Roar!

Issue number 18 • Autumn 2000

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

To pouch, or not to pouch?

The Red Lion Group exists as a support group not only for people who already have a pouch, but also for those who are considering having one. As more and more stoma care nurses become aware of the Red Lion Group, and put their prospective patients in touch with us, the question of whether they should go ahead with this surgery is asked more and more frequently.

Obviously, we cannot give any kind of medical advice. That is what your consultant and stoma nurse (or pouch support nurse) are there for, and presumably they would not even be discussing the possibility of pouch surgery with you if you were not medically suitable for it.

However, there are various issues which we do encourage potential pouch owners to consider if they contact us for advice.

I must stress that the point of this article is *not* to frighten anyone away from having pouch surgery. However, given that there is an alternative option in the form of an ileostomy, your decision to go for the pouch must be as informed as possible.

First of all, there is the question of your underlying condition. Most members of the group suffered from ulcerative colitis before their surgery. If you had UC to the extent of requiring surgery, this means you must be pretty ill with it, and so pouch surgery is envisaged as improving your health. Even pouch owners who have had lots of problems often say they are glad to have had the surgery because it is better than what they had before.

On the other hand, if you had familial adenomatous polyposis (hundreds of polyps in the colon), the idea behind taking your colon out is preventative: sooner or later, one of those polyps will turn cancerous, so by taking out the colon, you cannot get cancer of the colon. In some ways, the psychological rather than physical aspects of pouch surgery can be harder for FAP patients, because they go from being "well" (albeit with a lurking timebomb) to being ill and weak post operatively for a period at least.

But pouch surgery for both UC and FAP patients has its own associated risks: if you had UC, you may suffer periodic bouts of pouchitis - effectively a form of "mini UC"; if you had FAP, there is the possibility of developing a desmoid. There is also the question of pouch failure 20 years down the line - this surgery is still too young for the long term track record to be clear. Before opting for surgery, you should discuss thoroughly with your consultant the likely long term risks of this kind. It is then up to you to weigh up in your own mind whether potential risks are outweighed by the benefits of the pouch.

After this, there is the question of your surgeon and hospital. Pouch

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Our fabulous Red Lion Group Christmas cards are on sale in this issue - see the advertising supplement in the centre for full details. Many thanks to Stuart aged 7 from Dunfermline for his splendid lion...

My Story...by Gillian Appleby.

My story is one of hope, I hope! I have had my pouch for nearly a year now and had pouchitis only once..

I was diagnosed with colitis in May 97 even though it took quite a while for anyone to realise what it was. I was in Manchester when I first got ill. I started to have stomach pains in March 97 and at first I thought they might be due to the water I was drinking. (Some people may be disgusted by this but I used to fill up my water bottle from the bathrooms when I was at work, in desperation I will still do this however!) .

Following the pains I began to get bloody diarrhoea and feel very tired (sleeping for around 14 hours a day.) I went to the doctor who at first told me it was something which was going around and was just an infection, which would go away. The second visit when he had some samples he told me I might have a urinary infection (what a joke!!) and gave me some antibiotics for this. (I think he was misled by the fact that the first time I saw him I told him I also got very thirsty and drank loads of water – I still get that nowadays too.) I knew he didn't know what he was talking about so I visited a second doctor at the same surgery who said she thought it was colitis but I would have to have some hospital tests and I wouldn't be able to have these done for another 5 weeks..

At this point I felt like I would be dead in 5 weeks time. Luckily my mother was not averse to sending me to see someone privately (really I had no choice). I came down to London to see Dr Levi who promptly put a rigid scope up you know where and said I had ulcerative colitis and put me on Asacol but told me they would work very slowly. I thought I was never going to get better really but they did work after about 2 weeks..

So everything was fine after this - I thought I was cured. Dr Levi did mention something about not eating dairy products (and I didn't for about 2 weeks then when I was better I thought there was no need to continue this and I just went back to normal.) I did stay on the Asacol taking the minimum amount: about 3 a day. No one said anything about how serious colitis can be or about surgery (I think one statistic in the clinic said about 90% of people with colitis have surgery – that can't be true can it?) I was fine until December 97 when I had a small bout but I just upped the pills and I was again fine..

It started again though in May 98. I was in Manchester again visiting friends and I started to feel extremely tired. (I always wonder about the coincidence of the time and place.)

I came home and this time it was different because the whole thing escalated very rapidly. I was put on steroids for the first time – orally and the other way. Then I started to be sick. One Friday the doctor came round to see me and told me there was nothing else he could do for me and I had to go to hospital. I was getting a bit scared at this point..

I went into Northwick Park Hospital, the place I was born, as an emergency and was put in a room full of old people – a medical ward. Sometimes it wouldn't matter how many times you pressed on the nurse's bell they wouldn't come. Only one nurse seemed to really care – she caught me crying at some point after one of my toilet trips. She sat on my bed and said, "I don't like to see you like this." I said to her, "I just want to get better." It didn't seem to me like I ever would..

The week in hospital mostly involved going to the toilet about 24 times a day and I knew this because I had to write it down every time I did go. Every morning the doctors would come and see me and say "how are you" and what could I say? Once I even said I did feel a bit better but my toilet record didn't show any improvement. Every toilet trip was preceded by this funny leg jerk which started from my pelvis and I'd know I couldn't put it off anymore..

My doctor was talking about putting me on some kind of drug, which would suppress my immune system (called chlorosporine – I'm not sure of the spelling) if I didn't get better on steroids.

They could only put me on this drug though if my cholesterol levels where normal otherwise I could fit (that sounded great to me.) Inevitably my levels were low, which was obvious because I hadn't been eating. I think it was the day before surgery when Dr Pitcher came round to tell me I would have to have my colon out. My parents were there and I just looked at him stunned.

When he went I just cried and cried and my dad put his hand on mine (I will always remember that as my dad isn't the most touchy of people.) I said, "I don't want to have my colon out." I had no choice..

I woke up high on painkillers and people fussing around me. Later my brother told me I looked like death. Well I hadn't eaten for over a week so it wasn't surprising. The nurses were very nice to me this time, and giving me attention when needed (surgical wards perhaps being better staffed.)

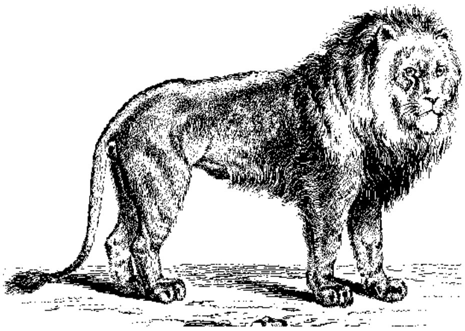
Food wise, after a couple of days, I started out on soup and jelly. But of course I had a bag, which was especially unattractive when they give you a clear bag to start off with. Lots of lessons on how to change it etc. And I took it all in my stride believing I would not have to do this for the rest of my life. As I started to get better I also wanted to leave hospital and about a week later I did. Taking my bag supplies with me. After the shock wore off I hated having a bag, I felt like a freak. But I survived it for another 14 months..

The second operation seemed to be even tougher on my body. I

Editorial

It seems that no sooner is the last newsletter coming through the door than the next one needs to be done! Many thanks to those of you who take the time to send me articles and snippets of information for inclusion, as these do make the task a lot easier. If you can send these by e-mail or on floppy disk, so much the better, and all floppy disks (or zip disks) will be returned.

As soon as we have gone to press on this issue, we are allowing Tim a tiny bit of "annual leave" so that he and Natalie can get married! From all of us at the committee, and on behalf of all of our members, many congratulations to you two, and we hope you will include a picture of your happy day in the Christmas issue, Tim.



This is the first issue in which we are including advertising, which is a separate 4 page supplement in the middle. As Christmas is approaching, the Red Lion Group itself is doing most of the advertising - for our merchandise and our brand new Christmas cards. Do please use the order forms to select some lovely cards and gifts for your family and friends, while at the same time supporting the work of the Red Lion Group. A full colour reproduction of our stunning card, coloured by Stuart aged 7, is shown on the front page. Incidentally, the card is deliberately worded in such a way as to be suitable for other festivals as well, not just Christmas.

If you would like a T shirt version of Stuart's lovely lion, please contact me to register your interest. We do not as yet have any of these, but if there is the demand, we will certainly provide the supply! The same goes for producing this card with a blank interior, in case people would like to use them for other purposes. It seems a shame not to make the most of such a lovely design.

Red Lion Group members can advertise in our supplement section for the very special rates of £10 per quarter page, £17.50 for a half page ad or £30 for a full page ad. These rates are also available to any small businesses outside of the stoma care/skin care industry, so if you know anyone who might be interested in advertising, please ask them to contact me as soon as possible. Corporate rates are slightly higher and are available for larger compa-

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found it very difficult trying to explain to people exactly what was going to happen to me.

Just before it I went to Ireland for ten days with a good friend and I celebrated my birthday there. During that time I developed a bad cough and I was starting to fear they wouldn't operate on me with it. It made no difference except that apparently I had a high chance of getting a chest infection after the operation.

It was very uncomfortable afterwards especially with the physio's nagging me to put a pillow on my chest and cough as hard as I could to get the phlegm up. The last thing I wanted to be doing at that point in my life. The wound also got infected and I had a really hard time changing my bag trying to keep the fluid away from the wound. But I knew it wouldn't be for long…The second operation was in March, the third and last was in July.

What a relief. It was very weird getting used to using my bottom when going to the toilet and at first I was scared to go at all.

The only bad thing about it was that during the night whilst I was in hospital I had complete incontinence and the first time this happened I was horrified. I thought it was going to be like that for the rest of my life and I'd have to wear incontinence pads. As soon as I realised this was just until I started to eat and then it would thicken up and I would have control over it I was glad I had my pouch after all. To this day it has been very well behaved.

I felt wonderful for the next seven months. The only difference to my life as opposed to when I had a colon was that I was now going to the toilet about four times more and there were certain foods I couldn't eat. (Of course I had all my memories and I still felt and feel different in many ways.) I had brought my toileting down quite quickly from 7 or 8 in the beginning.

I started to plan what I could do with my life now that I didn't have illness or operations in it anymore. The first thing I wanted to do was go to Australia – what I had planned to do before I got ill. On the 18th of November I left England and I came back recently to see my brother get married. I have plans to go back as soon as possible after he is married. The only time my pouch has played up was in March of this year when I had an episode of pouchitis. Since then things haven't been quite so good but it still doesn't stop me from living my life the way I want to.

There's no denying I still get depressed about all of it, and talking about it - especially to my mother who has been so very good to me and has sometimes been the only person to keep me sane - helps a lot. The other thing, which helps me, is just trying not to think about it anymore because even I can get bored of my dwelling on it. For most of my time in Oz I was able to forget all about having it and being ill. Only, now, coming home to my parents house reminds me of it all again and that's one of the reasons I am writing this now.

Pulling the pouch over our eyes

One of our older pouch owners asks some searching questions. Julia Williams replies in the following article.

Recently, my husband and I attended a pouch club meeting along with about ninety other pouchees. During one of the programmes, the audience was told by a very informed source that it is still possible for pouch owners to develop cancer or colitis in the "frilly bit" of the remaining rectum that forms the join between the pouch and anus.

This was the first time that we were made aware of this fact and naturally we are now quite upset and alarmed. Does this mean that all pouchees need regular internal examinations and biopsies to confirm continued good health and establish peace of mind? If so, do we have to ask for this, or hope that the hospital monitors the situation at regular intervals without needing a request from us?

Secondly, we were told that eventually I will need vitamin B12 injections. I was aware of this, but I did not learn of it until after the operation, again from a different informed source.

My operation was almost two years ago. How will I know when to ask for these injections? Shall I feel unwell? What symptoms will show?

Thirdly, we heard that the pouch cannot be emptied if lying in a prone position. So, if the need were to arise, will all of the hospital staff be aware of this, or do we need to advise them?

My husband and I feel strongly that every pouch prospect should be given all this important information up front, in order to make an informed decision. At my age (mid sixties at the time of my first op), I am past taking chances and would have been content to keep the ileostomy permanently had I been aware of these issues. Now I feel so full of dread at the thought of another big operation for a renewal, plus any possible complications.

Perhaps there are also other important issues which I have not yet learned about which should be discussed before the decision to have a pouch is made. Maybe this information could be included in the pouch booklets that we are given prior to the op, to give us a clearer idea of the risks arising in the period after pouch surgery. To find out after the event as we have done is depressing and hardly credible.

Julia Williams replies:

It is good that the writer could attend this year's National Association of Pouch Group (NAPG) meeting in Birmingham. It was a well attended information day that offered a sharing of ideas.

The three main concerns are:

Developing cancer or colitis at the junction of the pouch and anus

It is extremely unlikely that cancer will develop at this junction. There is no documentation within the medical literature to suggest a cancer has developed in this junction since ileo anal pouches were first formed in the 1970's. However, no-one can say that this will definitely not happen - simply that the risk is remote. Your surgeon is likely to examine your pouch yearly from approximately 2 years of it being formed. This is so that health care professionals can document the progress of your pouch and also survey it for irregularities.

As for developing colitis, this too is unlikely, unless your surgeon has inadvertently left some rectal mucosa behind following the formation of your pouch. Some people develop pouchitis which is an inflammatory condition associated with the fact that they once had ulcerative colitis.

Some people suffer from cuffitis. This is when inflammation occurs at the join of the pouch and anus. It is minimised by a procedure known as a mucousectomy that your surgeon may do before joining the pouch to the anus.

Pouch absorption changing after a period of 5-10 years

It is recommended that all pouch owners have a routine blood test to include Folate. This should be undertaken yearly and can be done by your GP. Not everyone becomes deficient in Vitamin B12 but monitoring is necessary in order to initiate treatment. The signs and symptoms are those associated with any form of anaemia.

It is unfortunate that you were not advised of the need for this test and I will recommend that this is added as a standard procedure in all pouch care routines.

General nursing knowledge about emptying pouches

Although pouch surgery for ulcerative colitis and familial adenomatous polyposis is on the increase when compared with other surgical procedures such as a hip replacement, very few pouch procedures are undertaken. It will therefore be necessary for you to advise other health care professionals outside of the speciality of colo-rectal disease, exactly what it is you have.

You may find it helpful to mention that a pouch does not empty well in a prone position if you find yourself in hospital.

In summary, the NAPG is working with pouch patients and health care professionals to develop a standard set of information for potential pouch owners. It is widely acknowledged that pouch owners are given varied information depending on when and where they have their surgery. The development of information to allow an informed choice to take place can only be improved upon.

The letter shows the importance of all health care professionals involved in the decision-making process, providing accurate and appropriate information about pouch surgery and its potential complications. Thank you for taking the time to air your concerns.

Committee News…and Another Plea for Help!

We are now in the position where one of our key committee members, David Irving-James, has been ill for some time and in fact has now had to have a reversal operation.

Although David is keen to continue being involved with the Red Lion Group, this is likely to be restricted to working with the East Kent group.

One thing is clear: he will unfortunately not be able to organise the 2001 information day and Annual General Meeting, which Julia Williams has now taken over responsibility for.

Some other committee members are also not well or have family commitments which prevent them from taking as active a role on the committee as they would no doubt wish.

To top it all, as mentioned in the last newsletter, I shall be having another baby before the next issue comes out!

Not that this will reduce our involvement in the Red Lion Group at all. But it does mean that neither Brian or I will be able to play any more of a role on the committee than we already do.

As a result of all of this, the committee has agreed that we must consolidate our strengths and concentrate on producing the very best pouch support newsletter that there is (and many of you have kindly written to tell me how much you value *Roar!* and the work we do). We simply do not have the manpower or cash resources to do anything else.

We would love to organise events to raise funds for research, or do more to help the local groups get going, but both of these need someone to take charge of them overall. As no-one has volunteered in response to previous requests, we unfortunately cannot pursue either course.

There are reps out there, some more active than others, and we wish them all the best in trying to organise local events. I have to say that local groups will only flourish where a number of members are prepared to get involved jointly, to spread the load. If you are a member of the Red Lion Group wondering why there is not more going on in your area, perhaps you could look at the question in a different light: what are *you* doing to help your rep keep a local group up and running?

Anyway, on a national level, I am delighted to welcome Christine Lawton as a co-opted member of the committee. She has kindly agreed (despite a job that takes her away from home a lot, a conservatory in the process of being built, dependent relatives and surgery planned for the end of the year) to take on the task of controlling the merchandise and card sales.

From now on, all orders for merchandise and for Christmas cards should be placed with Chris, as detailed in the advertising supplement to this issue.

It may be that there will be some break in this service after her operation, but we shall play that by ear when it happens.

For now, I am extremely grateful for Chris's generous offer to help us in this way, and hope that she will be able to become a full member of the committee at next year's AGM.

In the past, we have put out various pleas for help on the committee, and I know that there are people out there who would like to help but are unable to commit to four or five Saturdays a year, either because of time or the distance involved in travelling to Harrow.

As you know, we have had various good fund raising ideas and other plans in the past, but with a shortage of people to take charge of these, they tend to fizzle out to nothing.

The most recent committee meeting was held by telephone, and it was agreed by all who took part that this is a very valuable way of holding meetings (subject to Brian and me getting a decent speakerphone!).

Telephone conferencing has a number of advantages:

- People do not have to give up more than an hour or two of their weekend
- No travelling involved so people from any part of the country or in any state of health can get involved
- The conversation is very focussed and task-orientated, which should make the meetings more productive

Because the only expense to be paid is the phone call (which is billed direct to the Red Lion Group), it is a very cheap way for us to meet, which means more funds available for other purposes.

The main downsides are:

- The loss of non verbal communication, which can often say a lot more than words
- No more snacks and coffee provided by Julia!

We have agreed that in future all further committee meetings will be held by telephone except for the first one after the AGM each year. We are also provisionally planning to have that face to face meeting on the day of the AGM itself, so that a separate journey will not be necessary for members travelling from further afield.

I hope that this means some Red Lion Group members will consider joining the committee in order to spread the workload somewhat, given that the time commitment is much less than it has been in the past. It should also make it possible for those members whose health is not the best to contribute to the running of the group.

If you think *you* might be able to help, please do contact me so that we can talk about how you might get involved in a way that is manageable for you and beneficial to the Red Lion Group.

I must stress it is only with a regular injection of fresh faces into the committee that the Red Lion Group will continue to prosper.

Morag Gaherty

Helvellyn or Bust!

Helen Bradshaw's idea of a "holiday" seems curiously at odds with most people's, but it was certainly a challenge which she rose to meet (or, rather, it rose to meet her) …

No, this is not going to be another "I've got a pouch/stoma and it does not affect my life at all" type of article. It is more a description of an experience which shows you can adapt to anything.

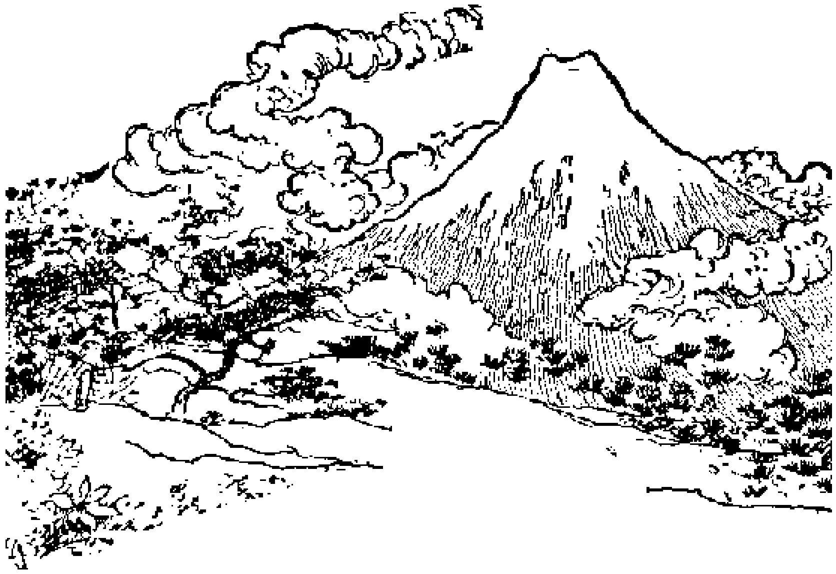
I have always loved walking and, admittedly, no-one goes to the Lake District for its easy flat foot work, but it seemed that the best way to conquer a strenuous project like Mount Helvellyn was to "work up to it". A sailing chum of Colin's had remarked - on hearing we were going to Cumbria: "Helvellyn and Striding Edge?" which, in my view, from male to competitive male, is a challenge as good as made.

The restless slight dissatisfaction the man in my life had been displaying would not, I knew, disappear after a few lakeside strolls. I knew I had to take his "but I want to *climb a mountain*!" wails seriously.

Life, as they say, is what happens when you've made other plans. The first week of the holiday was rushing past and the weather was not being generous. Then Thursday dawned a beautiful clear sunny day and we knew we may not get another like it.

We thought of the relaxed attitude of the people we talked to as we set off at 9am. "You'll be back in 5 hours" said the Information Office staff (had that individual done the expedition himself? we wondered) and "it's OK the path is two metres wide" said the lone male adventurer also setting off. Were they giving us well-meant encouragement? Probably.

We did not find any 2 metre wide path, but we did find what looks like a mile long heap of craggy stones, rocks and boulders which have been hammered together into a giant horseshoe shaped crest, with a sheer drop each side. There was no turning back, so Survival takes over and you concentrate on the next bit of "wall" in front of you, and the next foothold/handhold. You resist the temptation to look down!



I can honestly say that the only time I felt like panicking was when I seemed to be in a tight spot and could not see the next step up, down, left or right. I had one or two images of a mountain rescue helicopter being called out to a "frozen" female unable to move, and the sheer ridicule which that would involve soon got the grey matter going again.

As you work away at the task, you start to love the solid boulders and tough long grass, all cemented in for your benefit. You literally embrace them all as you ascend, and they don't let you down. Ever protective, Colin carried both our back-packs to make it easier for me. Chivalry is not dead.

It is a curious thing, but what had been bothering me physically as we toiled up the ascent path earlier disappeared. The aching irritable knee, burning irritable pouch even, the fibrositis in my neck … I don't remember even being aware of these as we rock scrambled. Is this adrenaline, or simply that I was too distracted to notice them? Is it the same phenomenon which makes soldiers in battle report that they don't get indigestion etc?

No-one hassles you as you negotiate your way along: everyone seems to accept that you have to go at your own pace. Everyone looks out for everyone else. On the summit, complete strangers congratulate each other and chat, willingly acting as photographer. It is heartwarming.

The summit of a mountain, even a modest 3000 foot one, is like nowhere else on earth. To be able to stand and command so many neighbouring fell tops, green velvety slopes and valleys, and watch the sun and clouds make moving patterns on the land and mysterious isolated blue lakes is eerie and humbling.

I would like to be able to say that my pouch caused me no problems all day, but it rebelled against the unaccustomed exertion all the way along the descent path. Fortunately, sheep are unembarrassed by humans diving behind piles of stones in desperate need of a private spot. I mention this to emphasize my point that people seem to find a way around their disabilities and life does go on.

I have no wish to "do" Mount Helvellyn again, but the sense of achievement is permanent.

Letters

Roar! Letters Page
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Dear Editor

I have now had my pouch in operation for over 6 months. To start with, I had very few problems, except having to go to the lavatory several times a day! Unfortunately, I have had two episodes of what the stoma nurse and I both think is pouchitis (not yet confirmed by a doctor). So at the moment I have been feeling ill and generally low for about 6 weeks. It seems to be clearing up now, but I am now being fast-tracked to see a specialist here in Southampton, where I moved to live with my Mum, as I expected to be out of work and under the weather for some months.

The pouchitis has left me a bit underweight and hasn't done my appetite any favours. I am a bit concerned that I will keep getting episodes, and will either have to go back to an ileostomy or otherwise have a very difficult life.

I have got a Law degree, and plan to study for my Legal Practice Course (1 year at University) in September 2001. Following this, I plan to do my Articles, probably in London. Having bad health would quite possibly prevent my doing any of this, hence I am eager to hear from people who may have had a similar experience. I would like to think that things will improve.

Jennifer Leeder
Tel: 01703 443548

Dear Editor

I thought I would tell you about the "Boots and Buckles" and the "Hillsborough Hoedowners" clubs to which I belong *(ed note: Sharon also sent us a newspaper picture of the line dancers in action, which we are unfortunately unable to reproduce clearly)*.

We danced for a few hours on the 1st and 4th of July in Lisburn Mall to raise money for this year's chosen charity in aid of Hodgkins Disease. We do various events throughout the year, with the money raised going towards the chosen charity. I have only been doing this for a couple of months so far, but enjoy it a great deal.

Maybe next year I could convince everybody to choose Bowel Research of some form!

Sharon Hendron

Dear Editor

Following on from the article on Probiotics and Prebiotics in issue 17 of *Roar!*, I felt I just had to write to tell readers how beneficial I have found Acidophilus capsules. These are the freeze-dried preparations mentioned in the article.

I have to date suffered three bouts of pouchitis in four years, each necessitating a course of antibiotics to clear it up. Unfortunately, on every occasion the cure produced its own problems, namely a yeast infection or "thrush" - which proved even more stubborn to eradicate than the pouchitis!

However, since a friend recommended Lactobacilli Acidophilus, I have been smiling. I call it my 'anti-antibiotic'! You can buy it at chemists and health shops or by mail order through some of the vitamin and mineral suppliers. The advantage is that, unlike yoghurts or the Yakult drink, you can keep a container in the fridge ready for when it is needed (rather than for use in the short sell-by period of fresh probiotics). One capsule is equal to about ten yoghurts.

Although I hate having to take even more tablets, it is a small price to pay to keep healthy.

Sandy Hyams

Dear Editor

I read with interest the letter in issue 17 from Judy Pix. First of all, I would just like to convey our best wishes to her son Daniel and hope he continues to do well following the terribly traumatic illness he has recently suffered.

My husband John developed UC in the mid 1980's. He also took Roaccutane for severe acne in 1982/83. We had never connected the two prior to Judy's letter. He struggled for several years through many flare ups and eventually had a pouch formed in 1996 following a three stage procedure.

If this information is of any help, please do not hesitate to contact us.

Patricia Noble

Ed note: Patricia's letter has been passed on to Judy, as she is collecting information from anyone who developed UC sometime after taking a course of Roaccutane.

Dear Editor

I am a 35 year old mother of twins who developed UC during pregnancy in 1998. After having an ileostomy in July 1999, I decided to go for the pouch op in March of this year, with closure in May.

Between the two operations, I was very unwell and lost two stone. I have not been well since May (it is now August). In the last few weeks I have developed sero-negative arthritis and am unable to walk very far, as I have very painful knees, feet, shoulders and left hand. I did not have arthritis before the pouch operation, or any symptoms.

If anybody has had a similar experience or suffers from UC and arthritis, please contact me on 020 8883 8216, as I am very keen to speak to other people who are in a similar situation.

Please keep up the good work with *Roar!* It really helps to read the magazine and to know that others have coped with similar experiences.

Joanna Reed

Information Day and AGM 2001

As you will see from the Committee News article, David Irving-James will unfortunately be unable to organise this event next year, and his skills and thoroughness will be sorely missed.

We were considering moving the event to Ashford Hospital, on the grounds that this has good access and facilities, and would be much easier for both Essex and Kent members to attend (who form a large proportion of our members), as well as being very convenient for David to organise. The choice was effectively between St Marks and Ashford.

Now that Julia is taking over responsibility for the event, Ashford is no longer a viable option, and so the venue and date are now definitely fixed as: **St Marks Hospital** on **7 April 2001**. Please put the event in your diary now.

David has already done some of the preliminary organisation, and I know that he has approached a good selection of speakers. Full details about the day will be contained in the next two issues of the newsletter, as they are finalised, and the booking form will be included with the Christmas issue.

We look forward to seeing you there!

Continued from page 3

nies on request.

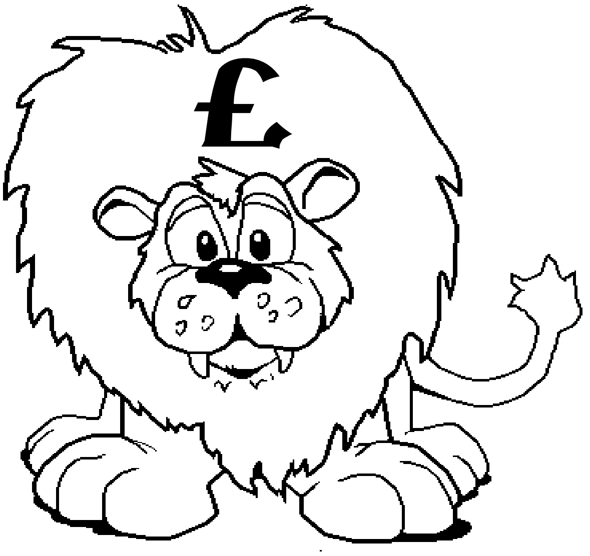
Please do read our Committee News section carefully and consider whether *you* could offer some assistance to the Red Lion Group, however small. It is not healthy for us to be reliant on a very small number of key committee members, as David's recent surgery proves. For instance, we really need someone to take on responsibility for the advertising - both finding advertisers and putting the supplement together. Equally, Julia could really do with someone local to St Marks who might be able to help her with the task of organising the 2001 AGM.

The AGM date and venue have now been settled on definitely, as you will see in this issue, so please do put 7 April 2001 in your diary now. There were criticisms that we clashed with NACC's day last year - in our defence, I can only say that our date was originally published well before theirs, even though both of us were late in issuing booking forms. This is partly a reflection of the fact that our Spring issue comes out at the end of March, and our AGM is in April. For 2001, however, booking forms will go out with the Christmas issue of the newsletter - and woe betide anyone who complains that this is too *early*!!!

The raffle tickets which were included with the last newsletter have sold pretty well, so far raising over £100 for the Red Lion Group. I forgot to include the practical information in my article last issue, but most of you worked it out pretty well: the cheque payee should be Red Lion Group, and ticket stubs need to be returned with your payment to our treasurer, John White, by 15 October 2000. If you have not yet taken part, there is still time to do so - the prizes are great and the Red Lion Group benefits directly. There are still a few tickets left, if anyone would like to order some more: contact me for these.

Morag Gaherty

Please support the Red Lion Group



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 John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE**

Getting Help with Water Bills

Morag Gaherty summarises the rules and provides a few suggestions on how to go about claiming help.

Red Lion Group member Gill Tomlin has been successful in her claim to receive a discount on her water bills, based on her medical condition and increased water need. Her water company is South West Water, but the rules concerning this discount are Government rules, and so apply nationally.

Here is a summary of the conditions:

You must pay metered charges rather than water rates AND

You must be in receipt of one or more of the following benefits: income support; income based jobseeker's allowance; working families tax credit; disabled person's tax credit; housing benefit; council tax benefit AND

You must either have three or more dependent children (under 16) normally living with you OR be diagnosed as having and be receiving treatment for desquamation (flaky skin loss); weeping skin disease (eczema, psoriasis, varicose ulceration); incontinence; abdominal stomas; kidney failure requiring home dialysis OR you have at least one child living with you receiving treatment for any of the above AND

As a result of your condition, you are obliged to use a significant volume of water.

You will not qualify for help if:

The home for which you pay charges is not your only or principal residence OR

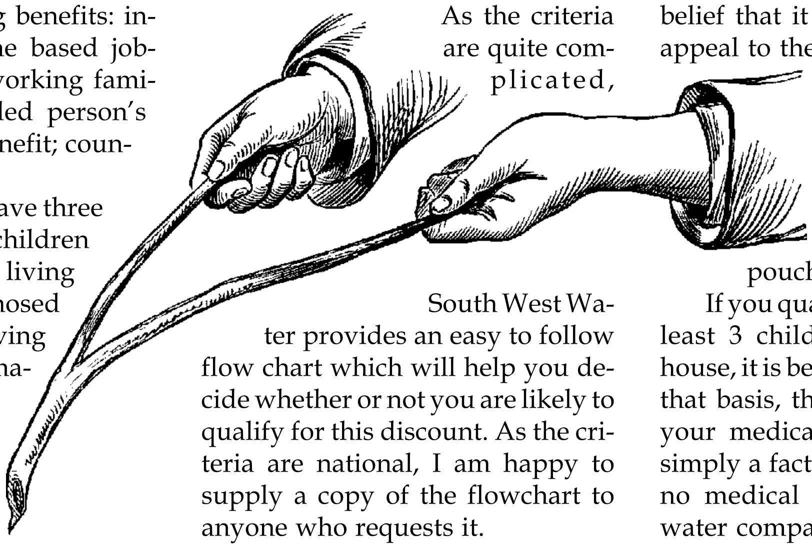
The premises where you live is largely used for "other purposes" rather than as your home (eg it is a business premises) OR

You have a swimming pool or pond greater than 10,000 litres capacity which is refilled automatically from the mains water supply.

Obviously, these secondary conditions are intended to stop people who try to claim the discount based on excess water usage which is not caused by their medical condition or children's needs.

If you meet the various criteria, you will not have to pay more than your local water company's average annual domestic water and/or sewerage charges. These are set by the Office of Water Services each year. At the end of each year, your water consumption is checked and if you in fact used less than the average charges, you will be refunded the difference.

As the criteria are quite complicated, South West Water provides an easy to follow flow chart which will help you decide whether or not you are likely to qualify for this discount. As the criteria are national, I am happy to supply a copy of the flowchart to anyone who requests it.



You need to reapply for the discount every 12 months from the date of your last meter reading before your claim was processed. If you do not reapply, or if you fail to qualify in a later period, your account will revert to standard meter charges with effect from the next reading.

As with the question of prescription exemptions, for Red Lion Group members the key issue is whether a pouch can be said to fall into the category of an "abdominal stoma". This is another case where the standard terminology used has not kept up with surgical advances.

We would advise all members to be clear about the nature of their surgery and to use the argument put forward by our founder chairman, Dr Martin Peters. This argument is that the pouch is effectively an internal equivalent of a stoma bag, and that the outlet is simply through the bottom rather than the abdomen. If you have a Koch pouch, which does have an abdominal stoma, then there should be no difficulty.

Success or otherwise of this claim will no doubt be on a case by case basis, although the independent Ofwat Customer Service Committee has binding powers of determining any disputes about a customer's entitlement to help. It is our belief that it is *not* a good idea to appeal to them if your water company does not agree that your pouch should qualify, as a negative decision from them would then be binding on all pouch owners.

If you qualify through having at least 3 children under 16 in the house, it is better for you to claim on that basis, than on the grounds of your medical situation, as this is simply a factual issue that requires no medical consideration by the water company.

If you think you may be able to claim this discount, you should contact your own water company for a copy of the application form. When you send it in, you will need to produce a photocopy of your latest notice of entitlement to the benefit(s)/tax credit(s) you receive, and will also need to provide your National Insurance number. In addition, if claiming on the basis of your medical condition, you will need to give your doctor's name and address and a copy of one of your prescriptions. Full details are given with the application form.

If anyone attempts to claim this discount but has their claim to entitlement rejected by their water company, please do let us know, so that we can continue to advise our members about the likelihood of a successful claim.

Please Complete our New Gift Aid Form!

Our treasurer John White explains why every Red Lion Group member is asked to complete and return the new Gift Aid form enclosed with this quarter's newsletter.

As I am sure many of you are aware, as from the 6th April 2000, all donations (including subscriptions!) made to a registered charity can have the income tax element reclaimed. Prior to the 6th April 2000, this could only be done where the donor had signed a deed of covenant.

To enable the Red Lion Group to make claims, it is necessary for each member to complete the form enclosed to advise if you pay tax or not. We must have your written instructions regarding this, or we can't claim.

It is of course possible that you do not pay income tax, but perhaps do pay tax on building society income or income from shares. In this case, we can still claim the amount back providing you pay at least 28p in every pound you donate (ie to cover a £10 subscription, you need to have paid at least £2.80 tax in the same tax year).

No more deeds of covenant will be issued, but those in force continue until their end. However, it is also necessary for those people who have signed covenant forms to complete the new form.

It costs you nothing, but can increase your donation to the Red Lion Group by £2.80 in every £10 you send. To put that into context, the £3,000 of subscriptions that we have so far received this year would become £3,840 for the Red Lion Group - I hope you agree that this "free money" is worth putting pen to paper for! That does not even include the value of the donations we have received, which are similarly increased in value to us.

Why not complete the form now and send it straight back to me, before it gets put to one side and maybe forgotten? My address is on the back page as usual. Thank you.

John White

Wipe a smile onto your bum

After a few false starts, Carole Moore finds the perfect wipe.

When I was in hospital having my W pouch formed, the stoma nurse seriously instructed me that on no account was I to use any sort of wipe on my rear end. She said that this was because they all contained alcohol, which is a drying agent, and it would damage the delicate skin.

Although my brain took this in, I was aware of something subconsciously muttering "Hang on a minute, surely a lot of these are designed to be used on the delicate skin of babies?" Maybe she was thinking of the kind that you take on picnics to remove the stickiness from your fingers? Oh no, she was adamant, all kinds of wipes were taboo.

So for over a year I kept sordid little cloths in the bathroom and even carried them with me when I went anywhere. Then I rebelled. I bought a pack of Camille wipes and tried them out. No problems. Next time, I tried Boots' own, which were cheaper. They seemed OK initially, but after a few days I noticed a faint itching, so I stopped using them. I also experimented with the ones made by Andrex. The scent was so strong I kept thinking that I had spilt a bottle of perfume. Definitely not for me!

Camille are great. They have a very mild fragrance which is not at all pervasive. You can buy them in boxes of 70, or as individual wipes packaged for travelling. These are a lot more expensive and you can just as well put one of the mass purchase ones into an airtight container to carry with you.

On reflection, I think that the nurse must have become confused with advice which was intended for those people with the Koch pouch, who have a stoma, as opposed to my model, which leaves me with a perfectly normally functioning anus.

It would be interesting to know if others have had this kind of mistaken advice. I have often thought that it is difficult to know when reading articles in *Roar!* which type of pouch the person means, and it really can make a big difference to whether the same instructions or information apply to one's own situation.

Incidentally, I would like to make it clear that I have no financial interest in promoting sales of Camille - I just think they're great!

Morag Gaherty comments:

When we use the term "pouch" in this newsletter, we mean an ileo-anal pouch. ie one that is inside the body and empties through the bottom. There are a number of different designs of ileo-anal pouch, such as the J pouch, W pouch and S pouch, but these all refer to the configuration of the pouch inside the body - externally, they all appear the same. Most of the time, this is the kind of pouch we mean.

Some of our members do have Koch pouches, which are technically abdominal pouches. This means the pouch is inside the body, but empties by catheter via a stoma situated on the abdomen. Whenever this kind of pouch is meant, the term Koch pouch or abdominal pouch will always feature when it is first mentioned, even though it may be referred to simply as a "pouch" later on.

Other groups which support both ostomists and pouch owners (our definition), may use the term "pouch" in their newsletter to mean either an internal pouch or an external stoma bag. It is sometimes not clear which is meant, except by reference to the context. To avoid this kind of confusion, we at the Red Lion Group tend to refer to ostomy products as a "bag" and I edit the *terminology of any articles if necessary to ensure that this editorial policy is consistently applied.*

Moving onto the subject of wipes and sore bottoms, this is a topic with which I am very familiar, in my other guise as The Nappy Lady (see my advert in the supplement!).

Although baby wipes are supposed to be designed for baby's delicate skin, midwives and health visitors do not recommend them, especially not for newborns. You only need to look at the list of ingredients on the pack to see why not.

When a child has nappy rash or a sore bottom, putting commercial wipes on these is nothing short of torture for them and the same applies for adults with sore bottoms.

Many of my nappy customers prefer to use washable wipes with their own wash recipe, so as to avoid any chemicals on their child's bottom. In case anyone is interested, I sell two varieties of wipe: flannelette squares or small stretch terry squares.

However, if you get hold of a pack of Sainsbury's Extra Thick wipes (these seem to be best!) and wash them, you will end up with a pack of fairly durable wipes of exactly the right texture for comfort which you can rewash for about a month or two of daily use.

To use any of these washable wipes, the most soothing wash recipe I have come across is an infusion of Twinings Camomile and Honey tea, stored in a dispenser bottle and added to dry wipes as required, or poured over the wipes while they are stored in an ice cream tub or similar.

The mixture should be changed every few days. When Bob's 1st stage molars were coming through, his poo was a dreadfully caustic green slimy thing which burnt as soon as it came out, and this wash recipe was the only thing he would allow near his sore bottom. It also cleared up the burns remarkably quickly.

Camomile is extremely soothing and honey is a natural non sting antiseptic. I know many women who swear by this as a miracle cure for nappy rash, so if you have a sore bottom yourself, I recommend trying it out. Camomile tea on its own is also good, but the addition of the honey really does seem to help clear up soreness.

What Katy Did

Sandy Hyams tells a poignant tale with a happy ending.

Katy must have been feeling ill for several months before we realised what was happening. After all, she was only just past her eighth birthday and notoriously fickle and picky.

The first we noticed that things were not quite right was when she appeared at times lethargic, off-colour and not interested in anything. Tara, her sister, wondered what she had done wrong, because Katy did not want to play with her any more. Her toys lay neglected in the corner. We thought it was probably just a phase she was going through.

Then, unaccountably, she started refusing her meals - not every day, but enough to concern us. We tried tempting her with little titbits and delicacies. Sometimes she would relish them with evident enjoyment, other times she would just turn up her nose.

But when she rejected chocolate biscuits and other favourite treats, we really began to worry. By now her ribs were beginning to show and we could tell that she had shed several pounds on her self-imposed diet. She was actually fading in front of our eyes, but it had been so gradual and over so many weeks that the seriousness and the extent of her illness had not been immediately apparent. We later discovered that Katy had lost 18% of her body weight. It was time to seek urgent medical advice.

Our sympathetic doctor carried out the usual examinations, prescribed a course of antibiotics and told us to come back in a week if her condition didn't improve. Meanwhile she took a blood test and a urine sample. The former showed up all kinds of abnormalities, but nothing specific.

After a few days it was quite evident that Katy was not getting any better. So it was back to the surgery and more deliberations about how to treat her and what to do next. As our doctor was worried that the symptoms suggested a tumour, she believed that an exploratory operation was the only way forward.

We were distraught to think we might lose her. And how could we pacify Tara as well as holding up ourselves? Katy looked at us piteously with her big brown eyes, and it was heartbreaking.

I will pass over the details leading up to the day of the operation. It was a tense, anxious period for all of us, bringing back memories of my own weeks in hospital.

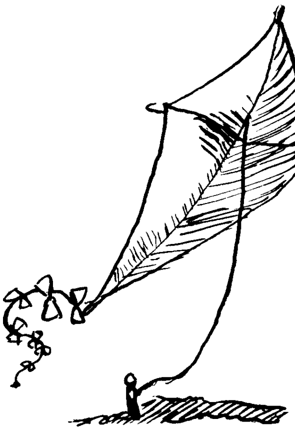
Following surgery, we had a nail-biting week of waiting for the biopsy to come back. Finally, we were given the news by our doctor: Katy had IBS - Irritable Bowel Syndrome. We were both relieved and incredulous.

It was also a relief to find out that medication and a hypo-allergenic diet can help the problem. So Katy is now restricted to wheat- and gluten-free food, and has to take steroids for the rest of her life.

The change in her is nothing short of miraculous. She is full of life again, enjoys her food and is back to the Katy we remember. Watching her play with her sister, running after balls and tearing around the garden, we were thankful that our doctor had been able to help her in time.

The effects of steroids are renowned, of course. Apart from causing mood swings and weight gains, they can give rise to hair growth on the face. But I don't think Katy will mind. I didn't know that dogs could get IBS - did you? Now we're wondering what Katy will do next!

See page 12 for a drawing of Katy.



Christine Lawton's Open Letter to the Red Lion Group

Hello everybody, I have just joined the Red Lion Group and hope to take good advantage of its support. (Have the tee-shirt already!) I am awaiting surgery (not less than three months from now, I think) and I have found the information and help I have received from the Red Lion Group invaluable in my choice between the two operations on offer – sounds like mail order, doesn't it? Anyway, I have chosen the ileo-anal pouch procedure and I hope it works!

I hope I am, to an extent, fairly *au fait* with some of the difficulties I might encounter, but will obviously have to see what happens. In 1978, in the days when pouch surgery was in its infancy, I was given an ileo-rectal anastomosis for ulcerative colitis.

Some people contemplating surgery for UC may be put off by the fact that it's not very nice. However, I found that there was no comparison between the way I felt before the operation and the way I felt the day after it: I was a new person immediately. I think the surgeon, Mr Arnold Elton, was fairly taken aback when, on the first morning after my op, I told him that it was the happiest day of my life! He must have thought I was still under the influence of anaesthetic. But little did he realise how *compos mentis* I was and I certainly meant it. Never have I been more overjoyed to get rid of anything than I was of that emaciated dangling useless mass they called my colon!

Unfortunately the bit left behind was the cause of continuing spasmodic inflammation of varying intensity – though not the agonising pain and devastating discomfort I was in before, and now I could at least stand up straight. However, this year, for various medical reasons, it was decided I should have an operation to remove the rest, whilst I am still relatively fit and of a more tender ??? age. Well…

I am wondering whether, with the pouch surgery, my muscles will work in the same way as they have been doing for the last 20 odd years, and consequently whether I will find it easy to adjust. When I asked the doctor this, he didn't know because they don't come across many people who have had an IRA. I would be interested to hear from anybody who has had the experience of changing from an IRA to a pouch. My E-mail address is christinelawton@aol.com and you can write to me at any time or ring me on 020 8904 7851.

I am determined to get fit before my operation. I am doing workouts at my local gym, which I just happened to have joined in January before I knew about any of this. I have consequently lost a stone and 12 pounds – don't ask me what that is in kilos; I can never understand my weight on hospital scales.

Between working, I am doing lots of fun things and, in a strange kind of way, looking forward to my hospital stay, as I always feel totally relaxed and confident in St Marks. They have such a clever way of putting you at your ease. During my stay, I shall look forward to meeting anyone from the Red Lion Group who feels like having a chat.

Above all, I think a positive attitude is invaluable to help one get over surgery and become fully fit again. No matter how uncomfortable, I never lose sight of the ultimate goal: a happy, normal, healthy life. I am sure that, with the help of the surgeon and staff of brilliant St Marks, that is what I will achieve.

In the meantime good wishes and good health to you all.

Katy the Airedale

A Cautionary Tale...By Ann Thomas

I was interested in your article on unconventional remedies in issue 17 of *Roar!*, in which you stated that you are keen to hear from readers who have tried any alternative remedies. I have had two particular experiences, several years apart. One was absolutely disastrous, and led me to conclude that these "treatments" are at best a waste of money and at worst very dangerous. The other was very rewarding.

In 1987, my UC which I had had since 1976 was amazingly well controlled with Salazapirine. I had reduced the dose to once or twice daily, and I was emptying my bowels three times within half an hour of getting out of bed in the morning, and not again until the following morning.

I was attending the Out Patients Department once or twice annually where, because I was so well, I no longer saw my consultant in person. On each occasion I saw a new young face, presumably as each doctor passed through this section of his training experience.

Then, like a bolt from the blue, I was told by one such doctor that, as I had had UC for over 10 years, I would be having my colon removed in the near future! Despite being a member of NACC for several years, this was the first time I had heard of any such possibility and I had no idea there was any such thing as a pouch, and if the doctor did he certainly didn't mention it.

In panic I had to find a "cure" to prevent such drastic surgery. I heard a herbalist speaking on a local radio programme, made an appointment for a consultation and the "treatment" began. My condition took a massive nose dive.

I felt extremely unwell, very weak, constantly feeling close to collapse or passing out. However, she told me that was part of the "detoxification" process, that I should persevere and would soon feel better. But I didn't improve. I felt so ill I couldn't drive; couldn't go to work; couldn't look after my small daughter and began to think I wouldn't survive.

I didn't keep my next appointment, even though I'd already paid for it. I stopped taking the various potions she'd recommended and my GP made an urgent appointment for me at my local hospital. My health immediately began to improve, but it was never to be as good as it had been prior to this little diversion from conventional medicine.

My Salazapirine was increased to a much larger dose which resulted in me developing a very severe rash which caused scarring for years afterwards. I went on steroids for the first time and couldn't get off them again, as each time I tried my UC spiralled out of control and I was given an even larger dose. I was admitted to hospital and developed all kinds of complications: pneumonia, pleurisy, blood clots, P.E.s etc.

By now the removal of my colon was undisputedly necessary, but I was too ill for surgery! Ten months later, in 1990, I finally had a colectomy. Would all of this have happened without the trigger of the acute reaction to the herbs? I don't believe so, but I don't know and I certainly couldn't prove it. Not surprisingly, it made me extremely wary.

Then in 1996, the time came for a decision to be made about my rectum, which had not been removed with my colon because of the severity of my illness. I was referred to Prof (then Mr) Nicholls at St Marks, who agreed to give me a pouch only if two out of three conditions could be met: the illness had definitely been UC and not Crohns; my blood clotting problem was under control; and my anal fissures - which I had had for a number of years - had healed.

During the twenty years I had had the disease, for three years one doctor had diagnosed Crohns, everyone else believed it to have been UC. After further tests and reports, Prof Nicholls agreed it was UC. For the blood clotting, I had been taking Warfarin since 1990, but I had also begun to eat loads of garlic, including garlic pills, which I had been told was good for this condition. The pro thrombin tests I had regularly seemed to bear this out. And last but not least, I took the plunge and made an appointment to see a practising NHS GP who also had a private homeopathic clinic.

Despite the relatively safe reputation of homeopathy, after my last experience, I was only prepared to consult someone who was completely au fait with my medical condition. He was able to carry out blood tests and prescribe conventional as well as homeopathic medication. This time I felt well, and in a matter of weeks Prof Nicholls confirmed that the fissures had healed.

The rest, as they say, is history. I have had my pouch for three years now. I no longer need to take the Warfarin, which I had originally been told I would need to take for life, and I have not any more fissures.

The pouch is not without its problems, for which I have again consulted a homeopathic practitioner. Unfortunately, the previous one had retired and moved out of the area. The new one was not medically qualified and I hadn't the same amount of faith in her understanding and knowledge. Whereas my previous experience had been relatively short and the results easy to verify, the latter seemed to be going on indefinitely without any discernible improvement.

Also, whilst I wanted to get to grips with some of the practical difficulties of pouch function, we seemed to be spending weeks working on improving my stamina and well being. I went along with this for a while, but decided that these would only improve as a result of improved pouch function.

Them of course, there was the cost. The GP had charged an initial consultation fee, for a very long and thorough case history, followed by regular telephone calls and medication for a much lower charge. This time, it involved frequent trips to the therapist's surgery, involving the full consultation fee plus charge for medication each time. And whilst the medication prescribed by the GP had arrived by post from a consistent source, the therapist had simply handed me a small envelope containing the pills after the consultation, without giving me any specific information about what they were supposed to improve. I've wondered since if she bought them from Boots!

I'm not really as cynical as I sound. I have in the past dabbled, in yoga for example. Basically I would say give these things a try - some could be very beneficial, but there are a lot of "therapists" jumping on the bandwagon. And whilst, apart from a bit of wasted cash and time, most people lose nothing from the experience, people with more serious conditions could lose a great deal, so be careful.

Also worth bearing in mind is that swallowing herbs brought what can be very potent medicine into direct contact with my diseased colon. On the other hand, any active ingrediants in homeopathic treatments are so diluted as to be rendered harmless, and they simply act as a trigger for the body's own defence and healing systems.

Ed note: Ann's frightening experience is a useful reminder that "natural" treatments are not always the harmless things they appear to be. Whilst homeopathy and osteopathy are both approaches recognised by the British Medical Association, it is still important for you to ensure that the practitioner you visit is suitably qualified and is a member of a recognised association. A conventional medical background is probably a good sign.

As for herbal treatments etc, these are potentially far more powerful and herb/drug interactions are often not known about. Herbalism is not (yet) recognised by the BMA, so it can be difficult to ensure that you are getting sensible and appropriate advice. Whilst we would not wish to discourage pouch owners from trying alternative remedies, an awareness of these risks is very important. It is always worth discussing possible interactions with your medical practitioner.

Continued from front page.

surgery is being offered at more and more locations nowadays. There are hospitals which have a high number of annual cases, because it is what they specialise in. And there are hospitals and surgeons which only do 2 or 3 such operations a year, although they will usually have trained in pouch surgery at one of the recognised centres of excellence.

It is essential to feel confident in your surgeon's knowledge and ability. Any surgeon should be willing and able to give you details about the number of pouches they do each year, and what their complication rate is. If this information is not forthcoming, or the answers you get do not reassure you, I would recommend a request for a second opinion at a centre of excellence.

If you already have a satisfactory ileostomy, and have been offered a pouch, you must consider what advantages a pouch will bring you. If you feel a bag either curtails your lifestyle or makes you feel a "freak" (to quote one of our members), you will consider the idea of a pouch far more positively than someone who does not suffer from either of these concerns. Swapping a known situation that you are happy with for an unknown quantity which may bring with it various new risks is not an easy decision to take.

I recently spoke to one young man who had an ileostomy and a very active sporty lifestyle. The bag was no hindrance to him at all, either physically or emotionally. In the end, he decided against pouch surgery, because the bag in no way interfered with his chosen lifestyle and so the potential benefits of the pouch were negligible for him, in comparison with the disadvantages of the post operative recovery and the potential future risks.

There is also your age and situation to consider. The older you are when you have a pouch, the more important the risk of possible future problems becomes. As each year goes by, you will necessarily be older and frailer, and so any surgery will be harder to recover from physically. An ileostomy may offer a surer outlook, although of course there is the downside with an ileostomy that the bag can be harder to manage as you get older. Having said that, we have many older members who had their pouch at an advanced age and have never regretted it, even if it has not been all plain sailing.

The younger you are, the more you may be prepared to accept the *potential* risk of pouch failure after 20 years as a price worth paying, if it gets you 20 years of bag-free living in the meantime. The younger you are, the more important the question of body image is likely to be, thanks to pressure from the media and our peers.

The decision of whether to opt for a pouch rather than an ileostomy is not a straightforward one, as the above article shows. There is no "right" answer. All you can do is consider carefully the issues, and attempt to weigh their relative importance to you. A pouch can always be reversed to an ileostomy, whereas the decision to go for a permanent ileostomy usually rules out the chance of a pouch at a later stage. If you are prepared to undergo a further bout of surgery if necessary, choosing a pouch gives you more options for the future.

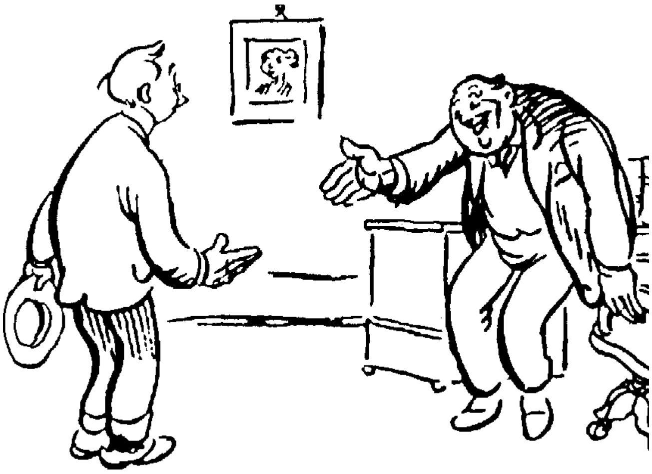
In summary, before making the decision to have a pouch please do take the opportunity to speak to your healthcare professional to obtain as full a picture as possible. Our specialist pouch nurse, Julia Williams, is also available as a sounding board, if you require further information or help. Her number is on the back page.

Finally, speak to as many pouch owners as you can - you can contact any of our regional reps, or any member whose number is published in the newsletter, and you can ask me to be put in touch with others. If the one person you speak to has a great pouch, this gives you no more balanced a view than if the one person you speak to has had nothing but problems. In your attempt to make an informed decision, you do not want to be swayed by the personal experience of a single individual, and the more people you talk to, the less likely this is to happen.

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 Red Lion Group rep, please contact Morag Gaherty (phone number on back page).



AVON		
David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
Wendy Gunn	Luton	01582 423714
BERKSHIRE		
Liz Davies	Langley	01753 586593
CAMBRIDGESHIRE		
Joyce Shotton	Peterborough	01733 706071
CLEVELAND & NORTH YORKSHIRE		
Christine Jackson	Saltburn	01947 840836
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DEVON		
Gill Tomlin	Kingsbridge	01548 810028
DYFED		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
EAST SUSSEX		
Lisa Critchley	Brighton	01273 699286
ESSEX		
Peter Zammit	Benfleet	01268 752808
Clare Shanahan	Ilford	020 8591 2936
GWENT		
Robert Challenger	Cwmbran	01633 866820
HAMPSHIRE		
Phil Smith	Portsmouth	01705 426541
Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Carol George	Stevenage	01438 365707
KENT		
David Irving-James	Folkestone	01303 894614
Phil Elliment	Barnehurst	01322 558467
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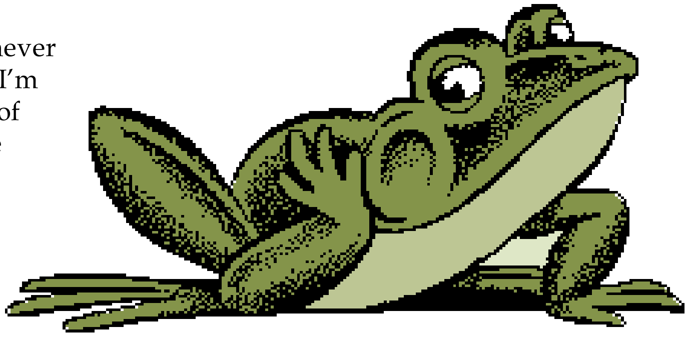
Hopping Mad!

A little frog recently made Christine Lawton smile…

My cousin lives in a bungalow in a Durham village. Her mother went into the toilet the other night and came rushing out immediately. My cousin went in and there, leaping around in the toilet bowl, was a large frog! She managed to catch him with a jamjar and the little fellow almost leapt out of it on his way out to the garden!

I hope it never happens to me - I'm not sure which of us would have the biggest shock! So the moral of the story is look before you sit!



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* contributions to the newsletter should be sent to Morag Gaherty

PRESIDENT
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PATRON
Claire Rayner

Join the Red Lion Group

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

Don't forget to look at the Red Lion Group website on the internet:

WWW.RED-LION-GROUP.MCMAIL.COM/

Write for *Roar!*

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar!*?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything.

Perhaps you've taken up a new hobby since having your pouch operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something.

You'll get the satisfaction of seeing your name in print and you may give hundreds of fellow pouch people an insight into an aspect of their condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes.

With your contribution we can keep the newsletter bursting with life and make reading about pouch issues fun and stimulating.