Roar!

Issue number 23 • Easter 2002

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

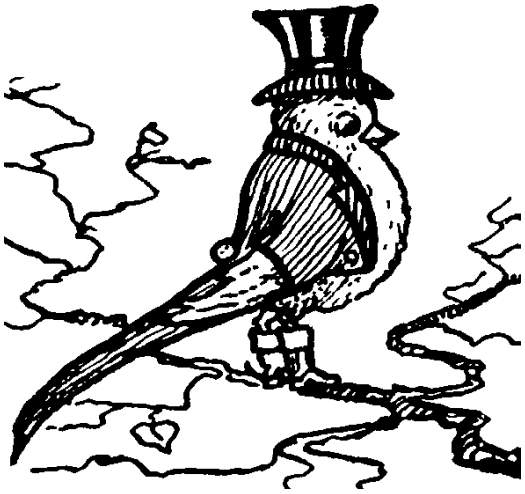
Red Lion Group Proved Right

Morag Gaherty reports on new research published which confirms conclusions the Red Lion Group tentatively reached nearly five years ago.

In the Easter 1997 issue of *Roar!*, we published the results of our family planning survey. We had received 55 replies, of which 29 were from women, 26 from men. At the time, ours was the only survey into the impact of pouch surgery on family planning that we were aware of.

Although the numbers were small, and so we warned about drawing too many conclusions from them, I commented in my analysis that "Overall, it seems that, if you can get pregnant, having a post pouch baby need not be any different than having a non-pouch baby. However, it's the getting pregnant that might be the problem…"

Fast forward five years, and researchers are now publishing statistics which bear this conclusion out. The January 2002 issue of Gastroenterology contains details of research undertaken by Dr Kasper Olsen and colleagues at Aarhus University Hospital in Denmark. They compared the reproductve ability of 290 female UC patients before and after restorative proctocolectomy with that of 661 similarly-aged women drawn from the general population.



The women with UC had similar fertility levels as the control group prior to diagnosis and to surgery, but were significantly less able to conceive than the women in the general population sample afterwards. As we had found back in 1997, this trend was anecdotally recognised before the research, but this is the first proof positive that it is not just coincidence.

And, like us, the researchers pointed out that it is not necessarily the surgery itself which causes this change. By definition, the women who had surgery were those with the severest forms of UC (25-40% of UC sufferers), and so it might be the severity of the disease rather than the operation(s) causing the change. However, this does not equate with findings from other severe disease states, such as perforated appendicitis, where fertility is apparently not affected. Therefore, Dr Kaspar and colleagues concluded that it was indeed the proctocolectomy with ileal pouch-anal anastomosis which caused the drop in fertility.

In This Issue...

Information Day/AGM News

Don't forget the Red Lion Group 2002 Information Day and Annual General Meeting at St. Marks on 13 April 2002.

Your invitation is contained with this issue of the newsletter. Inside on page 11 you will see latest details of what we have planned for you. Reduced rate parking is also available if paid in advance – you save a lot of money by doing this, so make sure you apply for your ticket as soon as possible.

13 April 2002

These findings have important consequences for all women still of childbearing age and faced with the decision as to whether or not to have a pouch, and they should be made aware of the fertility risks associated with the procedure. In my original article I suggested that – where circumstances permit – these considerations might lead some women to put off actually having their pouch formed until their family is complete. Elsewhere in this issue are some common questions about UC and pregnancy, which would be worth reading, in this context.

In addition, women who cannot conceive following surgery should be "referred early to a gynecologist to allow for investigations and the possibility of in vitro fertilization," the researchers emphasize. Most cases of UC are diagnosed in patients in their early 30s, according to American findings, by which point, the biological clock is starting to tick quite heavily. Hence the importance of fast tracking such women for IVF if necessary.

Gastroenterology, published monthly, is the official medical journal of the American Gastroenterological Association, an organization of more than 12,000 physicians and researchers, and one of the oldest medical specialty societies in the United States. The Institute for Scientific Information has ranked Gastroenterology the number one journal in the subspecialty and in the top two percent of indexed medical journals internationally.

Contact

After a long period of difficulty with her pouch, Red Lion Group member Kanta Patel is considering having a reversal. She would like to hear from anybody who has had this procedure, and who has any information to share. Good and bad points, please!

Please contact Kanta c/o Red Lion Group Liaison Officer (details on last page) – we will pass your letters on.

Family Planning and Ulcerative Colitis

Here are some common questions, with the answers as best we know them at present.

This information is summarised from www.living.com, where the relevant answers are supplied by Dr. Daniel H. Present, Clinical Professor of Medicine at the Mount Sinai School of Medicine and Attending Physician at the Mount Sinai Hospital, New York City, and a recognized specialist in treating inflammatory bowel disease. This website is owned by Proctor & Gamble, makers of Asacol, the site's sponsor. This might explain the importance in the article attached to proper medication – I'm guessing they probably have something that's just what you need! A full list of sources for the information in the article is given on the website.

Q: Does having UC make it harder for a woman to get pregnant?

A: A woman's fertility is not in itself reduced by ulcerative colitis. However, it is usually recommended to be in remission before you get pregnant, and this may involve taking medication to maintain this remission. Your consultant will advise you on which drugs are and are not suitable for this purpose.

Q: What about the fertility of men with UC?

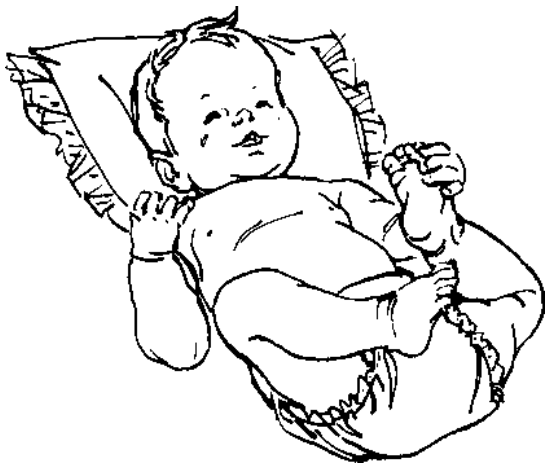
A: Again, the UC itself does not reduce fertility. However, medications such as sulfasalazine are known to have a temporary effect on sperm, causing abnormalities and reducing sperm count. If planning a family, talk to your consultant about compatible medication.

Q: How does ulcerative colitis affect pregnancy?

A: In general, complications during pregnancy are no more common in women with ulcerative colitis in remission than in the general population. However, *active* ulcerative colitis increases the chance of miscarriage and other complications. Should you experience a flare-up during pregnancy, your doctor will treat your symptoms depending on the severity of the flare-up with the appropriate medication.

Q: How does pregnancy affect ulcerative colitis?

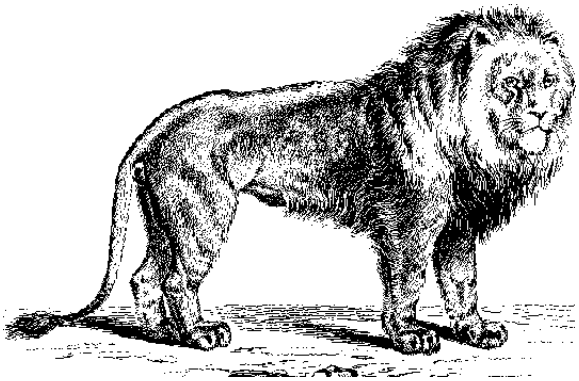
A: There is some evidence that suggests that ulcerative colitis can worsen if the condition is active when pregnancy occurs. That's why it's important to get ulcerative colitis into remission before you become pregnant and to make sure that any medication you take is appropriate for a pregnancy. Do your best to have a healthy pregnancy in terms of proper nutrition, keeping stress levels as low as possible, getting adequate sleep and exercising regularly and sensibly.



Q: What is the likelihood that I will pass ulcerative colitis on to my child?

A: The risk of inheriting ulcerative colitis varies widely, but is known to be higher in the children of Jewish patients. Current studies suggest that there is approximately a 5-10% chance that a child will inherit IBD if one parent has the condition. The risk is greater if both parents have IBD.

Editorial



Well, my biggest apology of all time is coming up in just a minute. Were you thinking you had missed the Winter issue of *Roar!*? Some of you contacted me in a panic to find out if your subscriptions had lapsed, so you already know what happened. Essentially it is this: I had planned to get the Winter issue done during Christmas/New Year, so that it would at least get out in the first half of January. Unfortunately, for various reasons, this did not happen, and I apologise profusely. We were then running into problems with timing, as the Spring issue has to come out plenty early enough to contain invitations for the AGM in April.

As a result, I took the decision to merge the Winter and Spring issues together into one bumper issue (you will see that it is thicker than usual). We are therefore one issue short for 2001, but I hope you will find this one makes up for that. I certainly found it interesting putting it together, especially when I came across the new research published in Gastroenterology journal.

On the one hand, it is gratifying to see that my original conclusions from the information we had back in 1997 have been verified – what an analyst, eh?! On the other hand, I wish it were not so. As someone who has had two children with my pouchie spouse with no great difficulty, my heart goes out to those who long to be parents but for various reasons have not managed it I do hope that the IVF recommendations in the published research do help you to get ahead in the queue, if this is the route you choose to go down. But don't give up hope: you *can* have a baby after having a pouch, but the more you look after yourself, the more you give nature a hand.

I also researched some frequently asked questions about family planning and ulcerative colitis, so it seemed sensible to include these in the same issue. A kind of mini theme, if you like.

Whilst having a look at the material currently available, I decided to home in on the Mayo Clinic, whose work we have mentioned before in this newsletter. I got really interested in their website, and the medical research and information they publish. So what started off as a little introduction to the work of the Mayo turned into a bumper section all about colorectal cancer issues. I hope this redresses the balance a bit between FAP/cancer and UC members of the Red Lion Group, as I know that most issues are geared more towards UC pouch owners, given that they make up the bulk of our membership.

This issue also contains the information about the 2002 Information Day and Annual General Meeting at St Marks on 13 April, and an invitation to attend. Please do come along. Those who get there say it is always well worth it, not just for the information content, but also for the chance to meet other Red Lion Group members. Like it or not, bowel function is a big topic for many of us, and one that is just impossible to discuss outside of the Red Lion Group for the most part.

As in 2001, we are also holding a workshop specifically for partners to talk about issues affecting them, away from their pouchie partners. Emotionally, this can be a very intense session, which just goes to show the importance of holding it – if pouch owners can't easily talk about their experiences, think how much harder it is for "other halves". It's considered weird enough to want to talk about your own poo, but to want to talk about someone else's, well…!

Of course, people don't really want to talk about poo, they want to talk about all sorts of emotional, psychological and personal issues surrounding the whole surgical and medical experience.

I'm sure I have mentioned before in this newsletter about my fears when Brian's surgery was first mooted, that he was somehow going to have his bottom sewn up. I spent a good many hours trying not to be worried at what it would look like afterwards, I can tell you!

What a relief to find out that I was agonising about nothing. I so wish I had known this beforehand. Somehow it was not a topic I felt I could raise with his consultant, John Nicholls, for fear of looking stupid (as I really would have done!).

Anyway, do return your invitations as soon as possible, and we hope to see you at St Marks on 13 April.

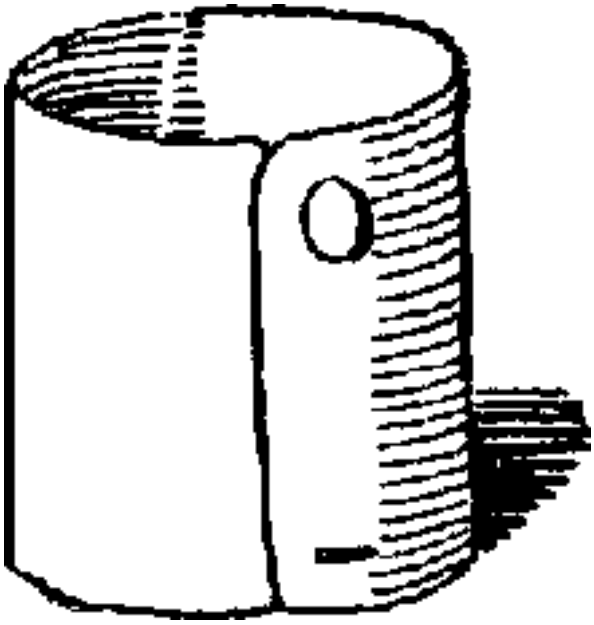
Final arrangements for the big day are still being settled, and more details will be published on our Yahoo Group as and when they become available – what better reason for joining the redliongroup (no spaces) at www.yahoogroups.com than this?

Fisticuffs

St Marks Pouch Nurse Specialist, Joanna Sweeney tells us more about cuffitis, or inflammation of the join between the pouch and the anal canal…

The term cuffitis describes a condition which can occur following formation of an ileo-anal pouch. It is caused by inflammation of the columnar epithelium or mucosa (the outer lining) of the upper anal canal. This region, sometimes referred to as the "columnar cuff", occurs just inside the internal sphincter muscles but below the joining of the pouch to the anal canal. Hence the term cuffitis.

Sometimes the surgeon may perform what is called a mucosectomy which is the removal of this columnar epithelium, which may reduce the risk of cuffitis. In a study of 113 patients, 13% of patients were found to have acute inflammation of the columnar epithilium which required treatment.



The symtoms of cuffitis include anal discomfort, anal irritation, mucus discharge and bleeding via the anus. The condition is diagnosed from clinical symptoms, endoscopic examination, for example pouchoscopy, and finally histologically from biopsies taken from the mucosal wall of the anal canal. Evidence from all three of these investigations must be present before a diagnosis can be established.

Cuffitis is not related to the condition pouchitis, which is inflammation of the pouch.

Once diagnosed, cuffitis can be treated with the use of topical steroids administered via the anus, oral steroids such as prednisolone and 5-aminosalicylates such as asacol.

Food for Thought

At last, someone's decided to listen on the subject of food!

As pouch owners well know, food is a very important subject when you have any form of bowel disorder. What goes in affects what comes out (and how it comes out!). Traditionally, nutrition plays an almost negligible role in medical training. It's all drugs, surgery or gene therapy these days.

Being the kind of person I am, I believe that many symptoms can be ameliorated or even cured by looking at the food level first. A lot of you believe that too – which is why you spend so much time researching the foods which do and do not work for you. Many pouch owners and UC sufferers have a standby meal to which they resort when the health going gets tough – see Jackie's lovely soup recipe elsewhere in this issue as a good example.

So it's nice to see some form of official recognition of the importance of nutrition to personal health.

The University of Surrey is now offering a course on nutritional medicine, aimed at GPs, consultants and dietitians. Course director Dr Margaret Rayman devised the programme and says that nutritional methods of treating disease are powerful, safe and effective.

Compared to the average 15 minutes reputedly spent on nutritional matters in a typical Medicine degree, the course on nutritional medicine takes two to six years to complete, and includes modules on diet, the gut, food allergy and intolerance. By being structured in this way, it can be studied on a part time basis without disrupting employment.

Uterine Artery Embolisation

Sally Thelen's pouch persuaded her consultant that traditional techniques would not be suitable to deal with her monster fibroid. After some family research as to the options available, she underwent a very new procedure instead…

As, like no doubt many of *Roar!*'s readers, I have had a great deal of major surgery I was not too happy when in October 2000 I was told I had a large grapefruit size fibroid at the back of my womb and should seriously consider a hysterectomy.

Following my mother's good advice, I decided to follow up the findings with my bowel surgeon, Mr Windsor at Northwick Park. He put me on to a gynaecologist colleague, Mr Lamont, who advised - in view of my previous medical history - to think long and hard before going in for a hysterectomy. He also agreed with the original gynaecologist that, again because of previous surgery, other alternative treatment such as a myomectomy (cutting the fibroids out of the womb) and laser treatment would not be advisable.

So I was faced with the daunting prospect of grinning and bearing it. My problems were chronic lower back ache and heavy periods. Then early in 2001 my older brother sent me an article from the Observer about uterine artery embolisation (UAE).

UAE is a new, hitherto unproven, procedure for treating fibroids by blocking off the arteries that feed the fibroids, the uterine arteries, and making the fibroids shrink. I did not think that my medical history would bode well for this but, to my surprise, received a positive response from Mr Lamont. He wrote that ' whilst it is still a bit of a research tool…… the technique is getting better all the time and may well be suitable for someone like yourself where we are trying to avoid open surgery if at all possible'. He put me on to a radiologist, Deirdre Campbell, who also works at Northwick Park.

Having met Deirdre and having discussed the procedure at length I decided to say ' yes' and a date was confirmed. It was agreed that Mr Lamont and Mr Windsor would be on standby in case an emergency hysterectomy had to be performed. I felt reassured in this knowledge.

I went in on Monday 3 December for a blood test and ultra sound scan to check the size of the fibroid.

It was still the size of a large grapefruit and was at the back of the womb pressing on the bladder. The following day I returned as an inpatient. First of all I was given a catheter and then wheeled into the specialised screening room within the X ray department. Before that I had to sign that I was aware that the procedure was a new one, and I had to give my permission for a hysterectomy to be performed in the event of any problems.

It is important to note that anyone who would not want a hysterectomy under any circumstances should not opt for this procedure as - if anything does go wrong and there is infection - a hysterectomy may be necessary, potentially to save one's life. A daunting prospect but nevertheless one to consider.

Once in the screening room, Dr Campbell gave me sedatives and painkillers. She also gave me oxygen through two small tubes into my nose and then started the procedure. This involves the radiologist inserting needles and fine catheters into the blood vessels through the skin. Once the needles are positioned correctly, a guide wire is placed through the needle and into the femoral artery (the major artery supplying blood to the leg). Then the needles are withdrawn allowing a fine plastic tube catheter to be placed over the wire and into the artery. I felt no pain from this, only slight discomfort.

The radiologist then uses the X ray equipment to make sure the catheter and wire are moved into the correct position into the uterine arteries feeding the fibroid. I felt a warm sensation from this, but nothing to distress me. The fluid containing thousands of tiny plastic sand-like particles is inserted

through the catheter into these small arteries, which nourish the fibroid. This silts up these small blood vessels and blocks them so the fibroid is starved of its blood supply. Dr Campbell and her colleague worked on the right and left arteries respectively so a needle and catheter were inserted on both sides. I now look like a plucked chicken with lots of bruising.

Although a lot of the procedure was hazy I can remember at the end both of the radiologists pressing down with force on to my groin – hence the bruising. This is apparently to prevent any internal bleeding. All in all, the whole procedure took approximately one hour.

For me the worst part was after the procedure because, due to a misunderstanding, the self-operating morphine pump was not set up in my room when I was wheeled back. I think that is the worst pain I have ever had, or at least pure unadulterated pain, as after my bowel operations the pain has always been experienced through a haze of drugs.

It got so bad that my blood pressure, normally low, went sky high and I had to be given an interim injection. Once the morphine pump was in place, I was more comfortable although I had to lie still and flat on my back for six hours so that there was no risk of internal bleeding. In the evening I went to the bathroom to wash and nearly collapsed, so had to be helped, unwashed, back to bed!

That night I received intensive care treatment as nurse came in on the hour every hour to check my blood pressure and temperature and that the blood supply was still getting to my feet. It meant I was shattered by the next day but it was good to know someone was keeping an eye on me.

The next day I was sick after breakfast, felt sick after lunch but then improved considerably. I came off the morphine pump and Thursday afternoon was told I could go home as long as I rested for three or four days and took it easy for a couple of weeks. I was also given a letter, which told anyone in the medical profession what I had had done and that any fever within 2 weeks should be treated as urgent and requiring hospitalisation.

The biggest potential complication hence the biggest concern for the radiologist (and the patient of course!) is that the patient does not gain an infection. I was told reassuringly that only two out of the approximately 7,000 patients had died as a result of UAE procedure and only one of those through infection, the other patient died as a result of medical negligence.

So far, all has been well, although it has only been a matter of a few days since the procedure. Despite the extreme pain immediately afterwards I am glad I had it done instead of a hysterectomy and I would recommend anyone else in a similar position.

One important point to note is insurance. Good old insurance companies. If they can spot a way out they'll go for it. I was originally told the procedure would be paid for. Then I was told it wouldn't be, as it was an ' unproven procedure'. It then transpired that if the radiologist was Surnip registered, it would be covered. Surnip is, as I understand it, a government research register.

After numerous calls to Deirdre Campbell and the insurance company, it transpired that Deirdre was not Surnip registered but had been trying for months and was unable to get past the red tape. She spoke with a colleague at the Royal Free hospital who has performed 80 UAE procedures and who told her he had never had a problem with insurance companies, even though he also was not Surnip registered. Apparently for this procedure there is only one radiologist in the whole of the U.K. who is on the register.

I explained to my insurance company, the Royal Sun and Alliance, that in the long run UAE would save them money as it is a much cheaper option that a hysterectomy. Considering a hysterectomy is the second most common operation in the U.K. this is a quite an important point. The insurance company is now re-considering it.

Meanwhile I am waiting for the hospital bill. I have no idea what the final bill will be as no-one at Northwick Park seemed able to give me this information. I was told that it would be at least £ 3000 …

I asked for a package price (you can tell I'm in the travel business!) but was told this was not possible. Still, I did have a wonderful room with panoramic views of London and I must say the staff were wonderful and kind. Deirdre Campbell herself is a really lovely person who inspires confidence. She is also exceptionally kind and understanding.

I fear I have gone on too long but my reason for writing is that I hope that if any female readers have got fibroid problems they will be comforted by my story and feel free to call or e-mail me to discuss more. As I write, I am still having some pain but not much and I have co-proxamol to ease it. All that remains is the next ultra sound scan and then hopefully it's GOODBYE FIBROID, HELLO ENERGY.

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Letters

Roar! Letters Page
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Dear Editor

I had UC then a pouch was made (see *Roar!* a few years ago), which was reversed 18 months ago. I have been poorly on and off, but – fingers crossed – am now getting on fine. However, I am now left with arthritis, and wheat makes it worse. I also don't drink cow's milk as that hurts my tummy. So when things aren't too good on the health side, my soup recipe (see elsewhere in this issue) really works for me, and maybe other readers will benefit from it as well.

You might be interested to know that I became very tired after all the operations to make the pouch and then do the reversal. After several blood transfusions and even more investigations up and down, to see where I was losing blood, they discovered through taking some bone marrow from my chest (not as bad as it sounds!) that my blood had stopped reproducing. They think that after everything my body had been through that it had just stopped. Anyway, I seem to be OK now, through lots and lots of rest and heaps of help from my family. Slowly the blood factory is up and running again, and so am I.

Jackie Brooks
Maidstone

Introducing Marion Silvey

My name's Marion and I live in Gloucester. I answered Morag's plea for assistance and I hope I will be able to help, in a small way. I had my pouch operation in one stage in 1992 at Gloucester Royal Hospital. I've never regretted it for a moment. After 17 years of UC getting progressively worse, there was only one way to go. I've not had any problems since and I believe all thanks go to my brilliant surgeon Mr Hamish Thompson.

I have a son at University studying IT, which is invaluable help when I have a problem on the computer, which is quite often! I work part

time for a local authority and my husband is newly retired. As with so many newly retired, he's already wondering how he ever had the time to go to work!

I would like to take this opportunity to express my appreciation to everyone involved in running the Red Lion Group and with the publication of *Roar!*. I've always enjoyed reading my copy from cover to cover and have gained a lot of useful information.

I'm sure you will all agree that it makes such a difference when we can share our experiences. I know without the Red Lion Group I would feel, at times, quite isolated with this strange, but miraculous 'Pouch'. So once again, thanks to all of you who do the hard work.

Jean's Top Tips

Red Lion Group member Jean Mercer saw these two tips in another magazine which she receives, and thought they might prove useful to some. I'd be very interested to know what stoma nurses make of the first one!

Friar's Balsam

The writer of this tip has had an ileostomy for nearly 40 years and has never had significantly sore skin. He attributes this to the treatment he had onto the wound by the nurses right from day one: "the nurses anointed the peristomal skin with tincture of Benzion (Friar's Balsam). I would not have had the courage to do it myself as the initial application was so painful. By the third day I no longer felt this and have never done so since. This was long before stoma nurses, and fortunately I have never needed to consult one. On the occasions when there is a slight soreness, a dab of the Friars Balsam cures it immediately".

Peppermint Oil

Again, a tip for ileostomists rather than pouch owners. Add two drops of peppermint oil to the stoma bag when you first put it on. This very effectively seems to kill all other smells, reducing embarrassment significantly. Although peppermint oil is not cheap, this is a very cost effective solution, as a single bottle costing around £1 lasts for months.

Cross examination

Chris Lawton, our official "smileographer", passes on a genuine court transcript.

Q. Doctor, before you performed the autopsy, did you check for a pulse?

A. No.

Q. Did you check for breathing?

A. No.

Q. So, then, it is possible that the patient was alive when you began the autopsy?

A. No.

Q. How can you be so sure, doctor?

A. Because his brain was sitting on my desk in a jar.

Q. But could the patient have still been alive nevertheless?

A. Yes, it is possible that he could have been alive and practising law somewhere.

Please support the Red Lion Group

Registered Charity number 1068124

All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE**

Beating Bowel Cancer

If you watch the Watchdog consumer affairs programme, you will probably remember the original presenter, Lynn Faulds Wood. If you haven't seen her on TV for a while, you might have thought that she had reached her "sell by" date, which appears to happen much earlier to female presenters than to male ones.

Well, you'd be wrong. Lynn Faulds Wood is no longer on the TV, because she's a woman with a mission. And that mission is bottoms.

10 years ago, Lynn discovered that she had bowel cancer. Five years ago, she gave up most of her TV work in order to devote her time to helping save lives from bowel cancer. She set up a charity called (note the initials!) Beating Bowel Cancer, and the latest project from that charity is a video called *Having a Colonoscopy*.

Lynn was horrified to discover that many doctors learn how to perform one of these under the "see one, do one, teach one" method. No wonder that the British Society of Gastroenterology audits find that most of the doctors doing these procedures are not as good as they could be, and that many patients probably suffer more discomfort than they should.

It's an intensely personal project, as the colonoscopy in the video is her own, and she arranged to have the whole thing filmed, including her reactions, without prior knowledge of what the doctors would find. Her aim was to show how a good colonoscopy can be done, and to remove patient fear of the procedure. Apparently, various consultants have contacted her to say that they were so impressed by the method employed by the two doctors in the video that they have gone back to the drawing board to relearn their own colonoscopy technique.

The video should be going free to hospitals, to be lent free of charge to patients in need of a colonoscopy. If this procedure is on the horizon for you, make sure you see the video. One should be offered to you automatically, but if it is not, do ask for it, and also ensure that the hospital is aware that this video is supposed to be given out for this purpose – write an official letter to them. If your hospital does not have a spare copy of the video, they can contact Beating Bowel Cancer direct. If you want a copy for your own use, you too can obtain one for £6 including P&P from the charity, details at the end of this article.

Whilst you're at it, you might also like to ask your consultant if he or she has seen the video, and what they thought of it. Their answer might well influence your views on their interest in patient care!

You can contact the charity Beating Bowel Cancer at 39, Crown Road, St Margarets, Twickenham TW1 3EJ, or you can visit their website on www.bowelcancer.org.

Books

Well, I was looking to see how easy it would be to get hold of Barbara Barrie's book (see below) and look what else I turned up….

If you're feeling the need to read the authoritative guide to pouch care nursing, I can tell you that Julia Williams's book, *The Essentials of Pouch Care Nursing*, is available within 2-3 days from www.amazon.co.uk for £25. Surely it behoves us all to improve its current sales ranking from the current position of 535,369? But seriously, Julia, great to see it's available on Amazon at all. I was so tempted to write a glowing review – send dme a copy to read, and I'll definitely do so.

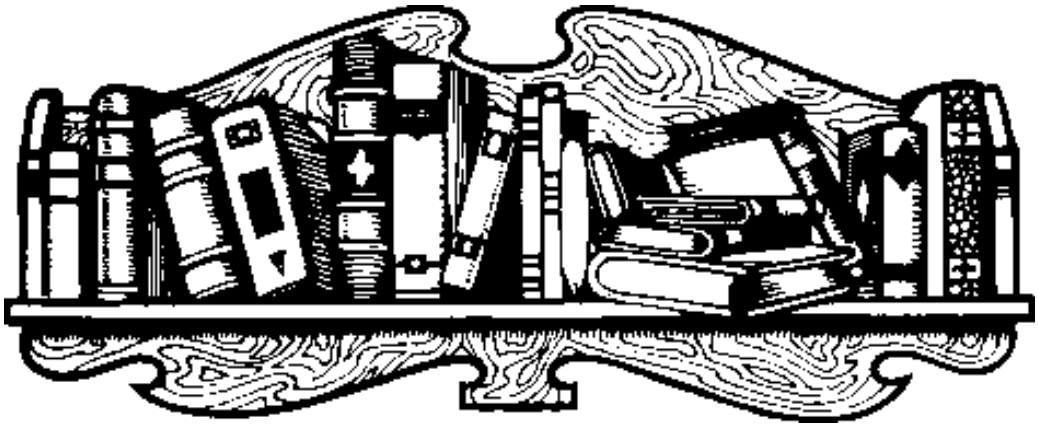
The Essentials of Pouch Care Nursing £25

Julia Williams BSc RGN Dip D/N (Editor), R. John Nicholls

Paperback - 200 pages (3 November, 2001)

Whurr Publishers; ISBN: 1861562217

What I was really looking for was Barbara Barrie's book *Don't Die of Embarrassment: Life After Colostomy and Other Adventures*. Ms Barrie is an American actress and writer, and this book charts her personal experience of colorectal cancer and the resulting surgery, starting with the initial emergency hospitalisation when cancer was diagnosed during filming. This was followed (after filming had finished!) by a colostomy, chemotherapy, radiotherapy and two further operations to correct a bowel herniation from her first surgery. I have not yet read the book myself, but am told that it is detailed, witty and frank, and can provide a useful reference point for patients and their families. Bear in mind, however, that Ms Barrie's experience is relevant to the American healthcare system rather than our own. Despatch in 1-2 weeks from www.amazon.co.uk.



Don't Die of Embarrassment : Life After Colostomy and Other Adventures £7.52

Barbara Barrie

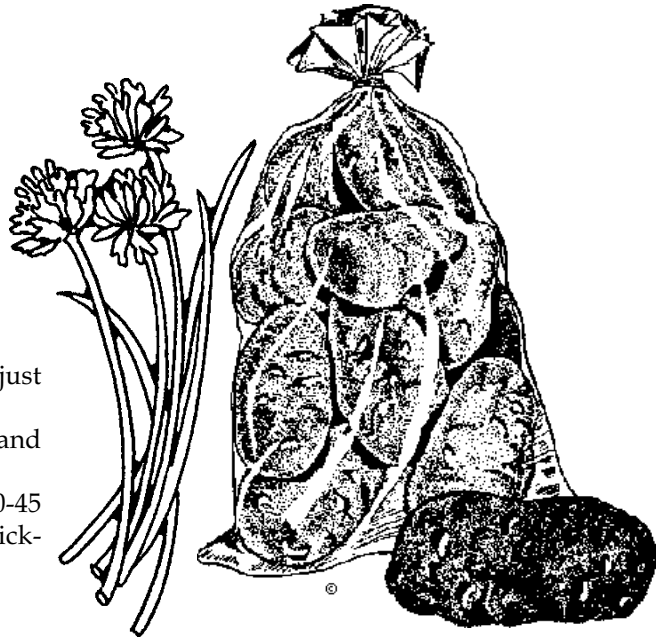
Paperback - 256 pages Fireside (March 1999)

Fireside Books; ISBN: 0684846241

Jackie's Potato Soup with Bacon and Chives

50g/2oz butter
1 large onion, chopped
750g/1½ lb potatoes, chopped
750ml/1¼ pts chicken or vegetable stock
750ml/1¼ pts milk or soya (sweetened or not)
6 rashers bacon, chopped and crisply fried
Salt and pepper
1 tbsp snipped chives to garnish

1. Melt the butter in a large saucepan and fry the onion until just softened.
2. Add the potatoes, stock and milk, and season with salt and pepper.
3. Bring to the boil, then reduce the heat and simmer for 40-45 minutes, stirring occasionally to prevent potatoes from sticking.



13 April 2002 Red Lion Group Information Day and Annual General Meeting

This year's Information Day and AGM will be held again at St Mark's Hospital Harrow, as this is the most accessible hospital with suitable facilities for the most number of people.

The provisional timetable is as follows:

09.45 Registration and coffee
10.30 Welcome/nomination forms
10.35 Seminar options: A. Current Research by Ed Westcott or B. Health Issues with a Pouch by Angie Perrin
11.35 Diet and Nutrition – talk by Morag Pearson
12.05 Red Lion Group Annual General Meeting
13.00 Lunch and exhibition of RLG merchandise
14.00 Workshops: A. Ulcerative colitis/pouchitis or B. Polyposis/FAP (Ends 14.20)
14.45 Workshops: A. Family Planning or B. Living with a Pouch (Ends 15.25)
15.30 Workshops: A. Pouch Partners or B. New Pouch Owners (Ends 16.10)
Workshop leaders still to be finalised. Handouts will be available for those workshops you are unable to attend
16.15 Closing remarks in main lecture theatre

How it Works

In order to reserve your free place(s) at the Information Day, please complete and return the enclosed form to Joanna Sweeney as soon as possible, and by **31 March** at the very latest.

Please enclose a deposit cheque for £12.50 per person made payable to Red Lion Group with your completed form. This cheque will not be cashed, and will be returned to you on arrival. Should you be unable to attend, your cheque will be returned to you as long as at least 48 hours' notice have been given. In exceptional circumstances only, your cheque will be returned to you if the relevant notice could not reasonably be given. We operate this system in order to prevent overbooking on food.

Location and Access

St Mark's Hospital is easily accessible from either the M25 by car, or by tube from central London.

Local area maps are included with this issue of the newsletter.

Parking

Parking for a full day at St Marks/Northwick Park costs £10, and this charge will be payable unless you have a prepaid ticket when you arrive. The charge for these tickets is yet to be finalised, but is likely to be £2, as in 2001. If you would like to order a prepaid ticket, please tick the relevant box on the invitation – you will be contacted with details nearer the time. *It is not possible to offer this discount to people arriving on the day, as the tickets need to be obtained in advance.*

Food

Lunch and refreshments are available free of charge. Lunch will consist primarily of salads and baked potatoes with a choice of fillings, including vegetarian options. Should you have any special dietary requirements, please let us know when you send in your form.

Nominations for Committee Positions

Please see page 18 for details of the positions on which we will be voting this year. Remember that you ARE allowed to nominate yourself for any position if you feel it is a role you would like to do.

Should you decide during the year that you would like to get involved with the work of the Red Lion Group in a less formal way than joining the committee, please approach the Chairman to discuss this. We can co-opt you for specific projects, if that would suit you better. Any help is better than no help!

We can co-opt you for specific projectsrather than to a permanent role as such.

Lashings of Mayo

Regular readers of *Roar!* will have read pieces in the past mentioning the Mayo Clinic. As this issue contains a significant extract from their website (www.mayoclinic.com), I thought it worthwhile telling you a bit more about the Mayo.

Here's how it all started: Around the turn of the century, Dr. Charlie and Dr. Will Mayo organized medical professionals in a new way to better care for patients. They created a system that allowed doctors to take the time to thoroughly investigate patient problems and to quickly and easily get help from other specialists.

The system was built on the idea that two heads are better than one and five are even better. It also encouraged a continual search for better ways of diagnosis and treatment. Patients flocked to the Mayos because of their ability to find answers to their problems. Doctors, too, came to observe and learn at "the Mayo's clinic."

Through growth and change, Mayo remains committed to its heritage: thorough diagnosis, accurate answers and effective treatment through the application of collective wisdom to the problems of each patient.

The Mayo clinic's overriding principle is: The needs of the patient come first.

Beyond this, they have a number of other core principles:

"To practise medicine as an integrated team of compassionate, multi-disciplinary physicians, scientists and allied health professionals who are focused on the needs of patients from our communities, regions, the nation and the world.

To educate physicians, scientists and allied health professionals and be a dependable source of health information for our patients and the public.

To conduct basic and clinical research programs to improve patient care and to benefit society."

The Mayo clinic meets these commitments in three distinct ways: through the community-based health practices, via their website

www.mayoclinic.com and through professional and laymen's publications.

There are three main Mayo Clinics, in Arizona, Florida and Minnesota. Between them, they employ over 2,000 doctors and another 700 or so scientists. Apart from the actual day to day work of the clinic, they are also involved with publishing health information both on the website and in publications.

If you have internet access, and are interested in health matters, the website is well worth a visit, and is clearly a priority information source for them. The site is separated into general information sections, as follows:

Diseases and Conditions A-Z

12 Condition Centres: Allergy & Asthma, Arthritis, Cancer, Diabetes, Heart & Blood Vessels, Mental Health, Alzheimer's, Brain & Nervous System, Children's Conditions, Digestive, High Blood Pressure, Pain Management

8 Healthy Living Centres: Family Life, Fitness & Sports Medicine, Food & Nutrition, Healthy Ageing, Men's Health, Pregnancy & Reproduction, Women's Health, Working Life

Drug Information, including Drug Watch, featuring important drug-related news (US information)

First Aid & Self Care Guide
Answers from Mayo Clinic

In addition to the general information section, there is also a section entitled Take Charge of Your Health. Here you can find a Personal Health Scorecard test (which you can retake and compare results with previous tests), Healthy Lifestyle Planners, Disease Self Managers (for Asthma, Depression, Headache and Low Back Pain), Health Decision Guides and the opportunity to sign up for a range of newsletters from the clinic.

What is so good about this website is that it is so clearly authoritative, which can be unclear with many health-related websites. I found it very easy to navigate and to find what I wanted. Everything was in easily readable format, and can also be printed out if required.

Elsewhere in this newsletter, you will find excerpts from the Answers section on topics of interest to Red Lion Group members, plus a reproduction of the section on how to choose appropriate bowel screening for colorectal cancer, with the permission of the Mayo Clinic.

Health Decision Guide: Colorectal Cancer Screening

Reproduced from the www.mayoclinic.com website, with kind permission

Can you reduce your risk of colorectal cancer or even prevent it?

A few years ago the answer to this question would have been no or at best doubtful. Today, if cancer is detected early or, even better, if precancerous polyps are removed, the vast majority of colorectal cancers can be treated or prevented.

Just as stopping — or better yet, never — smoking goes a long way in preventing lung cancer, regular testing to detect and remove colorectal polyps can prevent colorectal cancer.

This guide was created to help you make informed decisions in the detection and prevention of the United States' No. 2 cancer killer — colorectal cancer.

In this screening overview — your first step into the colorectal cancer screening guide — we'll help you determine your level of risk of this cancer and suggest some issues to consider as you and your doctor decide what screening method(s) is best for you.

As with most things, one size does not fit all. As you make your way through the individual components of the colorectal cancer screening guide, we'll show you — in detail — each of the most commonly used screening tests and identify the pros, cons, risks and benefits. Choosing a screening test isn't always an easy decision, but it is a potentially lifesaving one.

What is colorectal cancer?

Colorectal cancers generally are not fast growing. They may occur anywhere along the wall of the large intestine. Most have their beginnings as a tiny polyp that develops on its inner lining.

Not all polyps become cancerous, but nearly all colon cancers start as polyps.

Polyps are merely growths of tissue arising from the inner lining of the colon or rectum. They may be mushroom shaped (pedunculated) or flat (sessile). Large and flat polyps are more likely to become cancerous. The two most common types of polyps are:

Hyperplastic. Often less than 1/4 inch in diameter, these polyps rarely become malignant.

Adenomas. Adenomas more commonly become cancerous as they grow.

Once an adenomatous polyp grows beyond the size of a pencil eraser (about 6 millimeters [mm] to 7 mm in diameter), there's an increasing chance it will be cancerous. This is especially true when a polyp's diameter reaches 10 mm.

An adenomatous polyp takes an average of 7 to 10 years to become cancerous. However, in some people at high risk of colorectal cancer — such as those with a strong family history of colorectal cancer — the cancerous change may occur much more quickly.

Do you need to be tested?

Not everyone needs to be tested for precancerous polyps and colorectal cancer. Your need for screening will depend upon your level of risk. Three major factors determine risk:

Age. About 90 percent of people with colorectal cancer are age 50 or older. The American Cancer Society, the American College of Gastroenterology, the American Gastroenterological Association, the American Society of Colon and Rectal Surgeons and other organizations all recommend that adults begin a screening program at that age. Earlier or more frequent screening may be needed if you have other risk factors of colorectal cancer.

Family or personal history of colorectal cancer or adenomatous polyps. If you've had colon cancer or precancerous polyps before, you're at greater risk of developing colorectal cancer. The same is true if a family member (parent, sibling or child) has had the disease. Persons with more than one close family member with this condition are at even higher risk. Screening should begin earlier and be done more frequently for those with above average risk.

Inflammatory bowel disease. Inflammatory diseases of the colon, such as ulcerative colitis and Crohn's disease, also increase your risk of colorectal cancer. Thus screening may need to start earlier and be more frequent.

Other factors that increase your risk of colorectal cancer but usually don't affect screening recommendations include:

Gender and race. In the United States, men are at somewhat higher risk of rectal cancer than women

are, and blacks have a somewhat greater risk of dying of the disease than other racial groups.

Diet. Though studies are inconclusive, a high-fat, low-fiber diet appears to increase your risk.

Smoking and alcohol. Both smoking and regularly drinking alcohol seem to increase your risk of colon cancer.

Sedentary lifestyle. If you're inactive, you're somewhat more likely to develop colon cancer.

What are your screening options?

Although you may be embarrassed by colorectal cancer screening procedures, worried about discomfort or fearful of results, such concerns should not stand in your way.

When polyps and early stage cancers are found and removed before they've produced symptoms, the 5-year survival rate for people with early-stage colorectal cancer is more than 90 percent. This is why proper screening is very important.

Common screening procedures include:

Barium enema (colon X-ray). This test allows your doctor to evaluate your entire large intestine with X-rays. Liquid barium, which blocks X-rays, is put into your colon through an enema tube inserted in the rectum. Sometimes air also is added. Barium coats the lining of your large bowel, creating a clear silhouette of your colon and sometimes the rectum.

This test often is done in conjunction with a flexible sigmoidoscopy exam to aid in detecting polyps, because a barium enema X-ray may not visualize the rectum and sigmoid colon well. Preparation for the exam includes a limited diet and, sometimes, laxatives or enemas to cleanse the colon for better viewing.

Colonoscopy. During this test, a slender, flexible, fiber-optic-lighted tube containing a tiny video camera at its tip, which transmits images to an external monitor, is used to look for polyps and cancer inside your entire colon and rectum. If polyps are found, your doctor can painlessly remove them or take tissue samples (biopsies) for laboratory analysis. Mild sedation typically is needed during the test. Preparation for the exam includes a limited diet, laxatives and, sometimes, enemas to cleanse the colon for better viewing.

Digital rectal exam. This exam can be performed during an office visit. Using a gloved finger, your doctor checks the first few inches of your rectum. This test often is done in conjunction with other screening methods.

Fecal occult (hidden) blood test. This test checks for blood in your stool, which may come from a cancer or, sometimes, a polyp. It can be done at your doctor's office, but usually you're given a kit that explains how to take a sample at home. The samples are then sent to a laboratory for analysis. A flexible sigmoidoscopy exam often is done in addition to this test.

Flexible sigmoidoscopy. Similar to colonoscopy, a slender, flexible, fiber-optic-lighted tube, which contains a tiny video camera at its tip, is used to look for polyps and cancer. The camera transmits images to an external monitor, but is only able to view your rectum, sigmoid and sometimes descending colon, which is the last 2 feet or so of your large intestine.

This test often is done periodically in conjunction with a fecal occult blood test. Sedation usually is not needed during the exam. Preparation for the test includes an enema to cleanse the rectum and colon for better viewing.

What's best for you?

When weighing your screening alternatives, the best decision often is made by discussing the issues with your doctor. Important questions to consider when choosing a test may include:

- What is your risk of colorectal cancer?
- Do you need to be tested?
- What preparation is involved?
- How convenient is it?
- How experienced is the person conducting the test?
- What are the associated risks?
- What are the associated benefits?
- What is the cost? *(if relevant)*
- What is your payer's (insurance) preference? *(if relevant)*
- What is your physician's preference?
- What is your preference?

Whatever you decide, what's most important is that if you are at risk of colorectal cancer, some screening is better than no screening. Proper screening and early detection can go a long way in preventing and treating this potentially fatal disease.

"Flexi-Sig" Screening

Let's start with a reminder as to what the various "scopes" are for. A colonoscope is a long flexible tube which sees right around your insides to the appendix. A sigmoidoscope is the shorter version, used to examine the first half of the colon only, which comes in two varieties: rigid and flexible.

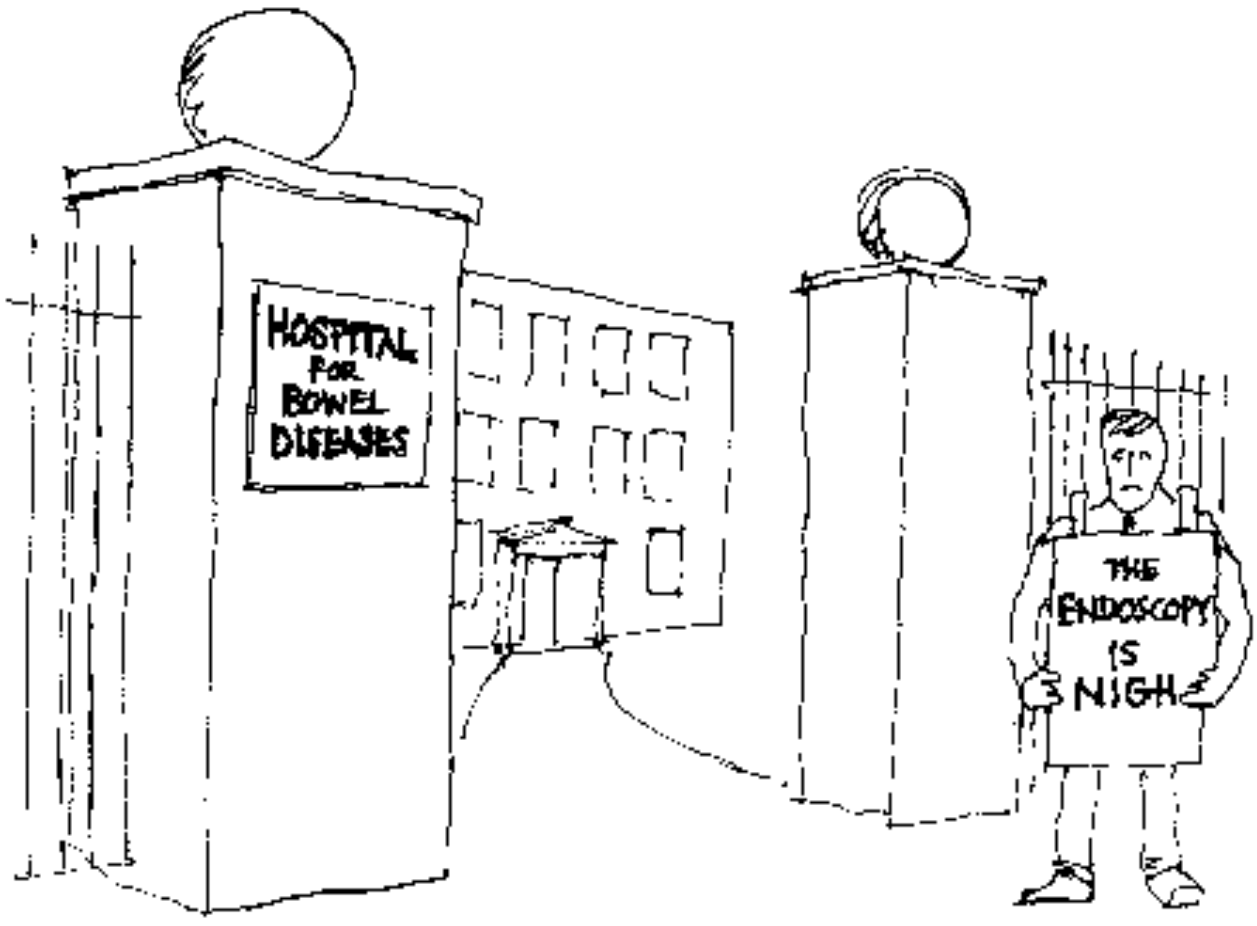
Whilst no doubt the cheapest form of diagnosis, a rigid sigmoidoscopy, with or without a barium enema to follow is not a pleasant experience. The sigmoidoscope is uncomfortable for the patient, and does not get far round the colon, and a barium enema is pretty disgusting for the patient and misses early or pre-cancers anyway. In fact, if you are booked for a screening at a hospital, I would recommend asking *exactly* what procedure is planned - if it is this one, that may well be your cue to ask to be seen at a specialist hospital instead.

So that leaves colonoscopy as the preferred method, doesn't it?

Not necessarily, is the answer, depending on what sort of screening you are looking at. If this is an initial foray into your insides to take a look at what is going on, there is an easier alternative, which has been around for 20 years, takes a few minutes to do and – crucially for the patient – does not require 24 hours of starving and "prepping"

That alternative is the "flexi-sig", or "flexible sigmoidoscopy" (short colonoscopy). This procedure is thought capable of diagnosing most cancers and pre-cancers at one short visit. In the US, flexi-sig is routinely offered on company health schemes, and because it is not such a palavar as a full colonoscopy, it is usually taken up. Yet, at the latest British Society of Gastroenterology audit, most UK hospitals do not even have a flexi-sig clinic.

Is it any wonder that the UK is worse at treating bowel cancer than most other countries in Europe, and significantly worse than in the US? Like any other cancer, bowel cancer is much easier to treat if it is picked up early. And it's much easier to pick it up, if people aren't frightened to come in for the checkup that could help save their lives.



Free or Reduced Rate Prescriptions

The following information is reproduced from the RNIB website and gives a good introduction to this subject in general (www.rnib.org.uk/sightlos/brit/freeprescrips.htm). Further information about claiming an exemption with a pouch is at the end.

Introduction

There are three ways you can qualify for free prescriptions. Your prescription may be free if:

you receive certain benefits because your income is low

your income is considered low under the Low Income Scheme

your age or health falls within certain categories

When considering whether you are entitled to free prescriptions, don't forget that if you don't qualify under one scheme you may qualify under another.

You can also get advice on free prescriptions from the Department of Health on the freephone advice line 0800-917 7711. Leaflet HC11 "Are you entitled to help with health costs"? is available from the Benefits Agency, GP, Pharmacist, Post Office or by ringing the Department of Health, Health Information Service on the freephone number 0800-66 55 44.

In April 1999, the Government introduced new rules which mean that your pharmacist or dispensing doctor must ask you to provide proof that you are entitled to claim free prescriptions. The proof required depends on which category you claim free prescriptions under. If you are unable to provide evidence, you will still get your prescription free but the pharmacist will make a note that no proof of your exemption was produced on your prescription and your entitlement will be checked further! The Department of Health has produced a leaflet, HC81 'Prescriptions', which contains details of these rules.

Benefits and free prescriptions - who qualifies?

If you receive the following, you will automatically qualify for free prescriptions:

- Income Support or Income-Based JobSeekers Allowance
  or
- Disabled Person's Tax Credit or Working Families Tax Credit, but only if less than £70 of your maximum tax credit has been withdrawn (from October 2000, your tax credit notification statement will show this)

To prove you are entitled to free prescriptions for this reason you will need to produce your benefit order book, or the letter which comes with your giro, at the pharmacy. If your benefit is paid directly into

your bank or building society account you will need to ask your local Benefits Agency office to provide you with a letter confirming your entitlement to one of the benefits mentioned above.

The low income scheme

If you are not getting one of the benefits mentioned above, you may still qualify for free prescriptions if your income is considered to be low.

You will qualify for free prescriptions under the Low Income Scheme if you have less than £8,000 capital and your income is considered low given your particular circumstances. The Benefits Agency will work out whether you qualify. A formula is used which depends on your circumstances, so there is no single threshold of low income for everyone. Your partner's income is also taken into account.

To claim exemption from prescription charges under the Low Income Scheme, you need to complete form HC1 which is available from places such as your doctor's surgery, post office or local Benefits Agency office. The address you should send it to will be on the form.

If you are eligible for free prescriptions on the grounds of low income, you will be issued with a certificate called a HC2 certificate. The HC2 Certificate can also be used to help you with other health service charges such as vouchers for glasses, sight tests and dental treatment. An HC2 certificate is normally valid for 6 months, or 12 months if you are aged 60 or over.

You will be asked to produce your HC2 certificate at the pharmacy when you collect your prescription to prove that you are exempt under the Low Income Scheme.

Age and free prescriptions

You qualify for free prescriptions if:

- you are under 16
  or
- you are aged 16 - 19 and in full time education
  or
- you are aged 60 or over

Most prescriptions will have your date of birth automatically printed on them. This will be sufficient proof of your age. If your date of birth is not shown on the prescription, then you will be asked by your pharmacist to show any official document which contains your name and date of birth, eg. your NHS Medical Card.

Health conditions and free prescriptions

If you are unable to get free prescriptions on the grounds of low

income, benefits or age, you may still qualify if you have one of the following specified health conditions:

- a continuing physical disability which prevents you leaving your home without the help of another person
- epilepsy requiring continuous anti-convulsive therapy
- a permanent fistula (including a caecostomy, ileostomy, laryngostomy or colostomy) needing continuous surgical dressing or an appliance
- diabetes mellitus (only if you do not treat by diet alone) myxoedema
- diabetes insipidus or other forms of hypopituitarism hypoparathyriodism
- forms of hypoadrenalism (including Addison's disease which requires specific substitution therapy)
- myasthenia gravis

You can only obtain an exemption on one of the health grounds if your GP agrees. If you are relying on the category regarding the difficulties you have leaving home without the help of another person, it is important for you to discuss fully with your GP the difficulties you have getting around out of doors without the help of another person because of your condition.

Qualifying for free prescriptions under this rule is particularly useful if you have a partner who works or you have too much income or savings to qualify for free prescriptions under any other rule.

If you think you could be entitled to free prescriptions on health grounds then take the following steps:

1. Get the form FP92A (EC92A in Scotland) - 'NHS Prescription - How to get them free' from your local Benefits Agency office, chemist or doctor's surgery
2. Included in the FP92A is form B. Ask your GP to sign this to confirm that you meet the health condition under which you think you qualify for free prescriptions
3. If you are registered as blind or partially sighted, it would be helpful if you could provide your GP with confirmation and explain to him or her what difficulties you have walking outside without another person's help
4. Once your GP has signed form B, send it to your local Family Health Services Authority (or Health Board in Scotland). You can get their address from your GP, phone book, directory enquiries or your local library

You will need to produce the Health Authority Exemption Certificate FB92 at your pharmacy each time you pick up your prescription to prove you are exempt from prescription charges under this category.

Other categories

Finally, you can get free prescriptions if:

- you receive a war disablement pension and need the prescription for your war disability
  or
- you are pregnant
  or
- you have a child under one year old
  or
- you are in residential accommodation and your place is funded at least in part by the Local Authority.

Pre-payment certificate

If you do not qualify for free prescriptions you may be able to reduce the cost of your prescriptions by obtaining a pre-payment certificate (for either 4 months or 12 months). This is particularly useful if you have a lot of medication to take and you have to pay for your prescriptions.

You can apply on form FP95 (available from post office, chemist, doctor) through your local Health Authority. You can find the number in the telephone directory or telephone Directory Enquiries on 192.

Claiming Free Prescriptions with an Internal Pouch – Red Lion Group Comment

Summary

Morag Gaherty summarises the current position.

Former Red Lion Group Chairman, Dr Martin Peters, successfully argued that his pouch should qualify as it is still effectively a fistula which happens to be located within his body rather than on the outside. However, the wording of the specific health condition relied on is very defined: "a permanent fistula … *needing continuous surgical dressing or an appliance*". It is this second part which causes the problem.

It can therefore be difficult to argue that a pouch owner qualifies for free prescriptions, even if you do require a great deal of medication. It is a classic case of the surgical techniques outstripping the legislative framework. We are aware of cases where the claim has been successful, but equally where it has not been.

Key to success is your GP's agreement to the basic argument – if they refuse to give it, and refer to the area Health Authority for a decision, consent will almost certainly not be given, and that ruling will be binding on all patients within that Health Authority. Northamptonshire has already ruled negatively on this claim, for instance.

It is therefore always worth a try, on the grounds of fairness and equal treatment with ostomists. It is important that you set out details of exactly why you think you should qualify, so that your GP can make an informed decision about your case.

However, if you are turned down by your GP, an appeal is not only not likely to succeed, but will also prejudice the situation for other pouch owners in your area. A better option would be to consider other possible grounds for claiming, using the guidelines above. If you do not fall into any of these categories, the best option might well be a prepayment certificate if your need for ongoing medication is significant. With current prescription charges as they are, it does not take much for a prepayment certificate to pay for itself.

Red Lion Group Committee Nominations

Chairman

The Chairman of the Red Lion Group is responsible for strategic planning of the Group's direction and for chairing committee meetings (usually held by phone). In addition, he or she oversees the arrangements for the annual Information Day and delegates tasks as appropriate.

Brian is no longer eligible to stand as Chairman for the Red Lion Group, and so a new Chairman needs to be appointed. Last year, Michael Dean became our Vice Chairman, with a view to becoming Chairman in 2002.

Since then, Michael's wife Margaret has been diagnosed with a form of cancer, and has recently had her operation. Effectively, therefore, Michael is unable to take on the duties of Chairman at this time – they are jointly taking time out until September, until Margaret has recuperated. Michael has suggested that he would be willing to take on the role of Chairman, in name only, with Brian "babysitting" the position until September.

Within the committee, we see no problem with this course of action. Michael is committed and effective, and a huge bonus to the team. We would be sorry to lose his help and leadership for a few years just because he needs 6 months free just at the moment. For this reason, then, we are nominating Michael as Chairman, on the understanding that he will not be actively involved with the role before September.

Other nominations for Chairman are, however, also invited.

Fundraising Officer

Nominees will be required to use their initiative to consider ways to increase the funding of the Red Lion Group, including merchandising and advertising. Once suggestions have been put forward to the committee, and accepted by them, the Fundraising Officer will be responsible for putting those plans into operation. A working knowledge of Word software is helpful but not essential.

Christine Lawton was co-opted to this role during 2001, and will be officially nominated by other members of the committee at the AGM. However, other nominations may be put forward for voting.

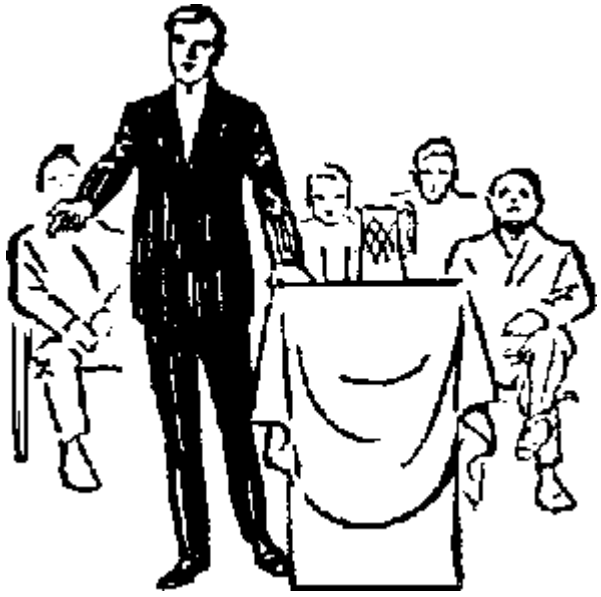
Liaison Officer

Nominees will be required to maintain the Red Lion Group database in Access software (working knowledge essential) and to add new members to the database as and when they join. Labels for the quarterly newsletter and any other projects are also produced on request from this database. Where members wish to contact other members, it is the Liaison Officer's responsibility to put them in touch with each other.

Marion Silvey has been recently co-opted to this role, and will be officially nominated by other members of the committee at the AGM. However, other nominations may be put forward for voting.

Reps Officer

This role has not yet been developed, and so is open to interpretation by nominees to a certain extent. The idea is to maintain contact between the Red Lion Group reps, and help them develop locally active groups. Should no-one be voted in to this position, it will become redundant for the time being.



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
		chrisjacks@supanet.com
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	01708 444359
HAMPSHIRE		
Phil Smith	Portsmouth	023 9236 5851
Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Carol George	Stevenage	01438 365707
Susan Burrows	St. Albans	01727 869709
KENT		
David Irving-James	Folkestone	01303 894614
Phil Elliment	Barnehurst	01322 558467
KENT (WEST)		
Rosalyn Hiscock	Pembury	01892 823171
LANCASHIRE		
Joan Whiteley	Clitheroe	01200 422093
MERSEYSIDE		
Blanche Farley	Liverpool	0151 286 2020
NORFOLK		
Sandy Hyams	King's Lynn	01485 542380
Sylvia Mist	Norwich	01692 580095
NORTHAMPTONSHIRE		
Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	01604 450305
SOMERSET		
Clive Brown	Chard	01460 234439
SOUTH LONDON		
Andy Jones	SE6	020 8690 1360
Jonathan English	SW12	020 8673 3092
SUFFOLK		
Anna Morling	Leiston	01728 830574
WEST LONDON		
Dee O'Dell-Athill	W10	020 8960 6726
		colin@odell-athill.demon.co.uk
WEST MIDLANDS		
Linda Bowman	Birmingham	
		0121 766 6611 ext 4332 or pager 0027
WILTSHIRE & DORSET		
Bernadette Monks	Salisbury	01722 327388
YORKSHIRE		
Neil Anderton	Leeds	0113 258 2740
Sue Appleyard	Huddersfield	01484 641227

More tree, Vicar?

Christine was told this by her vicar, so it must be true…

My vicar went on a three week mission trip to Kenya last year. While there he met a fellow traveller who said that he had recently taken a holiday to Tanzania. He and his family had alighted from their vehicle in an area which they deemed suitable for a picnic. They chose to sit under a tree and spread their picnic out. During their meal, he took a photograph of the rest of the family, framed by the tree.

When he got back home to the UK and went through his holiday films, he came to the picnic picture and drew his breath, because there, sitting on a branch just above their heads, was a lion! They hadn't noticed it at all at the time. Lucky for them that it wasn't hungry!

Contact the Red Lion Group

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** To fill this position please contact the secretary, Inez Malek (details on this page).

PRESIDENT
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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.