – including wound-healing.

Fat, too, is a concentrated energy source that is needed to help immunity, protect organs and help the absorption of fat soluble vitamins, though fat should be eaten in smaller quantities than the other food groups, she said.

Five portions a day

Evi urged patients to eat fruit and vegetables for their fibre content and vitamins, minerals and antioxidants to help prevent damage in the body. "Aim for five portions a day or whatever you can tolerate with a pouch," she said.

week for women). A unit equals half a pint of beer, a small glass of wine and a pub measure of spirits.

Cross-heading: Food tolerance Individuals' tolerances to food vary considerably, said Evi. "Identify on a trial-and-error basis the foods that are best tolerated and eat a varied and balanced diet, only avoiding foods that cause unpleasant symptoms," she said. She advised patients to introduce one food at a time and said they would find that their tolerance to certain foods may change over time.

She said a good way to handle eating in the early stages of a pouch was to keep a food and symptoms diary.

The foods that thicken the stool, said Evi, were bananas, rice, bread, potatoes, tapioca and pasta. While the foods that loosen the stool were chocolate, raw fruit/vegetables, highly spiced foods, greasy foods, sugary foods, fruit juice and leafy green vegetables.

She said the foods and liquids that increase stool output are fibrous and spicy foods, alcohol,

caffeinated drinks, fried food and chocolate, while bread, pasta, rice and bananas decrease stool output.

The foods to be wary of as they cause anal irritation are spicy foods, nuts, seeds, coconut, citrus fruit, raw fruit and vegetables. A group that increased wind were broccoli, sprouts, cabbage, cauliflower, onion, garlic, leeks, asparagus, beans, spicy foods, beer, milk, fizzy drinks and "swallowing air" [which it is surprisingly easy to do – Ed]. While fish, onion, garlic and eggs increased stool odour, added Evi.



(1 teaspoon-a-day) to your meals. In hot weather, or if your output is high, you may need to consider anti-diarrhoeal medication and rehydration solutions such as St Mark's Hospital's electrolyte mix.

Once your pouch starts to adapt, Evi said patients should follow a healthy, varied and well-balanced diet based around energy-giving carbohydrates such as bread, pasta, cereal, potatoes and grains.

You should eat such proteins as nuts, eggs, meats, pulses, seeds, lentils and meat alternatives for growth

Milk and dairy products provide patients with calcium for strong bones and teeth. "Some patients are advised to avoid dairy products but it is only a problem for 1-in-5 patients with a pouch or stoma. Most people can tolerate dairy products to a certain extent," said Evi. Her recommended portions are a glass of milk, a matchbox-sized piece of cheese and a small pot of yogurt three times a day.

Evi advised pouch patients to take alcohol in moderation (ie 21 units a week for men and 14 units a

Photos from 2017 Information Day



Top: Speaker Pramodh Chandrasinghe (left) and speaker Guy Worley. Above: A tasty spread for lunch. Speaker Dr Yoram Inspector (left) and Lisa Allison.



Speaker Evi Kyriakidou (left) and Lisa Allison

Lisa Allison and Pramodh Chandrasinghe (right)

David Skinner's Deliciously Difficult Summer Quiz...(and they all have the word 'summer' in the question)



Red Lion Group Liaison Officer, David Skinner.

1. What is the collective name of a group of 1,700 island summer resorts between Canada and the USA?
2. Who's summer villa is at Castel Gandolfo?
3. When is the Christian festival of Midsummer Day?
4. Where were the 1968 Summer Olympics held?
5. What is used in the filling of a summer pudding?
6. Which institution, introduced by Harold Wilson, consists of TV and radio lectures and summer schools?
7. In *Alice's Adventures in Wonderland*, what was done 'all on a summer's day'?
8. Elvis Presley was the King, Bruce Springsteen the Boss. What nickname was given to Donna Summer?
9. Which capital city in the northern hemisphere, named after a local tribe, has almost 19 hours of daylight during the summer solstice?

10. Which actor, who later starred in the TV series *It Ain't Half Hot Mum*, played the part of one of Cliff Richard's friends in the film *Summer Holiday*?
11. Which brothers wrote the song "Summertime"?
12. Esther Summerson is the heroine of which novel by Charles Dickens?
13. Which duo had a hit in 1978 with "Summer Nights"?
14. Which hit song describes summer as: 'Those days of soda and pretzels and beer'?
15. The film *Summertime* starred Richard Gere and which actress?
16. What type of shops is Anne Summers renowned for?
17. Who had a hit record in 1961 with "Summertime Blues"?
18. The tiny Summer Isles are a few miles northwest of which Scottish port?
19. How is the singer La Donna Gaynes better known?
20. Which group had a hit with the song "In the summertime"?



Alan suffered from pouch eye-test



"He does like a tippie, trouble is - it increases stool output something chronic"



Dracula's blood test was proving less enjoyable than he had planned

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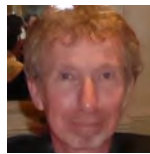
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Lynn Faulds Wood

Join the Red Lion Group

- Newsletter twice a year with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to the Membership Secretary (see above) for a membership form

Write for Roar!

Ideas, Ideas and More Ideas

Yes, Tim Rogers and I thrive on them for it's ideas that make *Roar!* the readable package that we all 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 in-

*Please email
membership@
redliongroup.org
if your email address
or contact details
change*

formation and make reading about pouch issues fun and stimulating. Please send your articles, letters and ideas to:

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