

Roar!



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Roar! is the newsletter of the Red Lion Group, St. Mark's Hospital, City Road, London, EC1V 2PS

The Launch of the Red Lion Group

This is the first newsletter of the Red Lion Group which is a support group for people who have a pouch or are considering having a pouch operation. The group was started by people who had their pouch operation at St. Mark's Hospital, London but anyone is welcome to get involved. In this first article Tim Rogers recounts the launch of the group on Sunday 10 April 1994.

I went up to Aintree this year to see the Grand National. I lost about £20, but I didn't mind because the following day Rachel Nicholson Abedi and I chaired the first ever meeting of the Red Lion Group. The group is largely made up of past patients of St. Mark's Hospital in London who have made the transition from ileostomy to pouch.

A pouch is constructed by stitching the end of the small intestine in such a way as to give holding capacity, and plumbing it through to the anus. The operation is suitable for people who have suffered from ulcerative colitis and is a direct replacement for an ileostomy. While having an ileostomy takes some getting used to, it does allow people to be free from the chains of inflammatory bowel disease. Gone forever are the days of ill-health, urgency and planning your life around lavatories.

Patients undergoing a pouch operation lose the bag, but all the old fears about incontinence return. It was partly for this reason that we formed the Red Lion Group: to help people to decide whether a pouch is for them, and to give support to people who already have a pouch.

A small band of us had been meeting once a month or so on a Thursday afternoon to plan the launch of the Red Lion Group. When

the big day arrived we did not know quite what to expect. Dansac kindly sponsored the event by laying on the venue in the beautiful grounds of Syon Park in southwest London and Mr. John Nicholls, one of the surgeons who pioneered the procedure, agreed to give a talk about the history of the pouch operation.

As Rachel and I sat nervously at the front of the conference room we counted that almost 100 people had turned up. Rachel stood up and spoke about the origins of the group which was the brainchild of her and the stoma-care nurse at St. Mark's Hospital Celia Myers. Then I spoke briefly about the events that had led to this first full meeting before introducing Mr. Nicholls.

Mr. Nicholls' talk was entertaining and informative. We were told that ulcerative colitis drives people to surgery in many ways. Some need it because the urgency ruins their lives. Others find that their health gets eaten away and they lack the energy and vitality to do things that everyone else takes for granted. By having an ileostomy people's health is restored and they can go out and about safe in the knowledge that they are not suddenly going to have to go any moment.

People have a pouch operation for purely cosmetic reasons and so it is crucially important that people only undergo the procedure if they

really want it. The operation is not suitable for sufferers of Crohn's Disease. The operation has evolved over the years thanks to the genius of some gifted surgeons to arrive at today's state-of-the-art 'W' pouch.

There was an animated question and answer session after Mr. Nicholls' talk. The question of cancer-risk in pouch patients was raised. Mr. Nicholls said that although there had only ever been one case of instability of the pouch lining which could possibly lead to cancer he insists that each of his patients undergo a biopsy every year. Not all surgeons follow this example and this was perhaps the biggest talking point of the day.

The question of conception, pregnancy and birth came up. Mr. Nicholls recommended that women with pouches give birth by Caesarean section to minimise any damage to the bowel, but there is absolutely no reason why people with pouches should not have children. Indeed it turned out that there were three or four mothers with pouches at the

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meeting.

The problems of uveitis (an eye disorder) and arthritis linked to ulcerative colitis were also discussed. Some patients had been led to believe that a pouch would cure them of these disorders. Mr. Nicholls said that the link between ulcerative colitis and uveitis and arthritis were still obscure but progress was being made, as it was in the search for the origins of ulcerative colitis itself. He told one questioner that there ➡

was every chance that by the time her son grew up ulcerative colitis may possibly have been eradicated through genetic engineering.

On this high note we filed out of the room to sample the delicious catering of Syon House, our appetites in no way diminished by the full colour slides of pouch operations that Mr. Nicholls had used to complement his talk.

After lunch about 50 people who were keen to get involved in running the group stayed on. We rearranged the chairs in the conference room to make it a bit more informal. During the discussion that followed it became clear that the day had been a great success. People found it a relief to be able to talk to fellow pouch patients and swap hints and tips. Up until today most of us had had to learn how to live with our pouch without the benefit of talking to someone else who had already been through it.

It was soon apparent that some of us had been through quite different experiences. One of those present said he only goes twice a day. This made those with 'bad pouches' rather peeved. However there was plenty of common ground and everyone came away having learnt something. Some of the things we talked about were:

- condensing **Mr. Nicholls' talk** into a leaflet to be given to people considering having a pouch.
- a **diet sheet** someone had been given by Northwick Park Hospital. This recommends that people with

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pouches eat high fibre food to absorb more water, consume fewer sugary snacks between meals and take fluids in between rather than with meals. It also lists foods that might increase bowel movement and cause anal irritation. Full details of the sheet are given elsewhere in this newsletter.

- distributing an **in-depth ques-**

tionnaire in order to assess why some people had relatively good pouches while others experienced problems. Those present said they would not be offended by very personal questions of a lavatorial nature if it helped shed some light on this mystery. It was generally agreed that people with pouches had been through so much it would take quite a lot to offend them! Even so, if and

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when such questionnaires are sent out, it will be made obvious that people need not answer questions that make them uncomfortable.

- producing a **fact sheet** for employers and GPs whom many in the room found were rather ill informed about pouches.

- **'Can't Wait' cards** for use in shops and to jump lavatory queues when nature calls loudly. There was widespread interest in these cards which are available from the National Association of Crohn's and Colitis (NACC) and several stoma care companies. Unfortunately one person had been refused the use of the lavatory in the shop of a major high street pharmacist who had actually sponsored her card.

- getting out of **jury service**. One person had managed to get exemption from jury service because he was fearful of interrupting the proceedings of the court by putting his hand up and running off the lavatory every five minutes. This was a handy tip because normally only people registered disabled can avoid jury service. There was a consensus that we did not want people with pouches to be thought of as disabled.

- worries about high **water bills** for pouch patients who tend to flush the lavatory more than most.

- the question of **free prescriptions**. Most people undergoing a

pouch operation have an ileostomy while the pouch is healing and so are entitled to free prescriptions. Some people continue to make use of free prescriptions after their ileostomy had been closed, while many choose to start paying. Because free prescription cards have to be renewed at regular intervals it was acknowledged that most people with pouches would be forced to pay prescription charges eventually. Some people resent this because they are dependent on 'thickeners' like loperamide and codeine phosphate.

- whether ulcerative colitis causes premature **menopause leading to osteoporosis**. Someone showed the group a newspaper article advocating the use of hormone replacement therapy (HRT) for past sufferers of ulcerative colitis. Not everyone agreed that this should be taken as gospel however.

- the bizarre finding of research that suggests that **smoking is good for controlling ulcerative colitis**. Some people gave anecdotal evidence that their disease had been less of a problem while smoking than when trying to give up. Some medical trials are being carried out to study the effects of nicotine patches on sufferers of ulcerative colitis.

As the afternoon drew to a close we split into regional groups and took down each other's names and addresses. The day had been more successful than I could have possibly imagined. The group seemed genuinely excited about building up a support network of people with pouches. As I drove home I could not help thinking that this was the beginning of something big.

We have not yet started planning another big weekend meeting yet, but people saw little benefit in us all meeting up more than a couple of times a year. In the meantime regional groups are meeting on an ad-hoc basis.

If you have any opinions about the topics of discussion covered at the meeting, or feel strongly about anything else, please send in your comments so that they can be included in future newsletters. ■

Letters

Please send your letters to:

Roar! Letters
The Red Lion Group
St. Mark's Hospital
City Road
London
EC1V 2PS



Dear Roar!

I have had my pouch operation and am waiting for it to heal before having the second closure operation. I'm finding it really tough going because the skin around my

stoma is extremely sore and I feel very weak. I'm quite miserable and wonder whether it was worth having the operation at all.

Yours faithfully

Fred Magpie, Colchester

The first of the two operations is by far the toughest and it takes many weeks to recover full strength before having the closure operation which is nothing like as bad. Also a loop ileostomy is much trickier to look after than an ordinary one with a much higher risk of exceedingly painful and irritated skin. I found the weeks between the operations very heavy going indeed, but it was all worth while when everything was finally closed up and plumbed through!

Don't forget to enclose your name, address and telephone number in case we need to contact you.

Regional Groups

Some of the people who were able to attend the launch of the Red Lion Group have kindly agreed to be regional representatives. They hold details of contacts and are helping to coordinate local meetings. Please get in touch with them to arrange or attend a meeting in your area or to be put in touch with another member of the group.

London Area

John Cowan (Rickmansworth)
 0923 720530
 Louise Marson (Stanwell)
 0784 421795

Central London

Rachel Nicholson (W1)
 071-491 3480

Sussex/Surrey

Lisa Critchley (Brighton)
 0273 699286

Beds/Bucks

Wendy Gunn (Luton)
 0582 423714
 John Weight (Leighton Buzzard)
 0525 220002

Herts

Carol George (Stevenage)
 0438 365707
 Tom Elves (Letchworth)
 0462 674617

Essex

Kate Batley (Colchester)
 0206 572726
 John Cook (Stanford-le-Hope)
 0375 672598

Kent

Beverly Dallen (Hawkhurst)
 0580 850221
 Roy Parris (Biggin Hill)
 0959 574703

Hants

Philip Cox (Bordon)
 0420 477334

Berks

Liz Davies (Langley)
 0753 586593

Northants/Beds

Cynthia Gunthorpe (Kettering)
 0536 82529
 Michael Brown (Near Sandy)
 0767 651614

Norfolk

Sylvia Mist (Near Norwich)
 0692 580095

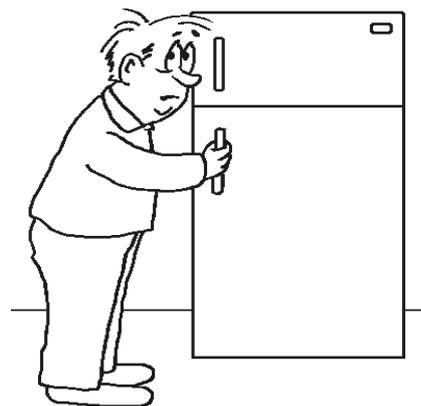
Gwent

Robert Challenger (Cwumbran)
 0633 866820

If your area does not appear in the above list and you are willing to act as a local representative, please send your home number to: **Rachel Nicholson Abedi, 9 Cavendish Buildings, Gilbert Street, London, W1Y 1FD.** Please also send your number if you are willing to be a contact for people who have had or are considering pouch surgery. It would be helpful to include your age, e.g. 24 to 35, 36 to 45, 46 to 55, 56 to 65, 65 and over and any other useful information such as whether you have had children since pouch surgery or whether your pouch was successful or unsuccessful.

Diet Tips

Northwick Park Hospital supplies a sheet containing dietary advice for people with a pouch which we have reproduced below. Not all the tips may be appropriate to you, but if you have a 'problem' pouch, it might be worth trying out some of them. Let us know how you get on, and please send in some tips of your own.



1. Try a high fibre diet to facilitate water absorption and aid regular bowel movement. You should include wholemeal bread, wholegrain cereals, wholemeal biscuits, brown rice and wholemeal pasta. Aim to include one portion from this list at each meal.
2. Reduce your intake of sugar and sugary foods, especially those between meals.
3. Take fluids in between meals rather than with meals.
4. Take regular meals during the day, but experiment with the timing or amount of food or fluid taken prior to bedtime to help reduce the number of bowel movements at night.

Foods that may increase bowel movement

- Leafy green vegetables
- Broccoli
- Beans
- Spicy foods
- Raw fruits and vegetables
- Beer
- Caffeine beverages
- Chocolate
- Red wine
- Fizzy drinks

Foods that may cause anal irritation

- Corn
- Popcorn
- Oranges
- Apples
- Coleslaw
- Celery
- Other raw fruit and vegetables
- Nuts
- Coconut
- Food with seeds
- Spicy food

Please support the Red Lion Group



All donations, however small, which would go towards our ever increasing administration costs will be gratefully received. If you have found this newsletter useful and wish to ensure that we have the funds to produce future issues, please send a donation to: **The Red Lion Group Treasurer, Mr. P B Johnson, 7 Chelston Approach, Ruislip Manor, Ruislip, Middlesex, HA4 9RY.**