Roar!

Issue number 22 • Autumn 2001

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

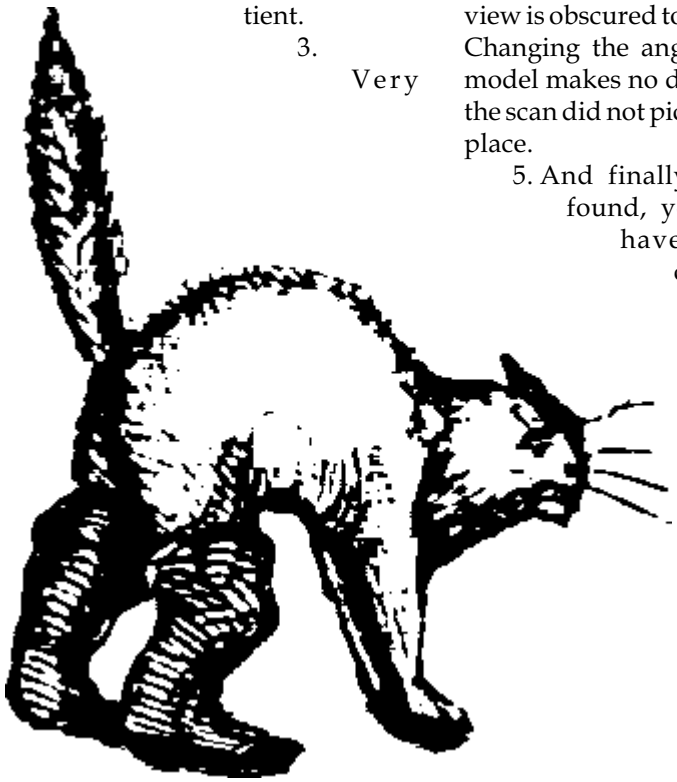
Bummer

Some people may have heard about a CT scan to replace the traditional colonoscopy. Before you get too excited by this idea, it is important to appreciate that this is currently still very much at trial stage and an effective replacement to the current method is some years off yet. In fact, as you will see, while it may help with initial procedures, a scan is unlikely to replace fully the current method in the final analysis!

Basically, the idea is that you lie on a CT scan table for a few minutes whilst a full scan of the abdomen is taken from all sides. This scan information is translated into a 3D model for doctors to study instead of your insides.

Sounds great, doesn't it? Well, yes it is, but there are disadvantages with the current technology and process:

1. You still have to do all the prepping for a clean bowel.
2. The bowel needs to be inflated with air during the scan to enable a clear view, which may be uncomfortable for the patient.
3. Very few centres have the necessary equipment at present. In fact, the information for this article came from an American source, and I am not sure if *anywhere* in the UK is trialling this technology - possibly St Marks, possibly John Radcliffe, but it is not likely to be anywhere else.
4. The virtual colonoscopy is less sensitive to polyps under 6mm in size and even large polyps (10mm) can be missed if they are flat and located in the wrong place. While a manual colonoscopy cannot guarantee to pick up all polyps, the doctor can home in on areas where the view is obscured to get a closer look. Changing the angle of view on a model makes no difference at all, if the scan did not pick it up in the first place.
5. And finally, if a polyp is found, you still have to have a traditional colonoscopy in order to get a biopsy.



Overall, some time in the future, this may well become a very useful non intensive method of general screening, but high risk groups are still likely to need that "poke up the bum"!

In This Issue...

Information Day News

The date of the Information Day and Annual General Meeting for the Red Lion group is now confirmed as 13 April 2002, location: St Marks Hospital Harrow.

As in previous years, we are not planning an entry charge. Instead, when you book a place you will be asked for a refundable deposit of £12.50 per person. When you turn up, your cheque will be returned to you, unless you choose to donate it

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The Way We Were!

If you think surgery is a painful process, thank your lucky stars that Frederick Salmon is not around to perform it, as Christine Lawton discovered recently…

As many of you will well know, Frederick Salmon was the founder of St Mark's Hospital. While walking down the link corridor there, I stopped to read those interesting boards depicting some of the history and found this intriguing piece.

Frederick Salmon devised an operation for haemorrhoids, which became very influential. He performed his operations without anaesthetic in order to minimise blood loss! The *Medical Times Gazette* of February 1857 spoke in the following terms:

Those who have been in the St Mark's operating theatre cannot have failed to feel surprise at the extreme quietness with which the patients almost invariably submit to these painful operations. The absence of chloroform is, indeed scarcely, noticed. Mr Salmon attributes this result to the organisation of the Hospital by which patients who are recovering become the attendants of those more recently admitted, and are sometimes used to impress upon them the absolute necessity, for their own good, that they should behave well, and assist the operator.

Pelvic (Kegel) Exercises

These exercise details are taken from the extremely useful j-pouch website at www.j-pouch.org

Purpose:

To strengthen the tone of the anal sphincter muscles.

Sphincters:

A group of specialized muscles that allow you to control your bowel functions.

Early Exercises:

Pelvic exercises may be started before surgery and safely resumed three weeks after surgery.

During the immediate post-operative phase, while you are still in the hospital and up to three weeks after your surgery, your tissues and muscles are healing. When this initial healing has occurred, you may begin to resume theses exercises

Method of Exercise:

Tighten your sphincter muscles as if you are stopping a bowel movement. While squeezing tightly, hold for a count of ten; then relax for a count of ten. This constitutes one step. Repeat this exercise ten times to equal one set.

You should complete six to ten sets a day, or as prescribed by your doctor.

These may be performed any time during the day, and while you are in any position — sitting, standing or lying down. Also, since they require no special positioning, you may do them while working at any location, while driving in your car, or even while watching television.

Follow-up:

When you visit the out-patient clinic for your final exam, your physician will advise you as to the continuation of these exercises. If you have any questions, please do not hesitate to ask your surgeon or ET nurse.

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to the Red Lion Group, as a number of members kindly did last year. Cancellations without notice will lose their deposit, except in exceptional circumstances.

This system is in operation to avoid huge overbooking on the food caused by people saying they would come and then not turning up, as has happened in prior years.

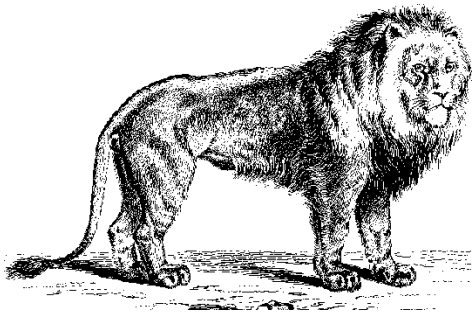
As for the food, most people felt it was adequate. However, there were a few complaints and so we will be looking into the possibility of providing something like baked potatoes with a choice of fillings instead of sandwiches. Perhaps people were comparing the standard against previous years, but that was when the event was paid for by Dansac, and so a larger food budget

was available.

It is the belief of the committee that most members would prefer a free event, with no-frills food, rather than a better quality of meal and an entrance fee. However, your views on the subject are very welcome, whilst we are still in the planning stage! Please contact the Liaison Officer with any comments you wish to raise.

Finally, parking at St Marks hospital currently costs £10 per day, but we hope to have prepaid tickets available for £2, as at this year's information day. Should you choose not to buy a prepaid ticket, the full parking charge will unfortunately apply and we have no discretion to get that reduced.

Editorial



As I write this, we are still within time for getting the newsletter out by the end of September or first week of October. I do hope we'll be getting back on target, as last quarter's issue took the prize for being the latest yet. As there are no photographs included in this issue (which caused a late complication at the printers while I was away last time), I am hoping that all will go smoothly this time. No, that's not a woodpecker you can hear in the background - it's me tapping on wood!

One article in this issue is about the importance of realising that "natural" remedies are not necessarily things that are safe in all doses or circumstances. In a recent issue we had an article from someone whose experience of natural remedies was in fact life threatening. Many of you know I am not a big personal fan of drugs or medical intervention where it may not be necessary, and so you may think I have had something of a turnaround from this viewpoint! Not at all, but here at the Red Lion Group we do take great care to present a balanced informed picture. That means pros and cons, good and bad.

I would like to add a personal comment the article, Nature's Remedies. You must bear in mind that the woman who wrote it is a nurse in a cancer clinic, where drugs are important. One sentence in the article leaps out at me: "One should always use the same degree of care when deciding to take herbal products that he or she would use in selecting non prescription medicines". Very, very true, but look at the degree of care which the article requires when looking at herbal products, and then consider whether you genuinely do apply that same standard to choosing over-the-counter medicines. Or indeed whether your healthcare professional does when writing you a prescription. Probably not, I'd guess.

Bear in mind, for instance, that the reason controlled studies have not been done for many alternative or complementary remedies is not because they do not need to be done, or even because the manufacturer does not want them to be done. It is quite simply a matter of funding. Who would pay for it? The drug companies do spend a lot of money on testing their products, not just because they are required to do so by law, but also because they patent them and make a great deal of money out of them in the long run. The same is not true for herbal remedies and the like.

So if an alternative or complementary approach appeals to you, do not simply be put off by negative attitudes from healthcare professionals. Do apply common sense and consider the matters in Marge Pearson's article. But do the same when you are buying anything over the counter at the chemist!

Included with this issue is a price list for our merchandise, including our lovely Christmas cards. We will be putting a little label on the back of the cards, giving the registered charity number of the Red Lion Group, as this was forgotten (by me!) when

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My Story...by Christine Lawton

Christine Lawton is now the proud owner of an ileo-anal pouch.

It all started in 1978 when I had most of my colon removed and my ileum joined to my rectum, an ileo-rectal anastomosis. This relieved my dreadful long-term UC, which had practically destroyed my colon. However, over the years since then, I have had colitis infections in the rectum until the time came when medical factors dictated its removal. At first I was quite nervous, not knowing which operation to go for, as I had a choice.

Mr Windsor, my surgeon, helpfully put me in touch with the stoma care nurses whose advice was invaluable, and I ploughed through numerous websites, spoke to lots of people, both medical professionals and patients in various support groups. I received great help and encouragement from the Red Lion Group, both from its members and from the very informative newsletter of which I was kindly sent a set of back issues. Anyway, I chose an ileo-anal pouch. If this didn't work, I thought, it could always be removed and I could have the permanent stoma.

On March 20 this year, the operation was performed at St Mark's. I left hospital 15 days later, having taken part in the feed programme organised by Dr Ed Westcott who could not have been more kind and understanding, and it was quite exciting and good fun seeing the graphs as he measured my stoma blood supply and trying to squeeze the hand grip to test my muscular strength. I once had fun when I was left with the grip over a weekend, trying it out on my visitors! I am glad to say that I did very well. I have to say the feed smelt horrible when I was given it through a gastro-nasal tube, and tasted horrible too, but it was very well disguised when I had to drink glasses of it a week before my surgery. It was coffee flavoured and very delicious indeed.

Of course, I didn't know, and still don't, whether what I was given was Fortisip or the special pharmaconutrient feed. Judging by my meteoric progress, I can only assume it was the latter. Three days after my operation, I could walk down the ward unaided. Strangely, I did dismally on the immunity skin tests, the first of which was performed the week before my surgery, and the second afterwards. I thought, fortunately quite unjustifiably, that I certainly would catch an awful infection as it seemed to indicate that I had no resistance to anything!

From that 20 March, Gordon and I went on a learning curve together until 7 June when I emptied his bag for the last time. As you will probably have gathered, Gordon was my loop ileostomy. I wasn't going to call it anything at first, but named it Gordon Brown because I was told I had a tight stoma so I thought I would name it after the Chancellor of the Exchequer (nothing personal, of course!). I could hardly believe it when the date for the reversal operation turned out to be Election Day!

During Gordon's time with me, we went through many trials, not least those leaks, resulting in more scrubbing of bathrooms and toilets and soaking and washing of nighties than I've ever done in my life. I even found myself talking to Gordon and telling him off! I think if anyone at the hospital had heard me, I might have been transferred to the psychiatric wing! However, perhaps poor Gordon was blamed unfairly because one morning at home, I was cutting around the flange of the bag when I noticed that the pointed end of the curved scissors I had been given as part of the stoma care kit, caught the back of the bag. Thereby was revealed the most likely reason for the leaks I had suffered: I may well have nicked the bag!

From then on, I made sure I held the bag right away from the flange when I cut around it. After that, I never suffered another leak! So do be careful if you have to do the same – after all, it needs only a pin prick! When I ordered more bags, I had the flanges ready cut but I always held them up to the light to make quite sure there weren't any nicks in them before putting them on.

Gordon was quite a colourful character. He had his little whims and fancies, loved playing bagpipes after cauliflower and suchlike but worst of all loved playing hosepipes after drinks, particularly during warm weather when the output was volcanic! This contributed to my severe dehydration and sudden re-admission into hospital three weeks after I first came out. I had been suffering from severe nausea and vomiting as a result of a suspected partial blockage from a kinked intestine, and felt so weak I was almost in a state of collapse. However, I was soon put right by a drip and almost immediately regained a very good appetite.

I was discharged with instructions to drink daily one litre of electrolyte mix, the St Mark's recipe *(see below)*. I called it 'Electric Light Mix' because it certainly switched me on! Although it doesn't taste very nice, one soon gets used to it. At first I used to squeeze a fresh lemon into it, which combated the sweetness of the glucose and made quite a pleasant lemonade drink. I found sweet flavourings no use at all. Then I gradually found I didn't need to flavour it at all and just drank it down.

From then, I have never looked back. Gordon and I even managed to partake in a couple of choir concerts given by a local ladies' choir, one afternoon at the local neighbourhood centre and another evening to a club for the disabled run by a local church. Fortunately my hope that some of the audience would be a little hard of hearing was unfounded because fortunately there was only me singing and not Gordon as well – he could be quite harmonious at times!

Since my reversal on June 7, everything has been improving very quickly. At first I had a big problem with soreness, which I was led to

understand, from my GP, was arising from anal fissures. However, on a visit to the hospital, I was advised by Mr Windsor that it was skin soreness because, after the pouch surgery, in the early stages one is prone to have little tiny leaks, not that one would particularly notice but enough to burn the skin. In order to combat this, I was advised, after each pouch emptying, to use barrier cream after washing and then to put a piece of cotton wool over the offending part to soak up any little leaks. I did this and within 12 hours began to feel better. I do this now each time and I have had hardly any soreness at all. What's more my system has settled down because it isn't irritated by the soreness making me feel as though I wanted to continuously rush to the loo. If you're sore, why not give this a go? It might work for you, too. This tip was mentioned as Mr Windsor's Top Bottom Tip in *Roar!* issue 21, page 13.

I am now well into my recovery and working towards total fitness. To this end, I hope to soon resume my workouts in the gym, not least because the weight is creeping back. My wound has healed well. I have been doing some pleasurable things, including a recent holiday in Cornwall, and I am continuing with my painting – I did think of entering myself in the RA Summer Exhibition next year, as my tummy now resembles an interesting piece of modern art! – and I painted a picture for the ward. I am thoroughly enjoying my recuperation.

The remarkable thing is that my body-clock works better now than it did after the 1978 surgery, so amazingly things haven't been as settled as this for the last 23 years!

It was a difficult decision to make but I am extremely glad I decided on the pouch operation and I am sure I will never live to regret it.

I am eternally grateful to my brilliant surgeon, Mr Windsor, and his team, the wonderful nursing staff and carers at St Mark's, everybody in the Red Lion Group, the stoma care nurses at St Marks, and to Julia Williams who helped me so much. I wish her well in her new lecturing post; our nurses will be very well taught! The terrific support of all these people and a little help from above has certainly spurred on my recovery.

A positive attitude certainly helped. It would have been easy, even with my daft sense of humour, to sit and cry when things weren't going so well, but I deduced that things would be the same if I cried as they would be if I laughed. So laughing was the best option, and it certainly proved to be good medicine.

If anyone is contemplating this surgery and wants any advice or wants a visit or to arrange a meeting with me, please don't hesitate to call me on 020 8904 7851 or email me on christinelawton@aol.com

I live in North Wembley, in fact quite near to St Mark's, and would be very happy to help in any way I can.

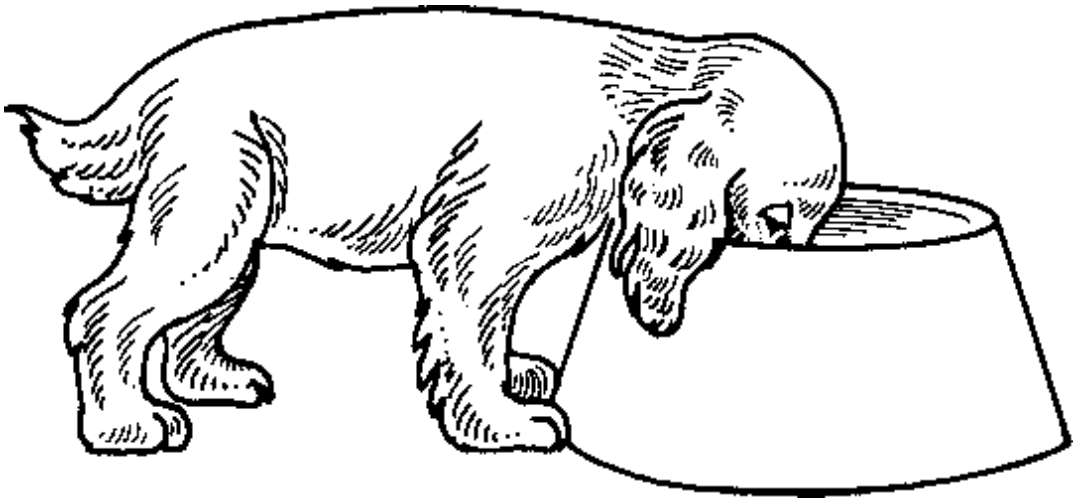
Some Diet Tips

Pouch owner Gillian Appleby has a few ideas to share about what works for her, and might be worth a try for you

This was inspired by all the letters to *Roar!* from people wondering what to eat. Also I think I am a very lucky pouchie. I am hardly ill and I thank whoever watches over me a lot for this. I thought that some of this might be useful, especially to new pouchies.

Morning Breaks

It took me ages to find the right breakfast for me. In the beginning I tended just to have a banana (and I'll come to those later) and feel extremely hungry by about 12pm. Cereal is a problem – obviously bran flakes are out and I used to love those before I was ill. I have Special K with berries nearly every day now. If you don't like the fruity bits then ordinary Special K is good. Soy milk caused me wind when I tried it so I avoid it at all costs. Obviously some people cannot have dairy at all (I do try not to have too much myself) so maybe rice milk would be an option. Alternatively I have porridge which is nicely filling for those never-ending hunger pains.



Lunchtime fillers

Bread and more of it. It agrees with me therefore I eat it, even if wheat is meant to be a serious no no. Avocado is Vitamin E-full, and squidgy enough not to cause problems. Soup can be tolerated, but it's best to eat lots of (guess what) bread with it. Not everyone can tolerate salad, so avoid it if it gives you problems. Lettuce is so fibrous it can be deduced in the toilet bowl. Likewise, skins outside tomatoes and cucumbers are better off removed. Cucumber skin is just made to repeat on us anyway!

Dinner Dates

QUORN pieces with rice. QUORN sausages with potatoes. QUORN mince instead of spaghetti bolognaise. QUORN (mushroom in origin) is a must-feature of your life! Something about its texture means it bungs you up. Lots of carbohydrate at dinner-time because you want to avoid midnight toileting. Pasta is best, then rice or cous cous then potatoes.

For fish-eaters chunky tuna steak and just about all are okay I've found. Meat I don't know about. Fish pie with gunks of potato on top is a must. Parsnips are a wonderfully thickening vegetable.

General Rules – Snacking

Bananas are brilliant. I hated them before I was ill but now my friends think I'm addicted to them. The most curious thing I have found is that I don't even fancy eating food that I know for sure doesn't agree with me.

Snacking is a very important part of being a pouchie but biscuits and cakes are not good. Try salty rice crackers, which can be found in most health shops. Be careful though, as some can be spicy. Plain or seaweed ones might be better.

Having hot drinks with food is generally not a good idea. If I want to have afternoon tea – e.g a cup of tea and cake I take some imodium with it, especially if I am out.

Alcohol

Binge drinking (my speciality) should be avoided as there's nothing like a hangover and a bloaty stomach and needing the toilet all at the same the time. If you were to do this, eat pasta either before or during as it absorbs the liquid. For me, a couple of glasses of wine is nice. Beer is a no go area and spirits can be okay. Vodka and cranberry juice should be tried by all!

Vitamins

I don't know if these work or just get rinsed out by your body but I take them anyway:

Vitamin B Complex; Calcium, Magnesium & Zinc and Co-Enzyme Q10 (for putting energy into your cells – whatever that means!)

Also found a natty supplement in Oz (can probably be found here but) called Digestive Zyme which is meant to assist digestion which you take before meals. It's got betaine hydrochloride, glutamic acid and pepsin in. That doesn't actually sound too nice but if you do suffer from bad indigestion it might help. Oh yes, and acidophilus every day.

All of this is trial and error of course and in no way do I guarantee good effects for all of these foods for all of you. It might work and it might not. I just hope you might find some of it useful.

Letters

Roar! Letters Page
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Dear Newsletter Editor

Since I had my pouch fitted six years ago, I've been suffering from vaginal dryness.

At first, it was just an irritation that I hoped would go away, but it's been getting steadily worse. After the birth of my baby eighteen months ago, the dryness has gone beyond uncomfortable to unhealthy - I've been suffering from recurrent vaginal infections and cystitis because of lack of lubrication.

It's not really something I want to bring up with my specialist, and my GP is running out of ideas - the Pill helps, but it gives me dangerously high blood pressure. Over-the-counter lubricants don't do the trick. Does anyone else have this problem, and if so, how are you dealing with it?

Anonymous

Dear Newsletter Editor

After 18 months of having an ileostomy I finally had the closure operation in July this year. I was going to the loo frequently whilst in hospital and it was burning so much I was pulling my hair out! My surgeon then put me on 8 30mg of codeine phosphate per day. This was a great help and when I left hospital everything was fine.

After about 3 weeks, I was feeling bloated and couldn't go to the loo so I called my stoma nurse. She said to stop taking the codeine phos-

phate altogether and to see if it helped which it did, and that same evening I was going to the loo again.

I woke up the next day and felt really bad. I was aching all over, sweating, feeling sick, and just felt really terrible. We put it down to the codeine phosphate, I was having withdrawal symptoms. I'm still not over it yet. I find it difficult in the morning and when I go to bed I can't sleep. Has anyone been in this situation and has anything helped to get you through?

Helene Sheeran (posted to redliongroup@yahoogroups.com)

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they were printed. Do please buy some and support the work of the Red Lion Group. And the T shirts, sweatshirts, baseball caps, mugs etc all make fantastic Christmas presents. None of it is cheap printed-on images, but quality embroidery, and the mugs are fine bone china. To place an order, send your form and cheque in to Christine Lawton as soon as possible.

In a previous issue of the newsletter, I mentioned the charitable ISP Care4Free, which donates a percentage of its profits to the charity of your choice. At the time of writing, the Red Lion Group had signed up to become one of their listed charities. However, Care4Free have since notified us that they are not taking on any new charities now, so you will not be able to donate to the Red Lion Group by signing up with them. If you want to use Care4Free as your service provider, you will have to choose one of their existing charities to receive the benefit from your surfing.

As many of you know, I run my own business from home, as well as having two small boys. Free time is in very short supply, and so I am hoping that someone else will volunteer to take on the role of Liaison Officer. I am more than happy to continue with the newsletter, in tandem with Tim, but cannot manage the member database as well. All that happens is that I get a pile of people waiting to join or asking for back copies, and I have a big blitz to sort them out every couple of months. I do not like this, and I am sure they do not either, especially if they are anxious to join the Red Lion Group and get support. However, it is unavoidable at the current time.

PLEASE consider whether you could do this role. A little bit done regularly, at most half an hour a week, is really all it takes to keep on top of things. The member database is currently being converted to Microsoft Access, and I could train anyone who volunteers on how to use it. It is very straightforward. Now that the committee tends to have telephone conferences rather than face to face visits, it could be done by anyone anywhere, even international members. Internet access is pretty important, as the committee tend to liaise this way.

Would *you* be prepared to volunteer no more than half an hour a week of your time to keep the Red Lion Group going?

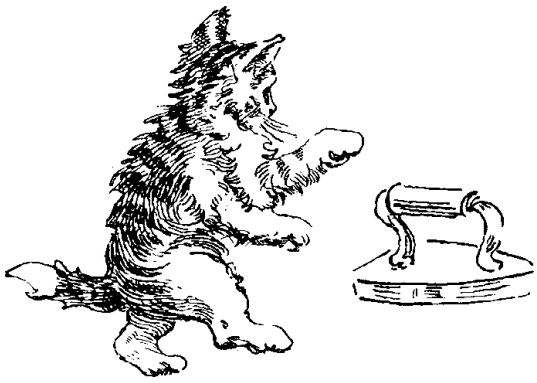
Before going, I would like to remind you that the redliongroup Yahoo Group forum is now active and available for you to join. Our Christmas card is on there, in glorious technicolour, if you want to see it. Like the newsletter, the forum is only as good as the input it receives from the members, so do please make it a group worth visiting. And while I'm on the subject, please write to us, so I have something to put in the next newsletter!

Support Groups on the Internet for Pouch Owners

Well, it seems that J pouch owners are best served, but I am sure that pouchies with other variations are also welcome to join! The following are really useful.

www.j-pouch.org

This is a fabulous pouch support website, and the discussion boards are especially good. They



are split into a number of different sections:

- Help! Need advice now!
- General Discussion
- Room to Rave and Rant
- Pouchitis
- Ostomy and Skin
- Pregnancy
- Who We Are
- Moms, Dads, Family & Friends
- The Meeting Place

Personally, I found the pregnancy discussion board very moving and I am sure will be a great help to those of you either finding it difficult to get pregnant after surgery or indeed wondering whether you should. As you can see, it's about far more than just talking about pouch surgery, problems and successes: it is also a great way to make friends with people who understand your experience. You can tell from the spelling of Moms that it is a US site, but is open to all. A strong recommendation for this one.

http://ibscrohns.about.com/cs/pelvicpouch/

The IBS/Crohn's site has loads of information about all sorts of topics, and serves UC sufferers well, despite the name. There are good links to other pouch resources on the net and useful summary articles about preparing for and understanding J Pouch surgery. I found it a bit confusing to navigate, I have to say. However, there is some very interesting stuff here, eg a section on Mental Health, and how IBS illnesses can have an impact on this. I have reproduced elsewhere in this newsletter the article about Mourning the Loss of Good Health.

One other article on this site that I also found interesting was about the growth of self help groups on the web, and how they can both help and - sometimes - hurt. Always worth keeping that one in perspective.

redliongroup@yahoogroups.com

Our own Yahoo Group for members to post messages and comments in a way which is more immediate than the newsletter. Still in embryonic form, until we get a reasonable number of members joining and interacting. Please do consider joining. To find the group, simply go to www.yahoogroups.com and search for redliongroup (no spaces).

UlcerativeColitis-Jpouch@yahoogroups.com

The description reads: "This group was set up to allow people suffering with Ulcerative Colitis, Megacolon and FAP, and are considering, or have had Pouch Surgery, to get and provide support and advice to each other. Anyone can post messages, All discussions concerning these illnesses and surgery are welcome." To find the group, simply go to www.yahoogroups.com and search for jpouch (no spaces).

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**

Mourning the Loss of Good Health

Reproduced from the Mental Health section of the website http://ibscrohns.about.com

In 1969, Dr. Elisabeth Kubler-Ross proposed 5 stages of death and dying in her book *On Death and Dying*. Most of us are familiar with what is often called 'the five stages of grief', which are:

1. Denial
2. Anger
3. Depression
4. Bargaining
5. Acceptance

Since this book was published, Dr. Kubler-Ross's work has been applied to the many situations of change people experience in a lifetime, including onset of a chronic illness. There is no time limit set for each stage, as every person progresses towards acceptance of their illness at their own pace. Some people may experience more than one stage at a time, or in an alternate order. Critics argue that the steps are too rigid, and are not applicable to the grieving process, yet people all over the world have found comfort in her work.

Take the pain and learn to accept it, not as a curse or punishment but as a gift to you with a very, very specific purpose.

—Elisabeth Kubler-Ross

The first stage in acceptance of a chronic illness like Inflammatory Bowel Disease (IBD) or Irrtable Bowel Syndrome (IBS) is **Denial**. The patient may convince himself or herself that the lab reports were accidentally switched, or the doctor is wrong. With the often-sudden onset of IBD, it can be easy to believe that symptoms are food poisoning, or due to stress, and will go away eventually. Patients might even refuse to take medication or alter their diet, because that would mean that the chronic illness is real.

The second stage is **Anger**. Anger at the doctor who made the diagnosis, the illness itself, and even at the rest of the world for going on about its business as if nothing had changed. Spending too much time at this stage can leave a person resentful of healthy people and bitter. Friends and family may even shun a person who gets stuck in this stage.

Bargaining is the third stage. A person with IBD may rationalize eating unhealthily or not taking medications. Thoughts like, "One day of missing my meds won't hurt", or "I'll schedule my colonoscopy when I'm not so busy" may be prevalent. Unfortunately, IBD doesn't go away for the weekend, and it doesn't care that a colonoscopy is something most people would rather avoid.

The fourth stage, one that is familiar to anyone diagnosed with a chronic illness is **Depression**. Patients may feel sorry for themselves, and lose hope of ever achieving remission. It is important to recognize that medical help is necessary if depression becomes all consuming or results in suicidal thoughts. Adjusting to a chronic illness is a difficult and stressful time, and seeking out help to deal with it is the best way to ensure a more healthy life.

The fifth and final stage is one of **Acceptance**. IBD is not going to go away, and becoming educated about the disease is the way to lead a healthier life.

Dr. Kubler-Ross's 5 stages provide a guideline in the lonely and perilous journey to accepting IBD or IBS as a part of life. That is not to say that a chronic illness should rule one's life, or that the search for a cause and cure should stop, but that regular doctors appointments and medication are going to be part of life. Ideally a very small part of a life that is filled with joy, love, and incredible experiences despite the illness.

I Did It Tie Way

Helpers are needed for the Loud Tie Day at St Mark's Hospital, Northwick Park, Harrow, on 2nd November. Please ring me Christine Lawton at 020 8904 7851 or Eileen Murphy, the St Mark's MacMillan Colo-rectal nurse on 020 8869 2472, or Bob Azevedo-Gilbert on 020 8426 5203 if you can spare some time or want to know more. The day is great fun and I found it very rewarding, and I will find it particularly rewarding this year: as St Mark's have done so much for me, it will be good to do something for them. The idea is to raise bowel cancer awareness and to collect for same. We collected over £320 last year and we're aiming for more this year.

If you can't help but have some very, very loud, silly ties — maybe that present you never could stand — we would be very, very grateful if you could donate them to us. The more the merrier. Last year we ran out!

Come and have a good laugh with us!

Christine Lawton.

Nature's Remedies

Non pharmaceutical drugs are an attractive self-medication option for many ailments and many people. However, just because it is not called a "drug" does not mean that it can be taken without further thought. Marge Pearson, RN of the MD Anderson Cancer Center, Houston, has the following to say on this topic.

The use of herbal medicines or supplements is widespread. Ads in print and on TV make claims about the benefits of using various products. Consumers wanting to know more about these products are faced with a large volume of conflicting information.

Opinions about the use of herbal medicines also vary among different health care providers. Medical professionals are aware that patients are interested in using these products and are currently using them to prevent or treat a number of symptoms or conditions. Individual practitioners and professional organisations are taking steps to educate themselves and their patients about risks and benefits of commonly used herbal products. Though such groups show a willingness to add this method of treatment to the choices they offer patients, they continue to urge caution. The medical community also stresses the need to base any decisions to use a herb on information gained through controlled research studies when it is available.

Safeguards for Using Botanical Products

Several questions should be addressed before making a decision about using a herbal product.

Consider the nature and source of any claims being made about a product

1. What is the reported effect of this product?

2. What is the producer's level of knowledge and experience in the use of herbs

3. What biases might the producer have?

Consider the quality of the product

1. Does the product contain the ingredients listed on the label, or have there been substitutions or additions?

2. Has an effective does been determined?

3. Are you able to determine how much product you need to achieve this does?

4. Is there pesticide residue or other contaminants present I nthe product?

What do scientific groups have to say about this product?

1. Have any controlled studies been done that back up the claims being made? (It is hard to determine what effect a product will have on the basis of a few selected cases).

2. Can people respond differently to the product?

3. What side effects have been documented?

4. Are there any reports of problems occurring when the herb was taken with prescription or nonprescription medicines?

5. How does this product compare with prescription or over-the-counter medicines used to produce the same effects?

6. How does the cost of the product compare with prescription and non-prescription medicines used to treat the same conditions, when taken in the recommended amounts?

Have you consulted your physician before using any herbal products?

1. Is the problem or condition one that should be self-treated? (This is especially important when using a product to treat a symptom or condition for which you are already taking medications. There is also the possibility of drug/herb interaction).

2. Some herbs can increase the risk of bleeding, so you need to let all physicians and dentists treating you know if you are using herbal products.

3. Are there any serious side effects or interactions with foods or medicines?

4. Are there any individuals who should not take the product, such as children, pregnant or nursing women, and the elderly?

5. Is there the potential for an allergic reaction in persons who suffer from hay fever or other allergies?

The ability to find answers to the above questions is limited by some important ways in which herbal or botanical products differ from manufactured medicines. Before a drug company is allowed to introduce a new drug, a series of research trials are required to prove a drug is safe and effective. This type of research also provides infor-

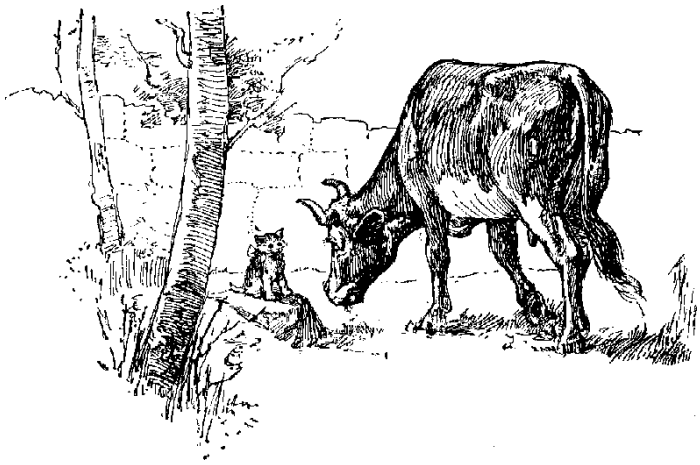
mation on the correct dosage of a drug and on the risks or side effects. However, this research is not required for herbal products and therefore is not often done.

Herbal products and dietary supplements have less stringent regulations concerning their marketability and quality control measures. With prescription and nonprescription drugs it is the responsibility of the drug company to prove that a drug is safe and effective. The Dietary Supplement and Health Education Act of 1994 only requires that a company not claim the product can be used to treat, cure or prevent an illness or condition and that the company add a warning that any claims made have not been reviewed by the US FDA. A product can only be removed from the market if the US FDA can show that it is harmful. The Act does not outline standards for ensuring quality, nor does it require a manufacturer to prove the herbal product is safe or effective.

Lack of quality control measures can lead to variation between products made by different manufacturers. Many factors influence the conditions under which the plant was processed to produce the product. Contaminants may also be present from pesticides and herbicides.

A common belief among users of herbal products is that such products are better than manufactured medicines because they are "natural". However, this is not always the case. While research has shown that some herbs are safe and effective, other herbs are known to be toxic or have serious side effects. One should always use the same degree of care when deciding to take herbal products that he or she would use in selecting nonprescription medicines. Though our current state of knowledge on the subject makes this task more difficult, more widespread interest in the use of alternative methods of treatment should improve the situation.

While this article is meant to be an overview of the subject only, more information on the subject can be found in the following resources:



Herbal Medicine Resources

Organisations:

1. American Botanical Council http://www.herbalgram.org/ Tel # (512) 331-8868. A non profit organisation formed to educate the public about the benefits of herbs and plants and to promote their safe and effective use.

2. American Herbalist Guild http://www.healthy.net/herbalists/ A self-described peer review organisation for herbalists.

3. Herb Research Foundation http://www.herbs.org/hrinfo.html Tel # (303) 449-2265

4. The University of Texas Center for Alternative Medicine http://www.uth.tmc.edu/utcam/

Books:

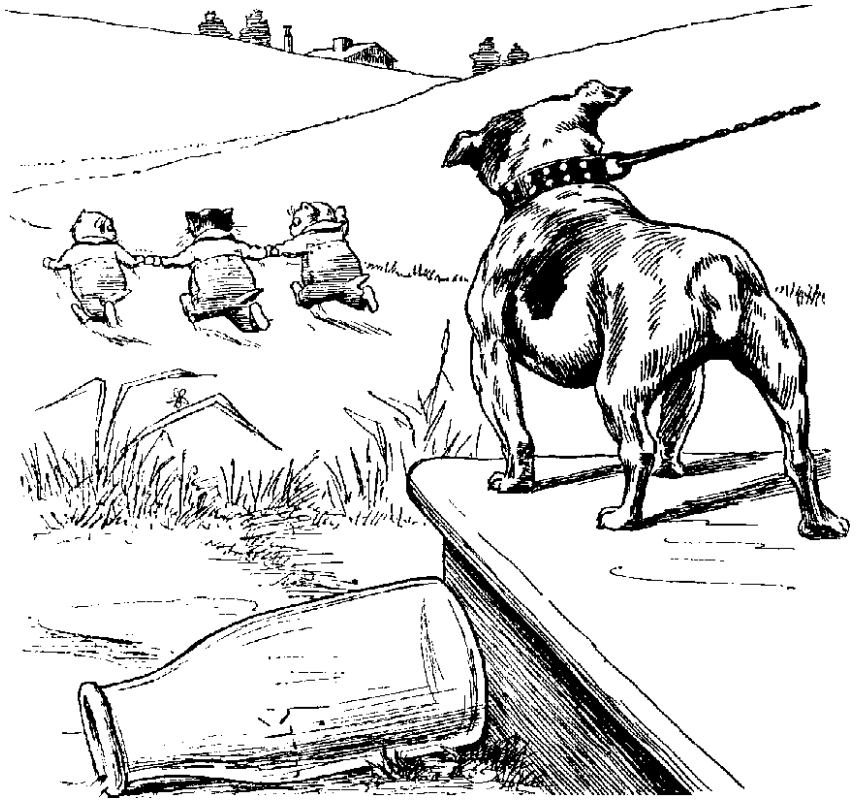
1. The Green Pharmacy by James A Duke, PhD Rondall Press, 1997

2. Herbal Remedies for Dummies by Christopher Hobbs IDG Books, 1998

3. Tyler's Herbs of Choice by James E Robbers, PhD & Varro E Tyler, PHD, ScD Haworth Herbal Press, 1999

4. Tyler's Honest Herbal (4th edition) by Steven Foster & Varro E Tyler, PhD Haworth Herbal Press, 1999

5. What the Labels Won't Tell You by Logan Chamberlain, PhD Interweave Press, Inc 1998



'X' Marks the Terminology Spot

Relevant terminology explained using the invaluable reference site www.xrefer.com

Loperamide

A drug used in the treatment of diarrhoea. It acts by reducing peristalsis of the digestive tract and is administered by mouth; side-effects are rare, but include abdominal distension, drowsiness, and skin rash. Trade name: **Imodium**.

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Peristalsis

A wavelike movement that progresses along some of the hollow tubes of the body. It occurs involuntarily and is characteristic of tubes that possess circular and longitudinal muscles, such as the intestines. It is induced by distension of the walls of the tube. Immediately behind the distension the circular muscle contracts. In front of the distension the circular muscle relaxes and the longitudinal muscle contracts, which pushes the contents of the tube forward. —**peristaltic** *adj.*

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Gardner's Syndrome

A variant form of familial adenomatous polyposis in which polyps in the colon are associated with fibromas and osteomas (benign tumours), especially of the skull and jaw, and multiple sebaceous cysts.

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Desmoid Tumour

A dense connective-tissue tumour with a dangerous propensity for repeated local recurrence after treatment. Intra-abdominal desmoids have an association with familial adenomatous polyposis (FAP).

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Electrolyte

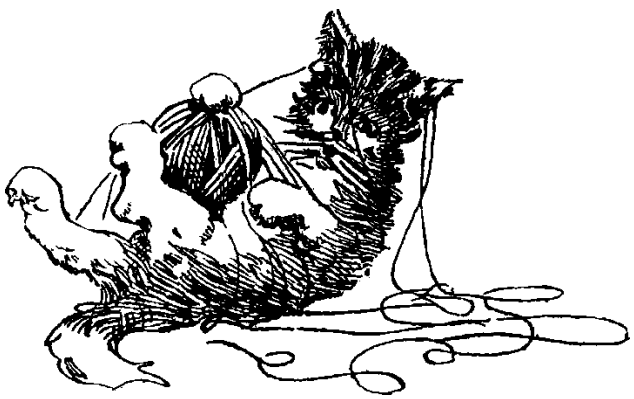
A solution that produces ions (an ion is an atom or group of atoms that conduct electricity); for example, sodium chloride solution consists of free sodium and free chloride ions. In medical usage electrolyte usually means the ion itself; thus plasma electrolytes are the ions in the circulating blood, which include sodium, potassium, calcium, chloride, bicarbonate, and phosphate. Electrolytes are essential for the normal functioning of cells: imbalances of electrolytes in the body can have serious consequences.

Measurement of plasma electrolytes forms part of a thorough medical examination. Concentrations of various electrolytes can be altered by many diseases in which electrolytes are lost from the body (as in vomiting or diarrhoea) or are not excreted and accumulate (as in kidney failure). Electrolyte depletion or retention can also be caused by drugs (e.g. diuretics). When electrolyte concentrations are severely reduced they can be corrected by administering the appropriate substance by mouth or intravenously. Severe diarrhoea is also accompanied by dehydration: both fluids and electrolytes can be replaced by oral rehydration therapy. Excess electrolytes in the blood can be removed by dialysis or by drugs, including special absorbent resins that are taken by mouth or by enema (see calcium polystyrene sulphonate; sodium polystyrene sulphonate).

Dictionary of Medicines, Oxford University Press, © Market House Books Ltd 2000

Oral Rehydration Therapy (ORT)

Solutions designed to replace fluids and electrolytes lost in cases of dehydration, especially caused by diarrhoea. ORT solutions contain salts, such as sodium chloride, potassium chloride, sodium citrate, and sodium bicarbonate, together with glucose or other forms of carbohydrate, which enhance their absorption. ORT preparations are available as powders or effervescent tablets to be dissolved in water and taken by mouth; they can be obtained without a prescription, but only from pharmacies.



Proprietary preparations: Diocalm Replenish

(glucose, sodium chloride, sodium citrate, and potassium chloride); Dioralyte Natural (glucose, sodium chloride, potassium chloride, and disodium hydrogen citrate); Dioralyte Relief (sodium chloride, potassium chloride, sodium citrate, and precooked rice powder); Dioralyte Tablets (sodium bicarbonate, citric acid, glucose, sodium chloride, and potassium chloride); Electrolade (sodium chloride, potassium chloride, sodium bicarbonate, and glucose); Rehidrat (potassium chloride, sodium bicarbonate, citric acid, and sugars).

Dictionary of Medicines, Oxford University Press, © Market House Books Ltd 2000

Anastomosis

(in anatomy) a communication between two blood vessels without any intervening capillary network. See arteriovenous anastomosis.

(in surgery) an artificial connection between two tubular organs or parts, especially between two normally separate parts of the intestine.

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Anal Fissure

A break in the skin lining the anal canal, usually causing pain during bowel movements and sometimes bleeding. Anal fissures occur as a consequence of constipation or sometimes of diarrhoea. Treatment is by soothing ointments, but if the condition is severe the operation of **lateral sphincterotomy** (cutting the muscle of the anal sphincter) is required.

Concise Medical Dictionary, Oxford University Press, © Market House Books Ltd 1998

Fistula

A communication channel between two hollow organs or from a hollow organ to the exterior of the body. A fistula may be abnormal and part of a disease process, such as following an abscess, created by surgery in the treatment of a disease, or may occur as a complication of surgery.

Oxford Paperback Encyclopedia, © Oxford University Press 1998

Sulphasalazine

A drug that is a combination of aminosalicylic acid and the sulphonamide sulphapyridine <sulfapyridene> (see aminosalicylates). It is used for the treatment of the inflammatory bowel diseases ulcerative colitis and Crohn's disease. Sulphasalazine is also used for the treatment of active rheumatoid arthritis that has not responded to NSAIDs alone; unlike NSAIDs, it does not have an immediate therapeutic effect and it may take 4-6 months to obtain a full response. Sulphasalazine is available, on prescription only, as tablets, enteric-coated tablets, a suspension, suppositories, or an enema.

Side effects: include nausea, diarrhoea, headache, rashes and more severe allergic reactions, fever, loss of appetite, blood disorders (see below), and damage to the kidneys and liver.

Precautions: blood counts and liver-function tests should be carried out at the start of treatment and may be necessary during treatment. Sulphasalazine should not be taken

by people who are allergic to aminosalicylates or sulphonamides and should be used with caution in those with a history of allergy or impaired liver or kidney function. Unexplained bleeding, bruising, sore throat, fever, or malaise should be reported to a doctor immediately as this may indicate a blood disorder. See aminosalicylates.

Proprietary preparations: Salazopyrin, Salazopyrin EN-Tabs; Sulazine EC.

Dictionary of Medicines, Oxford University Press, © Market House Books Ltd 2000

Whistle While You Work

Brian Gaherty remembers what it was like returning to work after a pouch operation.

I remember in the period from when I was first diagnosed to when I went on sick leave that I saw apparently numerous articles in the papers about people finding out that they were seriously ill, telling their employer and then being sacked.

When I broached the subject of my being off to my boss, he turned round and the only thing he said was – if you need any money for treatment please call me and we will sort it out. It was a great relief and meant that I had one less thing to worry about.

It had all come as a great shock, with no history of FAP in the family, to suddenly find that I had to have major surgery. Apart from what I had thought to being a mild stomach bug, I was reasonably fit. It did mean that when I went in for surgery that I could expect a quick recovery, given that I had not been under any lengthy drug regime beforehand, as UC sufferers often are until surgery becomes unavoidable.

In the event, I was off work from mid-September until early February. I had decided, although I was well enough between the two operations to return to work, that I didn't want to. Firstly, because of the commute – 90 minutes each way by train and tube. The thought of bashing into someone in a crowded space was certainly not appealing! Secondly, because I didn't want to have to buy a load of work clothes that were cut for my stoma just for 6 weeks or so.

Perhaps in the back of my mind I didn't want my work colleagues to see me before I had had my closure and was back to "normal". Body image is of course important to a couch potato like me (it's official: it's in black and white in my medical notes, courtesy of my loving wife. At the assessment prior to surgery, they asked for my interests among other things, and that's what Morag volunteered!). But seriously, whilst I was not aware of this consciously, I think it probably *was* a subconscious consideration in my decision to delay my return to work.

Before you ask what it is I do, Morag has never understood for the last 8 years - and I often find myself just trying to define what it is I do do when I met someone new socially. Suffice to say that I work with computers, but don't see myself as a geek.

Anyway, when I returned to work there had been major changes in the area that I had been working in prior to leaving, which meant that I had little to do. That was a little unnerving, as it made me feel vulnerable as an employee. Being the sort of person that I am, I thought I would spend time learning a new programming language which I hadn't had time to do before. It was probably another year be-

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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BERKSHIRE		
Liz Davies	Langley	01753 586593
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ESSEX		
Peter Zammit	Benfleet	01268 752808
Clare Shanahan	Ilford	01708 444359
HAMPSHIRE		
Phil Smith	Portsmouth	023 9236 5851
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HERTFORDSHIRE		
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KENT		
David Irving-James	Folkestone	01303 894614
Phil Elliment	Barnehurst	01322 558467
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Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	01604 450305
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Clive Brown	Chard	01460 234439
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Andy Jones	SE6	020 8690 1360
Jonathan English	SW12	020 8673 3092
SUFFOLK		
Anna Morling	Leiston	01728 830574
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		colin@odell-athill.demon.co.uk
WEST MIDLANDS		
Linda Bowman	Birmingham	
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Bernadette Monks	Salisbury	01722 327388
YORKSHIRE		
Neil Anderton	Leeds	0113 258 2740
Sue Appleyard	Huddersfield	01484 641227

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fore my workload had returned to anything like it had before I went off for the op, but on the bright side the stuff I took the time to learn then forms the basis of what I do now some 5 years later.

Since that time, no-one has asked me about that period in any of my subsequent work appraisals and whether it will affect my future performance. I count myself lucky that I have such an understanding and considerate employer. But if your employer isn't so helpful what can you do about it?

I asked this question of a friend of mine who is an employment lawyer, and she made some common sense suggestions. For instance, rather than just saying "I'm going to be off for major surgery", give your employer an approximate timetable and proactive plan. It could set out that you will be off from then until then (all being well), able to do X hours per week from then and so on. You could even make suggestions as to who could cover for you and so on.

Doing this gives you employer a structure to work from and is far more effective, as you are going to them with a solution, not a problem that they have to add to the pile.

In a future article I will be looking at our legal rights when faced with a period of illness. If you have had any good or bad experiences or useful tips, please write to me at the address on the last page, so that we can pass on your experiences to our members.

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PATRON
Claire Rayner

Join the Red Lion Group

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

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

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

Write for *Roar!*

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

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

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

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

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

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

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