

Roar!



Issue number 15 • Christmas 1999

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

Pouch Pioneer

Hannah Barrow has had her Kock pouch since 1972. She was born in 1914, and this was just about the very first Kock pouch operation in the UK, so she was a bit of a guinea pig. But she was so ill it was a risk worth taking.

I was born in 1914 in the small market town of Congleton. The two main streets were full of large and small shops, all owned by local people. We had three cinemas and three dances a week. These days, there is nothing for young people to do.

I started work at 14 years old, as a machinist in one of the many textile mills, mostly producing football and rugby shirts. In the winter, orders were very few, so we worked one week and the following week were on the dole. The week benefit was paid, we were compelled to attend night school to learn shorthand. I don't know what that did for us!

I was on piece work. You earned your own money. Sometimes we would sit at our machine waiting for work from 7.30am till 6pm and go home without earning a single penny. Still, we had some good times and it was lovely countryside around Congleton.

My husband died 14 years ago and I have one son, Robert. My first husband, Rob's Dad, died of cancer when Rob was five years old. They were hard times then with no extra allowances. I could not work, as Rob had severe asthma (there were no inhalers then).



In 1970 I discovered I had ulcerative colitis. My doctor sent me to Macclesfield Hospital for tests at the clinic. We only have a small hospital in Congleton. After a few months, I was discharged, without having seen the consultant. I weighed just 5 stone and I never went into what they now call remission. I was very ill.

My GP was wonderful. He asked me if I would go to the London Middlesex Hospital. For the

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Date for your diary

The 2000 Red Lion Group AGM and information day will be held on 15 April.

Full details in the next issue of *Roar!* If you can be a helper on the day, please contact David Irving-James as soon as possible.

following two weeks I stayed at our local hospital. The only treatment was codeine phosphate (60 mg). I then travelled to Crewe railway station by ambulance, which is just 12 miles from my home. I will not ever forget that rail journey. My husband and sister were with me, and I was met at Euston station by an ambulance.

I stayed at the Middlesex for five months for treatment. You were not told what that was in 1970. I did not improve, so a colostomy was the next step (resting the colon, hoping that the ulcers would heal).

I had a terrible time at home with leaks and blood coming from the colostomy, feeling ill. Early in 1972, I was back again at the Middlesex for another operation. Even in 1972 there was no explanation about the operation. I was just told that I would not use a bag. I had two consultants: Mr Cameron for the pouch and Mr Slack for the rectum (a valve was not used at that early time).

Of course, I was terribly ill and it was a big operation. When I was a little stronger and the pouch had started working, this was the time I had to learn to use the catheter. Sister and the nurses did not know how to do it, so Mr Cameron, doctor and sister took me to the bathroom to learn how to empty the pouch. Thinking back, what surprises me was that I did it without being embarrassed. Probably, I did it more by luck than judgement.

The problem was how to get some sleep without using the catheter, so the doctor came at night to put the catheter in the pouch, packed it round with cotton wool to hold it in and then attached it to a urine bag! Very cosy that was, until I needed to spend a penny.

The nurse would not give me a bedpan, as I was getting up in the daytime, but insisted I got out of bed. I could not wait any longer, so out of bed I got. Calamity! Out came the catheter and what a mess there was on the floor! I can laugh about it now, but I was devastated at the time. Then the nurse shouted at me! I cried all the rest of the night, and the doctor came and packed me up

again. I really wanted to go home.

This was Tuesday, and there were no visitors until Saturday. Mr Cameron was on holiday for a few days at home, but the doctor called him in the next morning to talk to me. I can understand how it looked to some of the nurses and patients: it was a first time operation, and I was having a lot of attention. Mr Cameron and the doctors were in every day, to see how I was progressing and of course it created a lot of interest amongst the other medical staff.

After 3 months, I came home again. In the following weeks, there were things to worry me but my doctor sorted it out for me. He was so good to me. He even went to London to ask Mr Cameron all about my operation. I was having a lot of leaks, which upset me. Two years later, I went back to London again for the valve to be fitted and stayed in six weeks.

I had just one checkup afterwards. Instead, Mr Cameron used to talk to me on my sister's phone. I still had leaks, but did not use a bag. Mr Cameron left the Middlesex later in the year. My wonderful doctor retired 16 years ago. I am still with the same surgery (sorry, medical centre!). It is a two doctor practice, but they don't know about pouches.

I asked, if anything went wrong with the pouch, which hospital I would be sent to. The lady doctor said Whythanshaw Manchester, which is not too far away from my home. I hope they have done a pouch there, because I feel very strongly about GPs who don't know anything about pouches, have a patient with one but don't bother to find out about it.

In the year coming up to 2000, I cannot say that things have improved for me, except for the arrival of the Red Lion Group. Since my doctor retired, I have no personal support. I can't express in words what a help the Red Lion Group has been to me.

My pouch leaks when the time comes to cook or eat a meal. I could empty it before this time, but when I have eaten it leaks again. That would mean using the catheter 8 or

9 times a day. I take codeine phosphate (15 mg) at bedtime, which keeps me continent during the night. I can't use them during the day as they make me too solid for the catheter to work.

Now I am nearly 86 years old, I do what is best for myself and use a Surgicare pouch. Although I have a flush stoma, the flange is fine, no leaks underneath it, so I use the catheter 4 or 5 times a day.

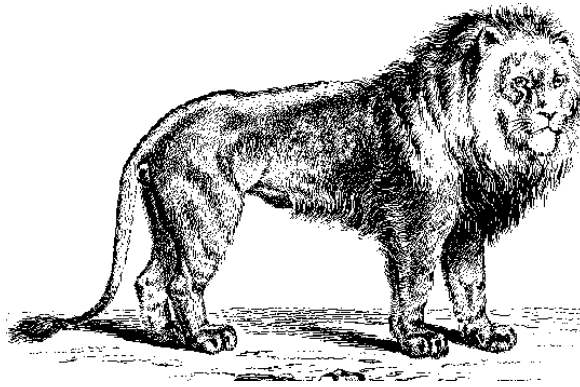
I live alone in a sheltered bungalow, and do my own housework and cooking. I can't walk any distance because I now have osteoporosis in the spine, which is bent. I also have arthritis. My sister takes me to the shops but I push the trolley around and shop for myself. I am able to write, and have a very active mind.

I have never had a car. I have had two falls fracturing both shoulders but I still managed the catheter. The doctor calls me frail, but I don't know about that!

During my illness, my husband went to work, shopped, did the housework and visited me on Saturdays. Robert sat A levels when he was 17 years old and went to Warwick University, where he stayed for just two weeks before coming home. He went to work in an Accounts office until he was 18, then went to do an honours degree in computing science as a day student at Stafford. I was in hospital most of this time.

Rob worked for ICL as a management consultant, and ten years ago the sales manager and he started a business of their own in Congleton, which has now done very well: they have floated the company and since bought a computing business in the USA, where they also have an office (as well as one in Denmark).

Things seem to have come full circle now. The mills where I used to work are now offices. They have been renovated, and the outsides are the same as they were all those years ago. Rob and Steve's company have one floor. I have been in the mill and they have kept the stone walls like they were when I worked there back in 1928. Now, of course, it is fashionable!



Editorial

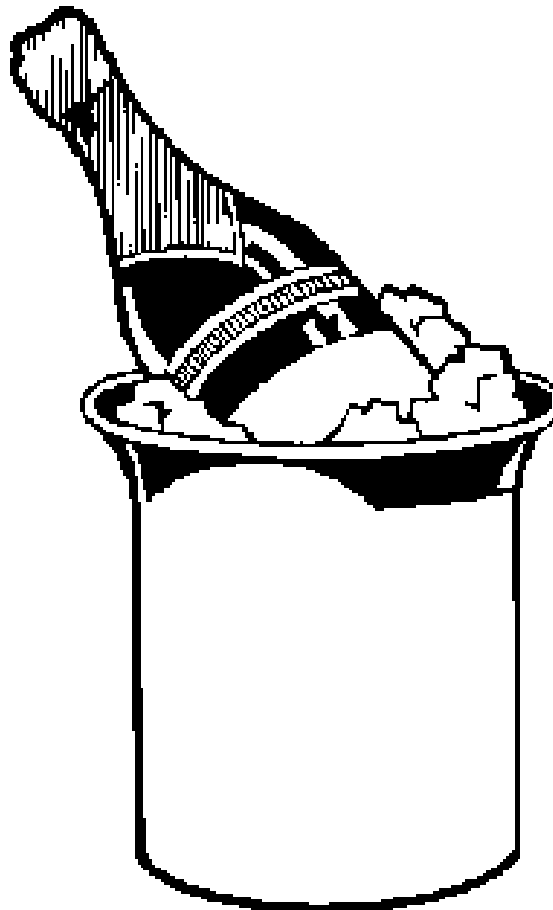
As I type this, December has just started. Not just the last month of the year, or even the last year of the decade, this is the last month of the 20th century. The *fin de siècle* is upon us, and even the Dome may turn out to be ready for it! The Millennium has been hyped enormously already, and it may just turn out to be another new year for all of us, bug or no bug.

Nonetheless, this seems just the right time to print as our leading article a piece from Hannah Barrow - not only our oldest member, but also a pouch pioneer in this country, she has seen enormous changes as the 20th century has progressed. On a personal note, I am humbled by the daily determination she continues to show and am pleased that the Red Lion Group has helped Hannah as well as others with ongoing pouch problems.

For all of us, the end of the Millennium provides a good time to take stock of how much we owe to the surgeons and medical staff who have done so much to improve the quality of our lives and those of our families. Not everyone's pouch is perfect, by any means, but so many members have said that they simply would not be here today, were it not for the work of their surgeon.

Sometimes, the Red Lion Group is seen as a St Marks support group, and this is certainly how it started off. We have broadened our horizons since then, but many of our articles continue to be centered on

St Marks personnel. This is not to say that we do not recognise the fabulous work being done in other hospitals by both surgeons and stoma nurses.



We would certainly like to hear more about them, so if you would like to see *your* medical staff featured in *Roar!*, please do write in and tell us all about them. If you could do an interview with them, even better, and I can help you with some questions to ask, if you need

help.

Along these lines, the survey this issue is on the subject of the information you receive from the Red Lion Group. The replies you send to this will affect the content of what should be *your* newsletters, so please do have your say, even if you don't normally complete the surveys. I know every company says "your views matter to us", but here at the Red Lion Group we really do mean it.

On our front page, we have a reminder about the upcoming AGM. This year, David has a few very different things planned, for those who don't want to spend the whole day digesting pouches (what a horrible thought!), so you or your partner may be in for a treat! Full details will be in the next issue of *Roar!*, including maps of both the exterior and the interior of the venue, to address problems reported in 1999. I and the rest of the committee hope to see you there.

I don't need to tell you about all the articles we have in this issue, because I know most of you read *Roar!* from cover to cover, so you will find everything that is in there. I hope this issue will come out in time for you to sit and read it by the fireside, wearing your Red Lion Group T shirt (or sweatshirt, if you have no fireside!), and surrounded by your Christmas presents.

And on that note, may I wish you a Merry Christmas, and a very happy New Millennium!

Is This a Bag I See Before Me?

Gillian Appleby has no doubts about whether the pouch operation was worth it.

I can't imagine my life without my pouch now. I have a recurring dream that I have a bag again but it is not meant to be in use, it's just in case (!) and it is over my scar. But even though I have my pouch, the bag keeps filling up. I have had other horrible dreams of having a stoma and it is overworking and somehow I forget/can't put the bag on it. All this proves how much I really fear ever having a bag again.

I love the fact I can look and touch my stomach without feeling something plastic on it. When I had my bag, I once went out with a really nice bloke, and when we were in bed (he didn't know I had a bag at first) he said "What's that, plastic?" and I said "No it's my bag". And as you can imagine, the room had an eerie silence to it for quite awhile.

Another quite amusing story is when I was at a party talking to a girl who said she had Crohn's disease when she was a child but it had since never returned (I have always wondered if this is possible). I was telling her I had had my colon taken out, emphasising the fact that all of it was gone. She said to me, "Well that's



horrible, but you know some people have to have a bag." I actually did reply "Yeah I know, I have got one". She either didn't hear (I did say it rather quietly) or she chose not to. The funny thing is that why

did she think I DIDN'T have a bag? Maybe she thought she'd be able to see it if I did have one.

I always felt a high class freak with a bag, even if people couldn't see it. and also the social taboo of being a little bit different to other people. But I didn't want to feel any of this because if people can't accept you the way you are, then it's them that has the problem. But then again, it's you that has the bag.

Anyway, most of all I am very grateful indeed to the wonders of technology and to my very clever and skilful surgeon, Mr MacDonald, because I feel almost back to how I was before I ever had my colon out. I don't feel such a freak and not having a bag stops me from thinking about the fact I don't have a colon.

Remember what those Feet are For? (or How I Got a Life)

John Drasar wrote about most of his experiences of owning a pouch, and everything which led him to one, when he had his letter inserted in the Spring edition of *Roar!*

One thing which I can add is that I have now moved to Aberporth, on the West Coast of Wales, into a beautiful bungalow. There have been one or two teething problems, but most things are very good.

I have a very good doctor, with an excellent support team to back him up should the need arise. All my neighbours are nice, but the main thing that has helped me in my day to day living - as I am also registered disabled - is that everything in the house is on one level except for one step down to the garden. The only drawback is that the garage is on a separate level and up a bit of a slope. But apart from this, WOW!

The sea is just a little walk down the hill, and I live just on the edge of the village. I have shops within a five minute walk, or one minute if I drive.

Overall, I feel a lot fitter, and my pouch doesn't seem to get stressed out. I know that might sound odd, but I used to have to go up and

downstairs all the time to reach the loo (I often go 15 to 20 times a day). Now, it seems to be on holiday.

So my advice is: *have a good look at where and how you live*, could I improve my diet?? Do I need more exercise? Could (or should) I move? What would be the benefits to me??...

I went through all these questions and realised that the answer to every one was YES for me. So I did something about it.

I realise that, for many of you, some of my options will be impossible now, but maybe later on ... After all, the doctors and nurses can (and do) perform miracles, but in the end it is really down to you.

My doctor once said to me: John, if you eat spicy food, well it is you that is going to suffer, not me. It's not me that is going to be running to the loo every five minutes. So I make my decisions based on whether I think the result is going to be worth it.

Anyway, I'm very glad that I have a pouch. Without I would already have gone to heaven. Yes, I have a cry and a growse now and then, but despite my various problems I think that I'm a very fortunate person.

Remember, only you can improve yourself: your body, given the right food and exercise, will last a very long time. I try to walk more these days. OK it takes longer than driving, but you miss so much that way.

Even if you are like me with my two-speed body ("slow" and "stop" are my only two gears!), a walk does you the world of good. And so what if it is not as fast?

I should add that the air is like champagne here. Go for it, I say. Just get out of that car. If you have children or a dog, then get walking, take them to the park etc. Only you can stop the rot. Your body will do its best, but it needs help from you...honest!

Gala Auction 2000

Unfortunately, the date for this has had to be put back to November 2000, as this is the earliest that we can get hold of the Atrium at PriceWaterhouse Coopers' prestigious offices at Embankment Place in London. We thought it was more important to keep the venue than the original date, and November is otherwise a quiet month so could prove an attractive time for our auction.

We are desperately in need of someone to project manage this whole event, so if you could volunteer your services, you would be more than welcome. Unless someone has the drive to see it through, it will not be the success we want it

to be, to bring the work of the Red Lion Group to the wider world. We have sent out some T shirts for signing, to get some variety of items for the auction.

Recently, we have received back a T shirt signed by all the regulars on TV's *They Think It's All Over* (and we are very grateful to Gary Lineker for arranging this for us).

Also, for those who watch Graham Norton on Friday nights, he has done us a lovely risque slogan on a T shirt as well as doodling on a Red Lion picture for us. The person who models it on the night will have to be either very brave or innocent enough not to blush at it. All I can say is, it won't be me!

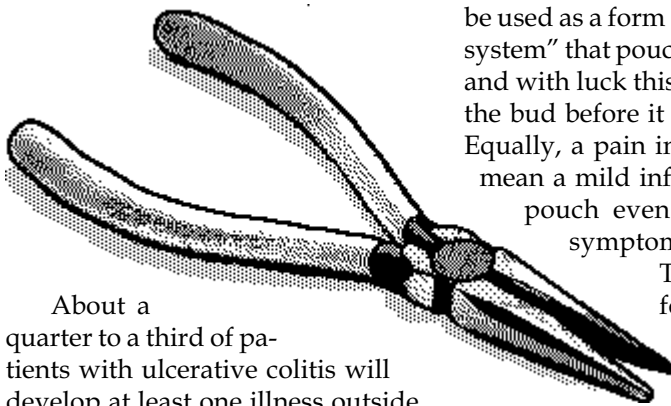
Trevor Baylis, inventor of the clockwork radio, has signed us a T shirt, onto which we are going to transfer an image of him with his famous radio.

Astronomer Patrick Moore has sent us a signed Red Lion logo, and actors Alan Bates and Ben Kingsley have sent us signed photographs. Comedian Russ Abbott has sent us both a signed photograph and Red Lion logo.

Finally, newsreader Jan Leeming has offered us a choice of items to auction, and we are waiting to receive either a framed watercolour or a signed lion photograph which she took herself while on safari.

What a Pain!

Morag Gaherty finds out more about the links between joint problems and ulcerative colitis.



About a quarter to a third of patients with ulcerative colitis will develop at least one illness outside of their colon which is tangentially related to their UC. The most common of these is arthropathy, or a disease of the joints.

The knees are a common location for this disease to strike, but other large joints may also be affected. According to the literature, the pain is related to activity, and disappears when the UC is in remission or after pouch surgery.

However, we know from our records that many pouch owners suffer from joint pain, and arthropathy is also known to strike if you have pouchitis.

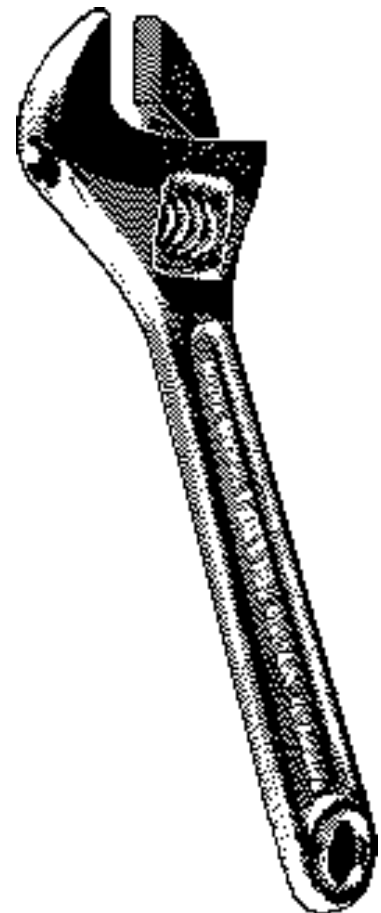
In fact, once you know about this connection, joint pain can also

be used as a form of "early warning system" that pouchitis is on its way, and with luck this can be nipped in the bud before it develops further. Equally, a pain in your joints may mean a mild inflammation of the pouch even without further symptoms.

This particular form of arthropathy is known as activity-related polyarthropathy (ARP) and affects up to a fifth of pouch patients.

Ankylosing spondylitis is another form of joint disease which occurs in up to 5% of patients. This affects the sacroiliac joints and one or more vertebrae. It differs from ARP in that it is not related to UC activity, and nor is it cured by the formation of a pouch.

Finally, a third form of joint disease known in UC sufferers is called asymptomatic sacroileitis, which is limited to the sacroiliac joint. Again, it is not cured by the formation of a pouch. It is more common than ankylosing spondylitis but less common than ARP.



My Story ... by Judith Harris

In 1980, I had the first symptoms of UC, but it remained undiagnosed for the next three years, until I became very ill in Malta while on holiday. Back in England and after extensive tests, the cause of the trouble was revealed, much to my relief.

For the next five years, I remained well, with six monthly checkups and Asacol tablets. Throughout this time, I continued to work as a chef whilst attending my local hospital.

1988 saw the birth of our much longed for son. Unfortunately, when he was twenty months old, the UC came back with a vengeance, and over the next year my condition gradually deteriorated. I had steroid enemas, oral steroids and any other amount of drugs, all to no avail.

I now felt so ill that I begged the local hospital to operate on me, even if it meant having an ileostomy. I was continually fobbed off with various excuses as to why I should not have an operation.

The pouch operation was mentioned during this time, and the local stoma nurse put me into contact with someone who had already undergone a pouch operation. He was a mine of information and told me about Mr Nicholls of St Marks, the surgeon who had performed his operation. I asked at my local hospital to be referred to St Marks, but was fobbed off yet again.

Fortunately, my husband had private health cover for the family with his job, so we made an appointment to see Mr Nicholls at his private practice. By this time, I was very ill. After I saw Mr Nicholls, I had the operation to remove my colon within the week. I was too ill to have the pouch made at the time of the first operation.

Over the next three months, I gradually gained weight, came off all the steroid treatments and learned to cope with a temporary ileostomy. I had the pouch fashioned by Mr Nicholls, again in a private hospital in London. Stage two was a very tough operation to



get over. I felt very poorly for the next seven weeks until I had stage three (closure of ileostomy).

It took months to get over all the surgery. In the early years I had the same problems as everybody else: sore skin, frequent trips to the loo and bowel obstructions. I sometimes wondered if it had all been worth it.

There was no Red Lion Group then, and not a lot of information to be had. I had a couple of contacts I made myself with other pouch patients, and I collected all the information I could relating to my condition and operations.

Nine years further down the road, I am very glad that I have had the operation. The pouch has settled, I go to the loo five times in twenty-four hours and do not need any drugs at all. My one big problem however is that I have had seven small bowel obstructions due to adhesions. Thankfully, these have all settled in hospital without the need to be operated on again. My last one was two years ago and - fingers crossed - it will not happen again. I have had a few bouts of fairly mild pouchitis, which have cleared up with a course of Flagyl.

I now have an active life, walk-

ing, cycling and generally enjoying myself. My diet is not too restricted: I can eat most things, but usually have several small meals a day. I find herbal tea very soothing, especially camomile, peppermint and ginger (all made by Twinings). I even managed to work again as a chef, but at the moment I am not working.

One major drawback was the lack of counselling for my husband and son. A situation that I feel has still not been addressed enough.

I am sure that this is all very familiar to UC and pouch patients everywhere. I find that my best course of action is to keep optimistic and to keep my sense of humour when things go wrong. I try to relax as much as possible, as stress makes my bowel problems worse. Things do get better in time, and I now thank God that I am alive. I look at my son who is nearly twelve and remember the times when I did not think I would live to see his third birthday.

I am now an outpatient of St Marks where I go for annual check-ups. This hospital specialising in bowel problems really is a "Centre of Excellence".

Letters



Roar! Letters Page

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Dear Newsletter Editor

I was very interested to read the article in Roar issue No 14 about the theory of an infection by a bug causing ulcerative colitis, because my own experience began with a bout of food poisoning, although this was salmonella rather than e.coli.

Events happened thus - I suffered with irritable bowels syndrome through the 80's, although the bouts seemed to be connected with me trying to quit smoking. Then in 1990 I finally quit, but was plagued with bouts of alternating constipation, diarrhoea and abdominal pain. The, in July 1993, I was taken very ill, passing blood, on and off the toilet and being very sick - I could not keep anything inside me.

I was admitted to Kent & Canterbury hospital and after a week was diagnosed with salmonella. I was then started on medication, and after a further week in hospital was sent home. However, I did not improve, so my GP sent me back into hospital, where I was given an en-

doscopy and then told I had ulcerative colitis - this was August 1993 and for the whole of that month I had no food pass my lips, but plenty of pills instead.

I was started on steroids, which rapidly increased to 40mg per day over the next 12 months. My doctors at K&C became increasingly worried as every time they tried to reduce my steroids the symptoms returned. My weight was increasing and my face resembled a football (all bloated).

In November 1995, I was sent to see Mr Hawley at St Marks in City Road, and I was admitted and had my operation within a week. I had my colon removed and a pouch formed in one operation.

After being in St Marks for 3 weeks, I went home and have not looked back. I was cured - it was great! Thanks to St Marks, and especially Mr Hawley and all the staff, I'm able to live a normal life again.

Looking back, I feel that the episode of salmonella was the start of my UC.

I enjoy reading the newsletter and find it both informative and amusing - keep up the good work!

Heather Austin

Dear Newsletter Editor

In April 1999, I had a J pouch formed at St Marks, with a covering ileostomy which I hope to have closed in November of this year, be reconnected and hopefully start to function in the "normal" way (or as near as!).

After reading various letters in Roar!, I am quite prepared to have to face a number of problems, including that of frequency.

I am an arthritis sufferer and have great difficulty moving around as the pain is concentrated in my knees. However, I am trying to adopt a positive attitude to all this, and with luck may be successful. My arthritis appears to be worse over these last 6 months and I wonder if there is any connection with my pouch operation (*Ed: there is a short*

piece about this very topic on page 5 of this issue).

Incidentally, I am 74 years of age and it occurs to me that I might be one of the oldest members to have this op. Maybe there are others even older - I would love to hear! Perhaps it would be interesting to know the youngest **and** the oldest!

Helen Nelson

Dear Newsletter Editor

Since having pouch surgery in January 1997, I still have to wear protection at night because of leakage. Anal soreness comes and goes, but this used to happen whilst suffering from UC as well.

I am more confident since having the pouch than when I had the ileostomy bag. I was always afraid the bag would leak or burst if I had a lot of wind.

Due to all the abdominal surgery, I was sad to find out that one of my fallopian tubes is blocked, so we will have to wait and see whether I can have children.

I had problems a fortnight after the final operation: adhesions caused a blockage, and I was in hospital for 6 1/2 weeks whilst they sorted it out. This entailed resting the pouch and being fed by a line in my neck. After a while, this led to septicaemia and I was quite ill, but the outcome was alright, and I have been alright since.

So all in all I am glad I went ahead and had the pouch, and if there is anyone in my area (Hampshire) who is contemplating pouch surgery, I would be very happy to meet them and tell them what I have been through, both good and bad.

Jane Teasdale

Dear Newsletter Editor

My favourite pouch experience has nothing to do with the illness, but at the time bucked me up no end and made a joke of it all.

My daughter was pregnant at the time I came home, having had the first stage and having the bag

fixed in place. Her older daughter was 3, and was told not to jump on Nan, because she had to be careful of Nan's tummy. In her mind, it was just the same as being careful of Mummy's tummy.

A few days later she felt the baby move in Mum's tum and decided she wanted to feel mine too. To humour her, I said okay but warned her that mine did not move. To her surprise, as she touched it, it did move (albeit with wind). Afterwards, she was convinced Nan also had a baby in her tum, and each day on visiting she asked how my baby was, had it moved, what was I going to call it etc!

The questions were endless and each day brought a different query. It was such a small thing, but at the time of feeling under the weather and trying to keep food down and being sick (which I had for about 2 weeks), it was just the tonic I needed.

Luckily, with the excitement of her sister being born and looking after a new baby dolly, her mind was taken away from Nan's tum! Now, 10 years on, I am grateful every day for my pouch. I have a very busy life socially with the British Legion and family life with 7 grandchildren. I do feel I'm one of the lucky ones.

Sylvia Atkinson

Dear Newsletter Editor

When I opened issue 14 of *Roar!* and read the front page article about the possible link between uc and food poisoning, my immediate reaction was: so *that's* when it started.

In 1991, in the Bahamas, there was a very serious outbreak of seafood poisoning caused by sewage being dumped in the harbour. In fact, 4 people died. I had a very severe reaction, and needed to be hospitalised because my trachea was so swollen it was closing up.

In the following year, my first daughter was born, and very soon afterwards I started to suffer with what I thought was irritable bowel syndrome. It did not help that the years 92-95 were particularly stressful for me in my relationship with my partner. In 1996, I had my sec-

ond daughter. However, my illness was no better, even though the stressful relationship I had been in was now over. Like everyone with IBS does, I put it down to other pressures: single motherhood, work etc.

However, in Christmas 1997, ulcerative colitis was finally diagnosed. That was just the start of a very difficult period of surgery and illness, details of which can be kept for another day. However, looking back now, I very much feel that the seafood poisoning was the start of my uc, which I mistook for IBS for many years.

Alexa Chiltern

Articles from back issues

For the benefit of newer members, this section mentions the most important articles for pouch owners that have appeared in previous issues. Earlier issues can be obtained on request from the Liaison Officer. Please enclose a large SAE (31p stamp for 1 issue, 60p for 2 or more).

- Prescription exemptions (and update) – issues 4 and 10
- Family planning – issue 5
- Electrolyte Mix, St Marks Formula – issue 8
- Keys for disabled toilets – issue 13
- Regaining bowel control after colorectal surgery – issue 14

The Invention of Toilet Paper

From James & Thorpe, *Ancient Inventions*

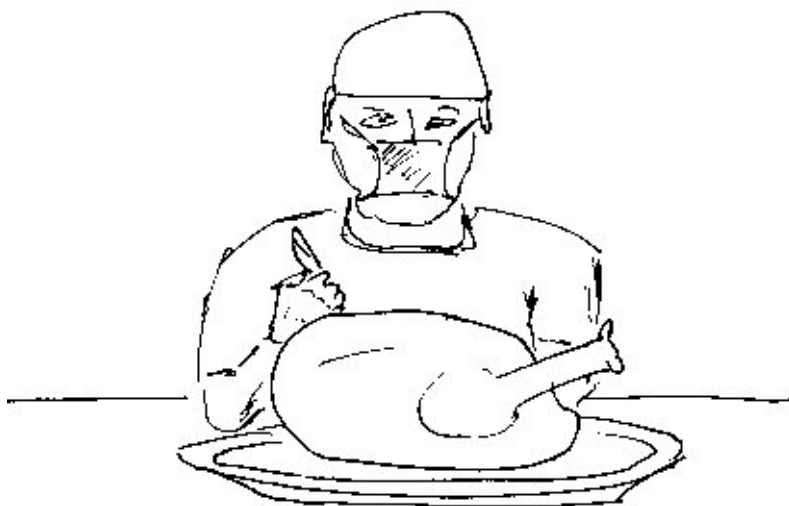
Toilet paper may seem like a modern convenience, but it actually has a long history. Excavations of public lavatories in ancient Rome suggest that people used sticks (ouch!), while evidence in Scotland reveals that moss was a common form of toilet paper well into medieval times.

Other archaeological sites through Western Europe indicate that piles of straw and hay were kept next to lavatories in castles and monasteries.

But it was the Chinese who invented the first toilet paper actually made from paper.

In AD 589, a Chinese Imperial court official wrote the following: "Paper on which there are quotations or commentaries from the Five Classics, or the names of the sages, I dare not use for toilet purposes." This shows that the concept of toilet paper was alive and well in AD 589.

Then, finally, in AD 1391, the Bureau of Imperial Supplies in China started producing as much as 720,000 sheets of toilet paper a year, each sheet measuring 2 feet by 3 feet, and later made softer, perfumed sheets for use year round by the imperial family.



A merry Christmas to all our readers

Chatting about Pouches

Morag Gaherty picks up some tips from an on-line internet conference on the subject of Diet and Nutrition with an Ileo-Anal Pouch

One of the marvels of the internet is the way people can interact with others, including professionals in on-line conferences or chat rooms. This can be a great way to share experiences with others across the world and obtain advice, although when seeking advice you should be careful to ascertain that the person giving it is qualified to do so.

The following comments were made in a recent on-line conference "Diet and Nutrition with an Ileo-Anal Pouch with Grace Williams, R.N.C.E.T": The full transcript can be found at

<http://>

my.webmd.com/member/531703

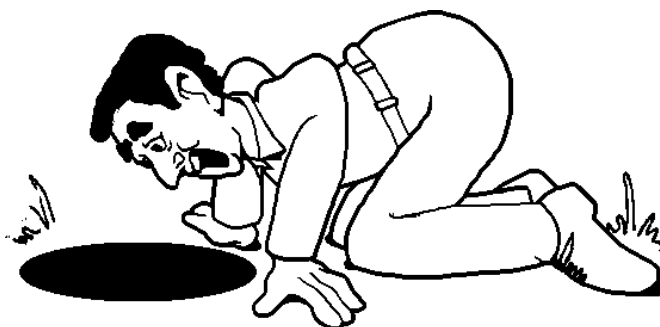
- There is no reason to suppose you will have dietary problems after surgery, unless you had specific dietary problems before your surgery. You probably will not suffer from lactose intolerance after surgery since lactose intolerance affects the large bowel.

- Avoid time release capsules because transit time tends to be

shorter once the colon is removed.

- Blockages typically occur in the upper intestine, not in the j-pouch itself.

- Certain foods can cause blockages if you don't chew well. Adequate fluid intake is also important.



- Scar tissue is usually resolved with dilatation or surgical intervention if it doesn't resolve with dilatation

- On the subject of limiting your diet, my advice is to start slowly, chew well and take everything in moderation.

- On the subject of liquid absorption, more fluid is absorbed in the intestine so that by the time it

reaches the pouch, it is thicker.

- Some patients have trouble differentiating between passing stool and gas in the early weeks after their surgery. This improves over time.

- Apple pectin is my recommendation for dealing with pouchitis.

Apple pectin is available over the counter (in the US at least) in tablets or powder. I prefer apple pectin because it is easy to obtain and it's a natural product that doesn't interfere with the normal environment of the pouch. It also helps to bulk the stool and combats bacteria.

- It is possible but not probable to get hemorrhoids with your j-pouch. Avoid straining.

- People encounter difficulties along the way with this surgery but most people (actually 95% of patients in a surgery) were glad that they had this surgery and were doing well. Approaching this surgery with a positive attitude is the best medicine.

My Story ... by Tracy Walker

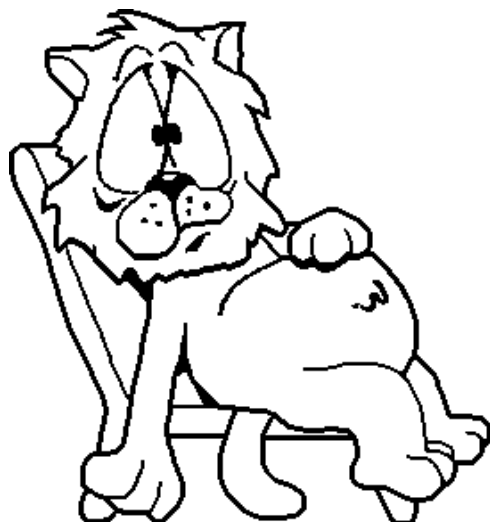
I have had my pouch for about 10½ years now, having had my surgery when I was 14 years old. I initially had a temporary ileostomy following a sudden attack of ulcerative colitis.

I am happy to say that most days I don't think about my pouch and lead the same sort of life any other 24 year old would. I don't regret having my pouch (even if one day I might need an ileostomy again) and take the view that I and many others (family, friends, doctors, nurses etc) have worked so hard to get me to the stage that I am today, that I should never waste any opportunities etc.

Everyone with a pouch or ileostomy knows how difficult those early days can be after surgery and how the days can run into months before any benefit is felt. The majority of people I am sure would agree that it is worth it in the end. Indeed you may even get to the stage I have reached, where you no longer dread hospital appointments, but see the yearly checkup as an opportunity to show your surgeon how well you are (although there have been times when this has not been the case!).

I know my surgeon takes great pride in seeing how much I've grown up in the last 10 years, and

so he should. If it wasn't for him, I would not be here today.



My Story ... by Collette Bijoux

I suffered from UC from 1981 onwards. I had two severe attacks in 1982 and 1995, which resulted in my hospitalisation. However, high doses of steroids worked well for me, and I was out of hospital after 10 days.

I had a colonoscopy in 1997 which showed that my whole colon was affected by the UC and had shrunk to such an extent that the doctor performing the procedure was well into my ileum and took several biopsies from there before he realised the problem. I found the whole procedure extremely painful and distressing. I could even see the light of the scope shining through my abdomen! I was advised to have the pouch operation, and my appointment quickly came through to see the pouch surgeon.

I was given a date for my operation (May 1997). However, in the previous few weeks I had received literature from the Red Lion Group which contained stories from people whose operations had not been very successful. This, along with the fact that I was told the Merseyside rep, Blanche Farley, was wanting her pouch reversed to an ileostomy put me off. I told the surgeon I no longer wanted the op.

I continued with my visits to Dr Walker, the gastroenterologist at Fazakerley Hospital in Liverpool. My health was not brilliant, but I think you get to a stage where you have felt awful for so long that you think it is normal.

However, in my job as a registered sick children's nurse, I was working full time shifts. This meant I was finishing late at 11 pm and starting again at 7 the next morning. By the time I got home and had to be up again at 5.30 am, I was exhausted. As you will all know, I would not be sleeping those few hours, but would be up 4 to 5 times to pass small amounts

of blood-stained motions.

On my days off, I had to force myself to clean the house and all the other tasks involved with looking after a husband who works long hours and has on-call duties. And three teenage sons who eat for England!

During one of my clinic visits, I spoke to Dr Walker about the op again. He again wrote to the surgeon, Mr MacKie, and I was given an appointment to see him very quickly, in March 1998.

However, before I saw him, the stoma nurse Maureen Stoddart came to see me, and I expressed to her my fears about the pouch being as bad as the UC. She put me in touch with Jenny Dobson, who had the pouch procedure two years previously, and she completely changed my outlook. The pouch had improved her quality of life 100%

I had the first stage of my pouch on 7 May 1998. The first 3 days were very painful. I have a very low blood pressure all the time, the nurse on duty on my first night post operatively thought it was the result of my epidural, and so switched it off! You can imagine the agony I was in, as I had been in theatre from 10 am until 7 pm that night. The nurse who had come with me to observe the op said her back was very sore with having had to stand so long.

The rest of my recovery was uneventful. I left hospital on 21 May with my ileostomy. I had a few problems with leakage, and was very happy when it was reversed on 30 July. I had no problems post operatively: no pain, and my bowels started working perfectly straight way,

and I have had no problems since.

I still use the toilet frequently, but there is no urgency. After my op, I was asked by my stoma nurse to speak to others about this sur-

gery, which I gladly did. However, the surgeon did not seem happy about this, as he said I might give a wrong impression about its success, and I was not asked again. I returned to full time work in November 1998.

(Ed: Collette's story illustrates perfectly the fact that everyone is different in whether a pouch works for them, and this is the point that the surgeon was making. It is certainly true that everyone who shares their experience with a potential patient must stress that what has happened to them may be completely different from what happens to other people, in both good and bad ways.)

However, it does seem a shame that this surgeon's potential patients are maybe being given an unnecessarily bleak picture of pouch surgery by being prevented from speaking to successful pouch owners as well. Had Collette not shared her fears with her stoma nurse, she too would still be living with a quite unacceptable quality of life, for fear of the alternative.

Very occasionally, I receive comments that Roar! presents too negative a view of life with a pouch, and I know that a large proportion of our members have a far more positive experience of pouch surgery - indeed, some find it enables them to get on with their lives without ever having to think about the pouch.

We do have a policy of presenting life with a pouch "warts and all", because the Red Lion Group is a resource for those weighing up the pros and cons of pouch surgery. However, we are limited in what we can publish by the material we receive from our members - and, if only those who have problems write to us, then it is difficult not to give the impression that all pouch owners do have problems.

Just because companies only have a Customer Complaints department, and not a Satisfied Customers department does not mean they don't have lots of satisfied customers - it's just that they don't write in to say so!

What I am saying is this: if your pouch has improved your quality of life, please take the time to write to us and TELL US.)



Polyposis People

I would like to make some comments about the "Quality of Life after Colon Surgery" article in "Roar 14" and the affect of psyllium fibre on me.

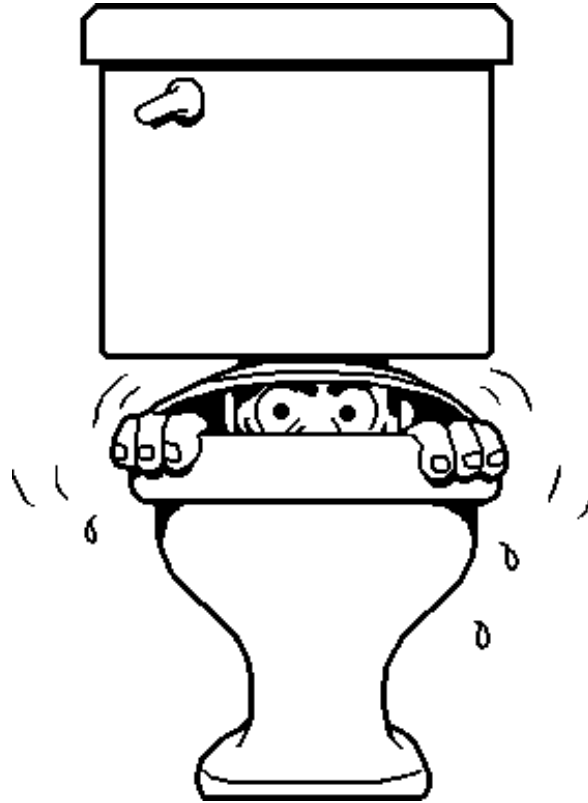
Before starting with the psyllium fibre I spoke to my GP and also mentioned it at hospital clinic. They were happy for me to try the psyllium fibre.

Psyllium fibre is available in U.K. health food shops. It is manufactured in the USA by Solgar Laboratories, Leonia, New Jersey for Solgar Vitamins Ltd (UK). Unfortunately I don't have their address, but I have found their products in several UK health food shops. It costs around £9 for a 12oz jar, which is enough for about 6 weeks.

The Psyllium fibre is working well for me. I started with one teaspoonful per day at the beginning of August. I am now up to 9 teaspoonsful a day, often taken with yoghurt drink (it goes down better than just water, and also the bacteria in the yoghurt drink could also be beneficial).

The main thing to remember is minimum liquid with the fibre. I

have in the past tried Fibogel, with the recommended (on pack) amount of liquid (which of course is de-



signed for somebody who has all their bowels intact). But I found bowel movements uncomfortable with a sense of urgency, which was

not actually very productive, leaving me tired with sore perianal skin, painful muscles and still attempting to go the loo about 15 times per 24 hours.

I am not attempting "bowel training" as I am somewhat wary about getting to a condition where it is suggested one should take a suppository. I shall be quite happy with 6 visits per 24 hours.

The bowel movement is much improved, and there is generally some shape. The output, not being liquid, does not burn the perianal skin. I would suggest Caroline Ingram whose letter was in *Roar! 14* should try psyllium fibre. The most important part of Q of L after CS article, after suggesting using small amounts of water with the fibre, is the reference to the balance of food, fluids, fibre and medication. That and keeping your sense of humour!

Wind at night can still be a problem so it is helpful if one's partner can keep their sense of humour also! I would add that drinking fluid separate to the psyllium is important and it is so easy to forget to drink.

Debbie's Story

This is Debbie's Story of when she was very ill
And to get her better, it took a lot more than just a pill.
It all started on a family holiday in Spain
When in Debbie's stomach she got a pain.
Bob was in such a panic just to get poor old Debbie home
He left Spain so quickly he forgot the kids and his hippy comb.
Debbie was getting even worse and threw up on the cat!
She screamed to Bob "I don't remember eating that".
When in hospital laying in her bed
She just looked like something from the living dead.
Climbing onto the trolley, she bent over and farted
And when she woke up her large and small intestines were parted.
Bob still in panic asked "Is she in a coma?"
The nurse replied with a smile "No, but she's been fitted with a stoma"
It goes without saying Debbie's been through the ringer a little bit
But the light is at the end of the tunnel, and she's looking forward to a great big s..
Even though Debbie feels like she's run a million miles
She'll look back on all this with lots and lots of smiles.



Introduction to St. Marks Registries

Judith Landgrebe writes

The Polyposis Registry at St. Mark's Hospital was established in 1924 by Dr. Cuthbert Dukes and Mr. Lockhart Mummery. It is a centre of excellence, which aims to increase knowledge and raise awareness of polyposis through ongoing research, lectures and talks.

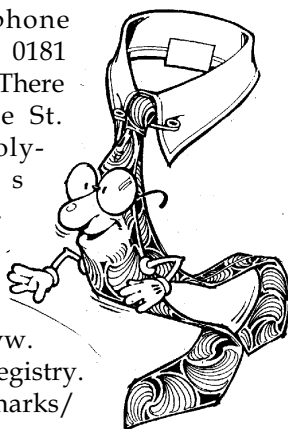
The St. Mark's Registry is particularly involved with people who attend the hospital, but also provides a help line for anyone wanting information. Kay Neale and Ruth Stafferton are the specialist nurses who run the Registry with the support of Kalpna Pindoria, the Registry Administrator.

Judith Landgrebe runs the Thames Regions Polyposis Registry which was set up in 1992 to provide a service for polyposis families and doctors in the South East who do not come to St. Mark's.

The main aim of all polyposis registries is cancer prevention. Full details of a family are obtained and, as far as possible, those relatives identified as being at risk of inheriting the faulty gene are traced. They can then be offered screening and, when necessary, can be treated.

Should you have any questions about polyposis please do not hesitate to contact us.

Our telephone number is 0181 235 4270. There is also the St. Mark's polyposis website, the website address is: <http://www.polyposisregistry.org.uk/stmarks/>



Air Freshener?

From the *Brighton Evening Argus*:

"A bowl of vinegar left in a room eliminates nasty smells".

Recipe corner

Lemon Chicken with Parsley (serves four)

1½ lbs. boneless, skinless chicken breast
2 tbs flour
½ tsp. salt
¼ tsp. paprika
¼ cup olive oil
1¼ cups Chicken Broth
¼ cup lemon juice
2 tbs. freshly chopped flat parsley

Cut the chicken breast into 2 oz. pieces. Mix the flour, salt and paprika together in a plastic bag. Add the chicken to the flour mixture and shake to thoroughly coat.

Preheat a large frying pan over medium high heat for 3 to 4 minutes.



Add the olive oil to the preheated pan. Add the chicken to the oil and allow to sauté for 5 minutes per side, turning only once. The chicken should be nicely browned.

Add the chicken stock, lemon juice and parsley to the skillet. Reduce heat to medium low and allow to simmer for an additional 5 minutes, allowing the sauce to thicken slightly.

Place the chicken on a serving platter and cover with the sauce. Bon Appetit!

And, with Christmas approaching, now would be a good time to indulge in something decadent - the following recipe is delicious with freshly squeezed orange juice !

Carol's Coffee Cake (serves 6)

½ cup vegetable shortening
1 cup sugar
2 eggs
1 cup flour
2 tsp. baking powder
¼ tsp. salt
1 cup soy sour cream
1 tsp. vanilla
½ cup brown sugar
1 tbs. vegetable shortening
2 tsp. cinnamon

In an electric mixer, cream the vegetable shortening and the sugar until thoroughly combined. Add the eggs and vanilla. Sift the dry ingredients together. Alternately add the dry ingredients and the soy sour cream to the batter. Stir until combined.

Preheat the oven to 350 degrees. In a small mixing bowl, combine the brown sugar, 1 tbs. vegetable shortening and cinnamon with a fork. Spray a circular tube or bundt pan (Ed: if anyone knows what this is!) with non-stick cooking spray.

Pour the batter into the pan. Sprinkle the brown sugar topping on the surface of the batter. Run a knife through the batter to slightly incorporate the brown sugar mixture. Bake the coffee cake for 50-55 minutes. Let stand for 10 minutes before inverting on to a serving plate. Dust with powdered sugar and serve warm.

From the Culinary Couple's Creative Colitis Cookbook \$12.75 including P&P from the UK. Order via their website at www.colitiscookbook.com or call free on 00 1 877-423-3438.



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

What is ... a Kock Pouch?

A *Continent Ileostomy* allows the patient to control when the waste products will be expelled. One type of continent ileostomy is known as the "Kock Pouch" named for the Swedish surgeon who created the procedure. This type of continent ileostomy is created when an internal pouch is constructed using the small bowel. A valve is then created at the point where the pouch meets the abdominal wall. This valve prevents waste products from being excreted until the patient chooses to

do so.

The internal pouch of a continent ileostomy acts as a reservoir for the waste products and is usually emptied 3 to 4 times a day. It usually has a capacity of 500 - 1000 ml and is emptied by inserting a tube through the stoma and valve into the pouch allowing the waste to drain out. The stoma is created flush with the skin and will not require a pouching system, although most patients will wear a gauze pad or stoma cap.

In addition to usual complications of major abdominal surgery, there are several complications specific to this pouch. These include valve incompetence, inflammation of the pouch, bleeding and fistula formation.

Indications for Ileoanal Reservoir:

- Ulcerative Colitis
- Familial Polyposis

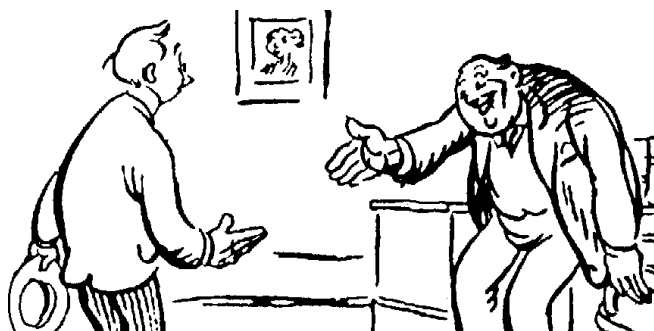
Reproduced from Convatec's website at:

<http://www.convatec.com>

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).



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BEDFORDSHIRE		
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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	0181 591 2936

GWENT

Robert Challenger Cwmbran 01633 866820

HAMPSHIRE

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Les Willoughby Winchester 01962 620012

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KENT

David Irving-James Folkestone 01303 894614

Phil Elliment Barnehurst 01322 558467

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Joan Whiteley Clitheroe 01200 422093

MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

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Sandy Hyams King's Lynn 01485 542380

Sylvia Mist Norwich 01692 580095

NORTH LONDON

Susan Burrows 0181 882 5318

NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529

David Smith Northampton 01604 450305

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Amanda Metcalf Arundel 01903 885682

WILTSHIRE & DORSET

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Sue Appleyard Huddersfield 01484 311334

Results of the Red Lion Survey on Steroids

Julia Williams found the Steroid survey responses very enlightening. Here is her summary of the findings.

Ulcerative colitis is an inflammatory disorder of the colon, which usually begins in the rectum and invariably extends to the rest of the colon. It does not however affect the small intestine. Inflammation within the colon is usually superficial but can result in severe symptoms of bleeding, diarrhoea, abdominal pain and bloating and urgency sometimes with incontinence. The principles of the treatment of ulcerative colitis are as follows;

- the prompt and appropriate treatment of acute attacks of colitis,
- the introduction of appropriate maintenance therapy to reduce the risk of further attacks,
- and the timely selection of patients requiring surgery.

The purpose of this survey was to focus on experiences during the maintenance phase of medical management. Most who suffer with ulcerative colitis will be prescribed steroids on the initial attack. This will then be maintained with a combination of aminosalicylates and immunosuppressives as well as antibiotic therapy and nutritional supplements.

Each time an acute attack occurs then steroids are likely to be prescribed. This initial dose will then be reduced, appropriately under medical guidance. It would seem that everyone is aware of the unwanted effects that steroids can bring, so the Red Lion Group set out to gain an overall view of what life is like whilst taking steroids and how health care professionals can provide support and information whilst the ulcerative colitis sufferer is on medication.

From the Red Lion Group members who returned their questionnaires 71% were female and 29% were male. There is no discrimina-

tion of which sex is more likely to suffer with ulcerative colitis although from this survey it would seem that the ladies are just keener to fill out the questionnaires than the chaps!



The average age of the respondents was 46 years of age. Interestingly people seemed to have suffered with ulcerative colitis for varying periods of time. The shortest time reported was less than 6 months

prior to coming to surgery and the longest period of time was 31 years, this gave an average suffering of 11½ years.

A third (32%) of all respondents reported that they suffered from other conditions, such as asthma, eczema etc, as well as ulcerative colitis. It was important for us to know this because some of these conditions if severe are also treated with steroids and we needed to be clear that this survey was aimed at steroid use for acute attacks of ulcerative colitis.

The conditions people stated that they suffered from in addition to ulcerative colitis were dermatitis, hay fever, asthma, eczema, arthritis, psoriasis, hypothyroidism and alkalising spondylitis. Within the medical literature it is well documented that these conditions are in fact associated with colitis.

In some cases when someone suffers with pouchitis a flare up of any of these conditions can occur. This will inform the medic that some inflammatory changes are occurring usually within the pouch itself.

When we looked at the drug therapy of the respondents, the majority (91%) had been prescribed Prednisolone, whilst the remaining (9%) had been prescribed Hydrocortisone or Budesonide or Methylprednisolone. The majority of people who were prescribed steroids took them orally (55%), whilst others took them in the form of an enema (35%) and the remainder (10%) took the steroids in the form of a suppository.

In some cases both an oral route and enema route were prescribed (34%). This is not uncommon in view of the fact that it is effective to treat proctitis (inflammation in the rectum) locally and systemically. The average length of time people took steroids for was 3

years and only 10% of respondents are still taking steroids. All of which are taking them in the form of a suppository.

Although steroids are prescribed in order to reduce the inflammatory condition in ulcerative colitis and therefore relieve symptoms, most people are aware that in general steroids can bring about unwanted side effects.

We wanted to find out how people felt about themselves (body and mind) in a positive manner as well as a negative one. Peoples feeling about physical changes in their bodies actually equalled the negative feelings. Of the respondents 73% experienced positive feelings and 75% experienced negative feelings.

The positive feelings included relief from acute symptoms of colitis, generally feeling well and full of energy, slight weight increase, improved appetite, hair more manageable, reduced skin disorders, able to get back to work, improved sex drive, and reduced joint pains.

Most of the negative feelings focused around how family and friends would see a change in them (i.e., their bodily appearance). Examples included weight gain, moon face and acne, bloating, insomnia, excess hair or the loss of hair, hot flushes and problems with menstruation. Emotions seem to fluctuate depending on the length of time taking the steroids. Most people (65%) felt that initially they had this feeling of extreme wellness but as the treatment progressed, the feelings changed towards being depressed and particularly tearful and irritable over trivial matters (35%). The insomnia seemed to get most people down because they felt so tired at work and therefore were more prone to be grumpy at home.

The majority of people (87%) reported that their surgery had not been postponed because they were still taking steroids. However they were advised to undertake the pouch procedure in three stages rather than two. This potentially concerned them because it might a longer recovery time and potentially longer breaks away from work.

In the main, post operative complications were minimal (22%). Most of the complications reported post surgery included intestinal blockages, wound infection, pelvic abscess, peritonitis, electrolyte imbalance, urinary tract infection and retention, and haemorrhage. However, not all of these complications are associated with steroid usage.

Long-term problems associated with taking steroids were reported in 39% of respondents. These problems included hair loss/thinning, osteoporosis, diabetes, generalised joint pains, and psychological trauma i.e., still seeing yourself as someone on steroids, thinner skin and mood swings.

Many of the respondents (76%) felt that there was little explanation at the time these drugs were prescribed and that information regarding the effects of steroids only came to light when re-prescribed for a further acute attack of colitis. However only 14% of people felt that their lifestyles had actually been affected.

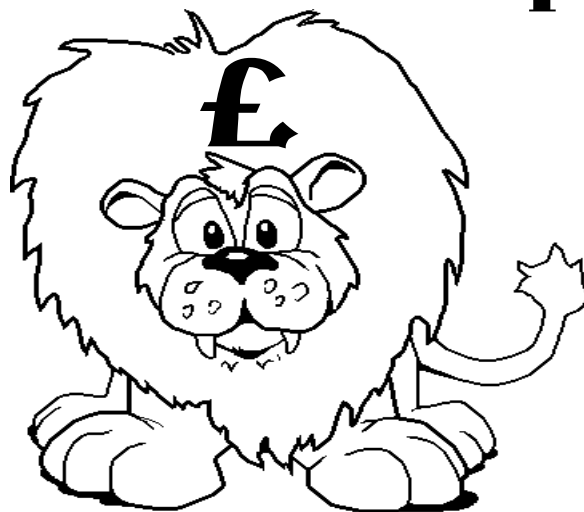
Only a small percentage of people (19%) reported having to take steroids since having a pouch formed, of which 54% are taking the steroid in the form of a suppository, 9% by mouth and 38% are using a topical steroid.

Overall, most of the respondents (79%) felt that they would have liked more information, probably written, so that they could take it home and read with their family and friends.

There seemed to be a concern that close family and friends didn't understand about the effects of the steroids and therefore sometimes appeared unsympathetic towards the individual's needs. From the comments, a lot of marriages and relationships have experienced stormy times purely through a lack of understanding.

Once again thank you to all those Red Lion Group members who replied to this questionnaire. It made very interesting reading and I hope you find this summary of the results useful.

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**
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FUNDRAISING OFFICER

This position is currently vacant. Anyone interested in applying should contact the secretary, Inez Malek (address and telephone number on this page).

* contributions to the newsletter should be sent to Morag Gaherty

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Professor John Nicholls

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

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 lit-

tle 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.

Don't forget to look at the Red Lion Group website on the internet:
WWW.RED-LION-GROUP.MCMAIL.COM/