



# ROAR!

ISSUE 49 • CHRISTMAS 2014

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.

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## Contents

Notes from the editor .....	3
Information Day 2014 .....	4
Letters to the editor .....	5
The loneliness of the long-distance hiker.....	6-7
A city of golden palaces, fine food and a mind-boggling metro network.....	8-9
Quality of life after colorectal surgery .....	10



Page 4



Page 6



Page 8

## 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, Mr Preash Lad, 62 Peartree Avenue, London, SW17 OJG**

Back cover: Image of a Jonathan Livingston Seagull look-alike on a Cornish rock by Roar's photographer-at-large Christine Lawton

## Notes from the editor



**H**ave you noticed how many of today's celebrities and sport-people are willing to "come out" and talk about their struggles with colon problems and what they have done to try to overcome them.

It's an encouraging trend that helps to dispel some of the familiar taboos you and I have faced when trying to talk about our symptoms and toiletry needs with friends, relatives and work colleagues.

We feature one such case in this issue of Roar. It's the story of Scotland and Manchester United footballer Darren Fletcher who chose to suffer in silence in a macho world of

super fitness and sporting prowess. Until that is his condition worsened and he decided to talk about it more openly.

It is this openness that makes Information Day such a boon for many of us. For while consultants and medical specialists talk about the causes and cures of colonic

illnesses, we are able to discuss our own personal difficulties among ourselves or in the afternoon workshops – something we certainly wouldn't be able to do in our local pub or coffee shop.

Perhaps we should rename it Self-revelation Day.

It was refreshing to hear the comments of one first-timer who said of this year's event: "I was blown away by [the] Information Day, so affirming to meet so many people with similar shared experiences and ongoing challenges after 30 years and with no such prior contact." He has since joined the Red Lion Group committee and you can read a fuller

account of what he said on the Letters Page.

### A sense of adventure

And speaking of fitness and outdoor sports, there's a lively article by Red Lion member Peter White about hill-walking, trekking and how to survive some of the UK's harder terrains – a sort of layperson's guide to nature.

In his article Peter's included many useful tips about what we should eat and drink in the wild and what to do in an emergency. It's recommended reading for anyone who's feeling adventurous or else planning an outdoor family holiday.

It's stories like these that really bring Roar to life so please don't hesitate to send me accounts of your own experiences. However personal. Finally, if you haven't yet been to a spring Information Day, I really do recommend that you do so. It's full of health and dietary advice, tips about coping with pouchitis and a great opportunity to meet your fellow Red Lion Group members. So do put the date of the next one in your diary. It's Saturday, 16 May 2015.

Meanwhile have a very happy and healthy rest of 2014.

## Revamped website

Red Lion Group

Information Stories Forum Help News Links About Us Home



Roar! archive

### Welcome to the Red Lion Group

The Red Lion Group is a UK pouch support charity

We were founded in 1994 by a group of patients and staff at St. Mark's Hospital in London.

Having a pouch can have its ups and downs, but we hope that by sharing the stories of people with pouches and providing support and information, this website will help you if you have, or are considering having, an ileo-anal pouch.

Join the Red Lion Group to receive a newsletter two or three times a year

### Join

Please download a PDF membership application form to join the Red Lion Group.

### Talk

Share your experiences of having a pouch or seek support in our online pouch forum.

## 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](http://redliongroup.org/roar)

For on-line support and advice from other members or to share your views about any aspect of life with a pouch, please visit our on-line discussion forum at: [redliongroup.org/talk](http://redliongroup.org/talk)



**T**he Red Lion Group website has been in need of a facelift for several years. Visit [redliongroup.org](http://redliongroup.org) to see the new look site.

# Information Day 2014

Some of the liveliest talks in Red Lion history were featured at this year's May 10 Information Day.

Sarah Harris from IA (the Ileostomy and Internal Pouch Support Group) gave a surprised audience of 60 plus Red Lion Group members and their families a remarkable account of how she has coped with a mounting series of medical setbacks. Though some of the content of what she said was both raw and gruelling she told her story with humour and wit.

Then *Roar!* editor Chris Browne gave members a series of tips about using a Medena catheter. He said the number of pouch-holders who now use a catheter as a practical, comparatively pain-free emptying technique has been growing steadily, judging by the number of emails and phone calls he receives each month about them. You can find out more about how to use one on the home page of the RLG website

[www.redliongroup.org](http://www.redliongroup.org). Or if you need medical advice, please contact Lisa Allison, St Mark's pouch clinical nurse specialist and RLG chair, on 020 8235 4126.

Red Lion Group member Georgie Lack, a university student, keen lacrosse player and pouch-holder, gave an entertaining and uplifting account of how she manages to combine serious competition with a lively student social life.

The final speaker was St Mark's consultant colorectal surgeon Janindra Warusavitarne who gave an enlightening account – with slides and case studies – of the history of the ileoanal pouch and how keyhole surgery – or to give it its technical title laparoscopic pouch surgery – has continued to grow in popularity. Not surprisingly, his talk was followed by many questions from Red Lion Group members.

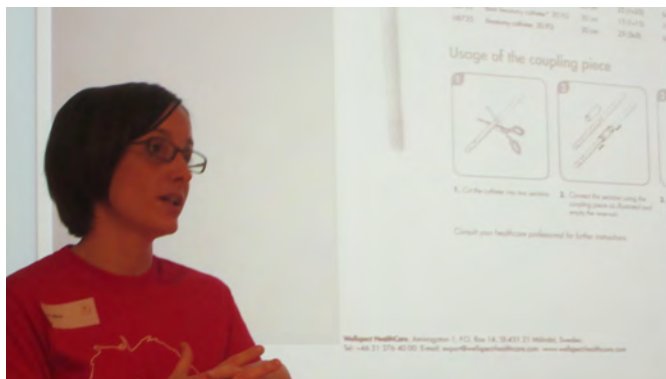
Red Lion Group chair Lisa Allison introduced the day with a welcome

address before chairing the annual general meeting. In her chair's report she said the committee had met five times in 2013-2014, produced two issues of *Roar!* and was seeking new ways to freshen up the website.

Treasurer Preash Lad, who is stepping down and handing over to new committee member Paul Mulot at the end of the year, said in his treasurer's report that income was slightly down on the previous year due to a small reduction in membership.

However, income from other sources had risen due to at least two large donations – including one for £10,000 – made to the group. The money was given to the St Mark's Hospital Foundation to help fund ongoing research work into the causes of colitis and pouchitis.

Apart from Paul Mulot, two other new members, Theresa Parr and David Davies, were welcomed to the committee.



Red Lion chair Lisa Allison opens the AGM



The 60 plus audience at the May 10, 2014 Information Day



Colorectal surgeon Janindra Warusavitarne during his "enlightening" talk



Red Lion member Georgie Lack entertains her audience



# Letters to the Editor

## I'm one of the lucky ones!

Dear Editor

When I hear speakers or fellow Red Lion members talk about their troublesome pouches, I feel very fortunate because since I had surgery more than 20 years ago I have had no problems apart from adhesions which can happen to anyone who has had invasive surgery.

It has meant I was able to carry on with a stressful job as head teacher of a large primary school in north London. I have also been able to travel far and wide from Peru to Cambodia. Neither do I take medication (much to many people's surprise when I mention this in the workshops at Information Day).

I guess that I have been lucky! Though I do have osteoporosis and it is very likely that this is due to the various medications I took to help control my UC before I had the operation followed by a huge loss of weight.

Susan Burrows

Red Lion Treasurer

## It depends what you mean by fats

**Andrew Millis's delicious recipes for dated Weetabix loaf and honey flapjacks in the Spring 2014 Roar!**

**drew this response from Red Lion member Jane Gregory.**

Dear Andrew

I just saw your recipes in Roar! and wondered about the issue of fats. Many people seem convinced that fats are a problem. Further to my experiments on myself, I decided it was emulsifiers that are to blame, not the fats themselves as high-fat foods use emulsifiers\* to stabilise the fat within the recipe. Emulsifiers do get everywhere unfortunately but they are labelled by law, and there are ways of telling: for instance, bread has uneven air-holes if no emulsifiers are used.

If chocolate is a particular problem, it might be worth an experiment with a brand called Willie's Cacao, which is emulsifier-free and sold in Waitrose and online. There is some research on this coming out of Liverpool University at the moment.

By avoiding emulsifiers, and my other demons, nutmeg, annatto and carrageenan, I do pretty well. I don't believe for a second the idea that 'we are all different' in regard to food. The doctors never say that when they are giving us the same few drugs.

Best wishes

Jane

**\*Emulsifiers are additives that are used to help make food more ap-**

**pealing. For instance, mayonnaise is mainly made of oil and water and by adding an emulsifier the two mix neatly together and do not separate. Emulsifiers are often used in low fat spreads and margarine to help prevent the growth of moulds which would occur if the oil and water they contain was separated.**

## My life-affirming visit to Information Day

I was blown away by the May 2014 Information Day, so affirming to meet so many people with similar shared experiences and ongoing challenges after 30 years and with no such prior contact.

I had no idea the group existed and I encourage you and the rest of the committee to raise your profile amongst potential members who may be unaware of this group, particularly those who had surgery a long time ago.

I was particularly pleased to see a potential member coming along to learn more about the consequences of the surgery and it was great to see people taking the time to talk to him throughout the day to help him on his journey to come, wherever that will take him.

Call me old-fashioned but I don't understand why pouch people would be in IA (Ileostomy and Internal Pouch Support Group) instead of in the Red Lion Group. So it was good to see two people from IA on the day and to hear from the very entertaining lady about her catalogue of challenges. I think it makes sense for all pouch people to be in the Red Lion Group....

Keep up the great work!

David Davies

**...who since this letter has joined the Red Lion Group committee - welcome David!**



**Information Day  
2015 takes place on  
Saturday 16 May at  
St. Mark's Hospital,  
Harrow**

## The loneliness of the long-distance hiker

The Scouts' motto of 'be prepared' is a valuable tip for energetic pouchees who fancy a spell of hiking, climbing or mountaineering, explains Red Lion member **Peter White**.

I've been coming to the Red Lion Information Days for three or four years now and have come across people with pouches who run mara-

colon (dehydration etc.) it gave me a freedom I hadn't had since I was 17.

Since then I've cycled the Sea-to-Sea cycle route – 140 miles from

and winter climbing, taken up canoeing and kayaking and, my favourite pastime of all, I've been camping – on campsites, in woods, at the top of mountains, with tents and without, car camping, bivvy bag (a lightweight single tent) camping and multi-day hiking.

You can't get deeper into nature any other way than camping in the mountains

There is something special about sleeping under canvas. You hear, feel and smell nature in a way you don't get by being indoors (assuming you've camped somewhere nice!). And there is something particularly satisfying about waking up



*Peter (left) with friends during a winter climb in the Scottish Cairngorms*

thons, are involved in competitive cycling, go scuba diving, and get involved (some at quite a serious level) in various sports and activities. So here is a piece of my story, and some of the things I've picked up on the way.

There is something special about sleeping under canvas

When I first had ulcerative colitis at the age of 17, I thought my life of outdoor activity was over. When I was 20 I had the colon removed and a year later ileo-anal pouch surgery (with a stoma for seven months in between). I found that despite the occasional challenges of managing the pouch and the absence of the

Whitehaven on the UK's west coast to Sunderland on the east – been mountain walking, gone summer



*Peter pauses by his tent during a four-day winter climbing expedition in the Cairngorms*



in or on the mountains. You can't get deeper into nature any other way than camping in the mountains or in other spectacular places. More than a walk from the car – you can go and experience those places day and night, morning and evening. And the chances are you will see night as well as day, especially if you have a pouch, or can't find any flat ground!

So, I've spent a good part of the last 20 years working out how to do this best with a pouch. And at the annual Information Days I've found

Planning can  
be summed up  
as 'Don't get  
caught out!'

there are clearly others who have been doing the same. As far as I can tell it boils down to two things: 1. Planning (i.e. the Scouts' motto: 'Be Prepared') and 2. Meeting your physical needs (i.e. food and drink).

Planning can be summed up as 'Don't get caught out!'. Every mountain walker knows what a trowel is for (if you don't know email me and I will tell you!), but with a bit of planning things can actually be quite comfortable. It doesn't take or cost much to get this right. I use a £5 folding mini trowel from Go Outdoors, a quarter-full toilet roll flattened to

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reduce its size (the whole thing can be quite bulky), a scented colostomy disposal bag (for used paper), and a waterproof bag to keep things dry. It's all about the size of my hand and weighs 160g. Even after 20 years I still have plenty of colostomy dis-

posal bags, but nappy disposal bags would do just as well.

As far as food and drink are concerned, for me it's not so much an issue of what I can and can't eat and drink, but more a matter of understanding the consequences. Understanding and preventing dehydration is a key consideration, and may well be for anyone doing sport.

The fact is that I dehydrate much faster than the average person, and this can have a physical impact (endurance and dry skin) and perhaps also a mental one – the ability to think clearly and act quickly.

My solution to these things is the following:

- a) I use sports drinks – normally isotonic, and probably not too far from the St Mark's hydration mix of water, sugar and salt; these are available in powder as well as ready mixed, which is useful for minimising weight. I don't drink pure water as it passes through faster than thicker liquids;
- (b) I take water purification tablets in case I run out of fluids – not

Go the loo  
before putting  
on a wetsuit

the nicest of tastes, but good for refilling from streams and lakes;

- (c) I carry hand cream – oily hand cream in winter. I am prone to dry skin at the best of times but getting hands wet and cold makes it much worse – particularly in winter when it can cause cracking and bleeding – not to mention pain;
- (d) Drink slowly and keep eating. Small amounts of food eaten with drinks slow things down and make the most of what is consumed. A quickly guzzled litre of water with no food won't stay in long!

In terms of food, diet is a more complex subject, and may vary from person to person.

On the hills there is the added complication that if you get it wrong you may have to go for a number two in bad weather, or you may have gone to the most popular spot in the Lake District and need a hiding place! This is where you have to

decide how committed you are to doing what you're doing, and I have seen the pity on my friends' faces as I have gone out in a blizzard in sub-zero temperatures with the trowel and a torch!

Here are some tips which I have found very helpful:

1. If you are doing outdoor activities eat an egg before breakfast (or at any time you need to slow things down). For me it's better than Loperamide, and I don't take any medication.
2. Never throw away a sachet of

On the hills  
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ketchup, mayonnaise, or any other sauce; moist sandwiches go down much better than dry.

3. Eat custard and cake, to mop up any spare liquid in the system, and of course for morale.
4. Know your body. Noting which foods cause wind, reduce wind (e.g. yoghurt), are full of indigestible fibre, or have other effects, enables us to choose, to a degree, what happens and when. I am convinced that for those of us with pouches who are relatively healthy, mastering this and ensuring we maintain a nutritionally balanced diet is the key to a better future.

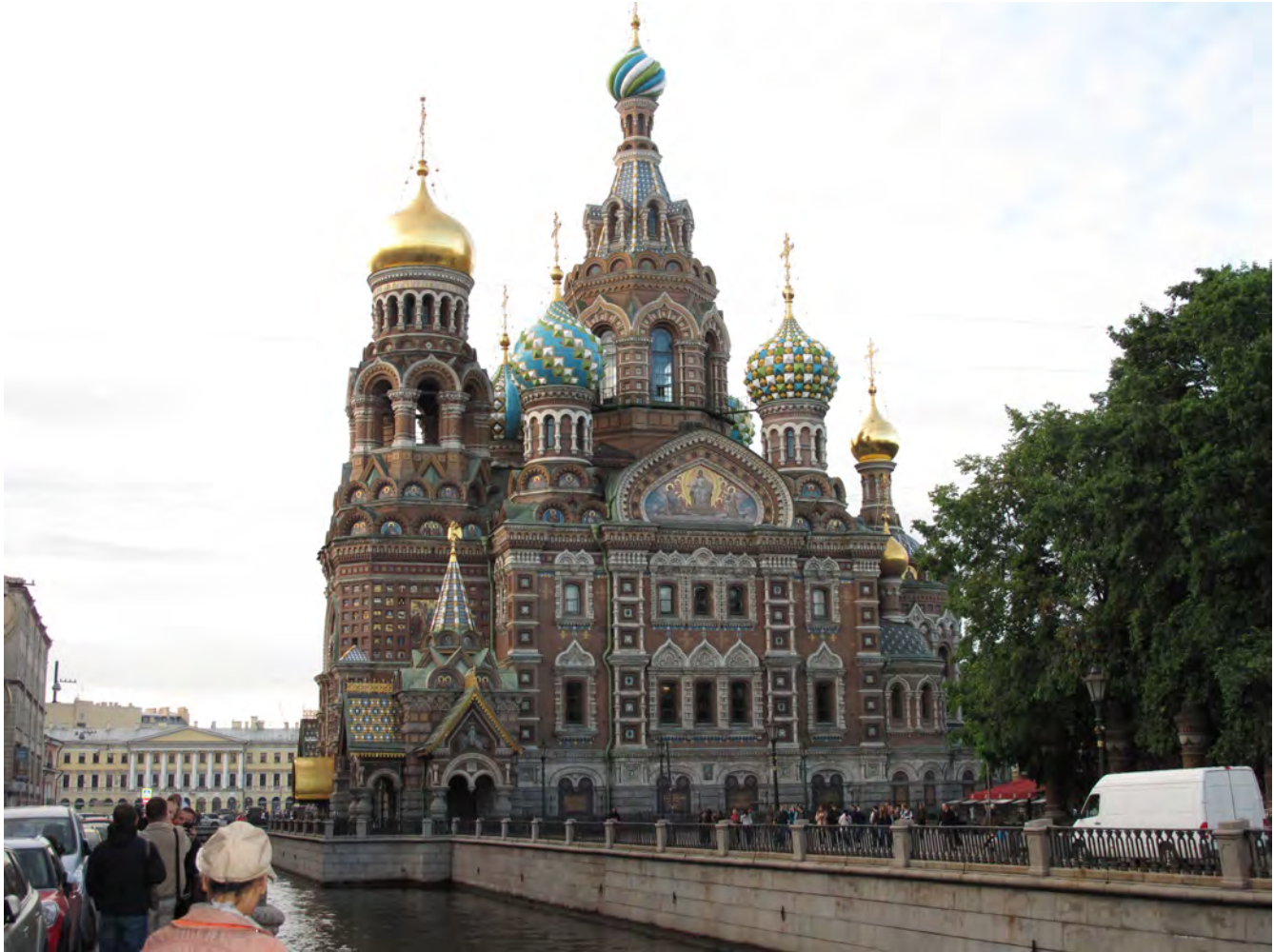
There is much still to learn, but between us pouchees we have a lot of knowledge and experience we can share, and shared diet and nutrition tips make a huge difference.

So, all in all, I've found being prepared and understanding the consequences of our choices can open up a whole range of possibilities.

Just make sure you go the loo before putting on a wetsuit or a climbing harness!

## A city of golden palaces, fine food and a mind-boggling metro network

Spectacular, smelly and with endless portions of smoked salmon. That's modern Russia for you. Our roving correspondent, **Andrew Millis**, reports



*The spectacular minarets and towers of St Petersburg's Church of our Saviour on Spilled Blood*

I had heard that Russian public toilets were pretty rough, so to find out if Russia is a suitable travel destination for pouch owners, I took myself off to St Petersburg for a few days. Oh, and there was a marathon on the Sunday so I thought I would do that too.

First of all, they seem to have a real problem with toilet paper. On arriving at the airport, I found a toilet by the baggage collection area, but none of the cubicles had any paper. I always carry my own, so I wasn't perturbed. Where there are attended toilet facilities, you pay to use them and are given paper as a way of preventing use without paying – and you only get very few sheets.

I ran out of paper in my room in the hotel, and it took two requests to get any more. One day the maid actually removed the spare roll of paper from my room, rather than provide more! Restaurants had quite good toilets, but one that I ate at on a busy street had a toilet which you could only use if you scanned the bar code on your receipt after paying, just to open the door! I took a picture of a typical public convenience, and felt sorry for whoever is trapped in there after paying a large sum of money. You have to pay 30 roubles which is about 60 pence.

The flight was quite expensive (BA, about £550 return) and my hotel was around £530 for four nights.

But the hotel was in the area of the most expensive real estate in the city and off the most famous street in Russia – Nevski Prospekt. So a comparable hotel in London would cost plenty more than that.

The visa cost £120. So quite an expensive trip in all, but once there, public transport is extremely cheap (anywhere on the underground network is about 70p and the half-hour bus journey to the airport was about 50p), and eating out is quite inexpensive too. I had a celebration meal after the marathon at a pleasant restaurant, of Russian pancakes and caviar, beef Stroganoff on mashed potato with grilled Mediterranean vegetables, a pint of Russian beer



and a bottle of sparkling water for about £21. That would have cost more in the UK. And the hotel served endless smoked salmon for breakfast.

St Petersburg airport is a ridiculous place, particularly for leaving. The queues for the passport control are dreadful. There was a line of 90 kiosks, at which officials check passports and visas, and they take several minutes per person. You stand in front of a window with a large mirror behind, which allows the officer to see your back as well as your front. As it is a three-and-a-half hour flight, I suffered from the normal flight problem of being unable to get to the toilet when there were trolleys in the gangway, or food on the trays of the passengers next to me.

Their underground network is extremely deep, requiring what could be some of the longest escalators in the world. That may be because of the depth of the river Neva. You literally can't see the end of them. So if the Cold War had become a nuclear war, anyone on an underground train at the time would have been fine.

You have to keep your wits about you though – some stations are not

named, so if you can't understand the announcement, you have to have counted the stops. And you need to remember, from outside the station, the name of the station at the end of the line in the direction you are going, as there are no maps in

If the Cold War  
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sight. And remembering something you can't pronounce is hard! While the stations are splendid, the trains are not, being smelly and noisy. It made me appreciate London.

After that, there is so much to see and do that you don't know where to start. I stepped out of my hotel and my jaw dropped. Palaces are just dripping with gold. All of the architecture is magnificent. Peterhof palace, which is 30km along the coast by hydrofoil, has some 1,500

fountains in the gardens. You'd travel the world to see it. So many of the city's streets had stunning-looking buildings and I took over 300 photos.

I have to say the marathon was disappointing, in that it was not as picturesque as I had hoped, and badly organised.

I got tired after about 18 miles and had to slow down, but finished in a reasonable 3:04:00. The police did a good job of holding back angry Russian motorists leaning on their horns, at junctions.

I passed by an open drain on the route, and have had nightmares ever since of the fate if a runner happened to step in it.

It was a wonderful and memorable trip, and I am very glad I went. I have talked to people who have been several times. I heartily recommend it, as a really special destination. But I don't think I would go again. I have to say, the people are hard and unfriendly, not endearing.

They seem to have considerable wealth now, judging by the cars (Range Rovers, BMW X5s, Porsches). From what they suffered during the 20th century, from Stalin, Hitler, and then their own KGB, we should give them all the respect they deserve.



St Petersburg's Peterhof Palace with some of its 1,500 fountains

## From the Archives: **Quality of life after colorectal surgery**

Our next issue of *Roar!* will be number 50 and for the benefit of members who joined after 1994 (and indeed those who were born since then!) we have decided to reproduce some classic articles from the 20-year archive of past issues of *Roar!* The following article by **Annette Bisanz, BSN, MPH** was published in issue 14 in Autumn 1999 with kind permission of the newsletter of the University of Texas MD Anderson Cancer Centre.

**F**ollowing colorectal surgery, there may be a change in bowel function due to the change in the anatomical structure of the colon or rectum, or both. This may necessitate a bowel management programme that is based on the same basic principles but needs to be individualized for each person. There is all the reason in the world to believe that your bowels can be managed after colorectal surgery.

These are the prerequisites for managing bowel control:

- Be committed to the programme and be willing to follow specific directions
- Seek guidance from a professional when you are not achieving the goals of your programme
- Keep your sense of humour.

Following colorectal surgery, many people find themselves having several stools per day. The normal frequency of bowel movements in a healthy population varies from 3 bowel movements per day to 3 per week. The goal is to return to no more than 3 bowel movements per day.\*

### **Transit Time of Food through the Gastrointestinal Tract**

Eating a large meal or drinking a hot liquid will cause a normal peristaltic push down in the gastrointestinal (GI) tract. When frequent bowel movements occur, drink less fluid with your meals, drink more fluids between meals and avoid hot liquids.

### **Medicinal Fibre to change the Transit Time**

If you are having frequent stools, then introducing psyllium, a medicinal fibre also known (in the US) as Metamucil, can slow down transit through the GI tract. Most people take psyllium for constipation or to speed up transit time through the GI tract; however, after colorectal sur-

gery, your goal will be to slow down the transit time. To do this, take the prescribed amount of fibre right after a meal in very little fluid, approximately 2oz., and no more fluid for 1 hour immediately after a meal. This allows the fibre to act like a sponge in the GI tract, soaking up excess fluid in the digestive system and thus slowing things down. One teaspoon should be taken after the same meal each day for 3-5 consecutive days. Then increase to 1 teaspoon psyllium 2 times per day. Gradually increase the fibre by 1 teaspoon every 3-5 days until the GI tract transit time slows down a bit.

### **Bowel Training**

Once your stools become better formed and the transit time has been slowed down, the next step is bowel training, with the goal of emptying the colon fully at an expected time each day. Pick a meal of your choice around which you'll bowel train yourself. Bowel training is done around a meal since a big meal causes a push down the GI tract to make room for the food taken in.

Choose a time when you can consistently follow the programme. Then,

- Before that meal drink 1 oz of prune juice
- Eat the big meal
- Drink a hot liquid

If this does not produce results, you may try using a glycerin suppository after the hot liquid.

Do this for 3 straight days.

If you don't empty as planned, substitute the glycerin suppository with ½ bisocodyl suppository.

If this is effective, stay with the programme for two weeks and then stop using the suppositories.

By this time, the stimulus for your bowel to empty will be the prune juice, big meal and hot liquid.

### **Adjusting the Bowel Management Programme**

Since each person's body reacts a little differently, don't get discouraged if your programme doesn't immediately help. Problem solving is the key to success, and little changes made after trying something for 3 days will help you determine what will work for you. Overall bowel management involves a gradual balancing of food, fluid, fibre and medications.

### **Food**

If your bowel is stimulated by a big meal, eat 1 big meal per day and 4 smaller meals. Certain foods affect people adversely, and you need to be aware of what you eat that may cause increased bowel movements. (High fat and/or spicy foods seem to affect many people).

### **Fluid**

Fluid with meals tends to increase peristaltic push-down, so drink fluid in between meals instead of a large amount with meals, and avoid hot liquids.

### **Fibre**

Adjust the amount of fibre gradually to determine how much fibre is required to slow down or speed up transit time through your GI tract and maintain soft, formed stool.

### **Medications**

If you are taking antidiarrhoeal medications such as Lomotil or Imodium, as you gradually increase the amount of psyllium, try to decrease the amount of Lomotil/Imodium.

Most people get good bowel control just by the use of fibre. However, keep yourself comfortable during the process of defining your maintenance bowel management program. Be patient with yourself. Remember, there is hope for bowel management, the goal being a high quality of life after colorectal surgery.

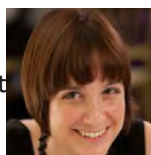
\* Editor's note: Pouch owners typically have four to eight bowel movements per day. Three may not be a realistic target!



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## 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-

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

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**Roar!**

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