Roar!

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Roar! is the newsletter of the Red Lion Group

A day in the bog is not always what it seems reports **Antony Divers** on page 9

Reports from the regions on page 16

Sandy Hyams on page 4 interviews consultant **Richard Miller**

Join the War against the Free Radicals

Morag Gaherty highlights some of the benefits of looking at your diet afresh ....

"Eat Your Greens ....."."You are what you eat". Do you remember your mother or grandmother using these phrases? Well, exciting research is beginning to show just how right they were.

In the world of today's high tech medicine and surgery, it can be tempting to think that all we need to do to stay fit and healthy is pop a few pills, put on a few lotions and zap any "nasties" with lasers or surgery. Many Red Lion Group members have had their lives saved by medication and/or surgery.

However, as some also know, that may well not be the end of the story. Medication may need to be ongoing, or it may not even help at all. For such people, life can become deeply depressing as you see no end to the cycle of illness.

Many drugs are really only symptom-suppressants, and do not really cure the underlying problem. The sad fact is that we still do not know what causes ulcerative colitis or pouchitis, and so any medication we use to treat these is more about making your life bearable than about curing the underlying problem.

In that sense, pouch surgery is sometimes used as a preventative. This is particularly true for familial polyposis patients, who may have had a pouch because "it's a question of when rather than if you get cancer" rather than because there were any problems at the time: after all you can't get cancer in your bowel if you don't have a bowel!
And this is why pouch surgery is not suitable for Crohn's patients: because their problem is not restricted to the bowel, and there is a limit to how much even the most ambitious surgeon can cut out of you!

However, one thing to bear in mind is your responsibility as a patient to doing the best you can to look after your own health. No, you can't prescribe your own pills or do your own surgery. But you can eat properly and - within your own limits - get enough exercise. If you don't, you may be actively counteracting many of the benefits of what your surgeon has achieved for you.

Pharmacology is the sexy name given to the study of foods and the impact they have on our health. This is a huge field just beginning to open up as scientists begin to realise that the human body is its

Sandy Hyams points out an item of interest in the last issue of Roar! to Richard Miller ..... *See page 4*

own great chemical lab, taking good things (and sometimes bad) from everything you eat, and synthesising them inside you. Dieticians have known for many years the importance of a good diet to maintain and improve health, but it is only now that the amazing properties of individual foods are being studied to any great degree.

At the same time, we are realising that so many of today's "convenience foods" are in fact slowly poisoning us because of all the artificial things that are added in to make them more like real food, or because of the way they are produced. Remember tartrazine, the colourant in orange squash, which makes some children hyperactive? And of course, what about the BSE scare, after the true contents of cattle feed became known? There are many more examples out there and no doubt even more we don't yet know about. Is it any wonder our poor old bodies get worn out when we do so little to help them?

That is not to say you can, or should, spend your life avoiding everything other than organic vegetables. The body has an amazing capacity to fight back against the rubbish we throw at it every day, as long as we eat enough of the arsenal of natural weapons it uses to neutralise the "baddies".

Those "baddies" now have a name that you may have heard in the press: free radicals. You will hear and see lots of advertisements promoting pills and potions which counter the signs of ageing by "banishing free radicals". What you may not know is that the body uses the "goodies", known as antioxidants to attack and destroy free radicals. Antioxidants are largely found in food (and indeed in supplements to a certain extent), and are quite probably far more effective than creams and lotions, because food goes right down into your insides.

In fact, if you suffer from poor health, the very first place you should be looking is at your diet, long before you start filling yourself up with drugs. The recommended daily intake of fruit and vegetables alone is five (count 'em!) portions per day, to combat all the other over-refined foods we put in our systems and the smoky, chemically environment we live in.

Think back over the last week and ask yourself whether you had five portions of fruit and vegetables a day, regardless of the other things that are recommended. It may seem a lot, but it is easily achieved with one glass of fruit juice, two pieces of fruit for snacks during the day, and two vegeables (and that doesn't mean chips!) with your main meal. It's just a habit that needs to be formed.

The following are already known to be nature's miracle foods and should ideally feature regularly in your diet, the less cooked the better in the case of fruit and vegetables:

Poet's corner

My Beautiful Body

My rectum's on fire, my gut aching;
My feet are throbbing, my knees are locking,
Mucus fistula is leaking, my scar tissue is weeping;
Only the stoma alone stands tall and behaves.

We trust in the surgeon, the aftermath we learn to dread;
Simple it's not, the knife clears but creates new scars
Overdo it and cysts are next.

Watching the writhing flesh, colitis in peristaltic waves,
I cringe, I cry, when will it be gone?

Like acid eating anything in its way,
It oozes forth and only the knife can clear it away;
Prednisolone, azacole, to name but a few,
I tried them all, alas in vain;
Side effects and all, as bad as a curse.

Cheery we must seem to keep the curious well meaners returning,
We try and smile outwardly to the world as our past life slips away,
A wondrous fading memory and the tears roll forth,
But brave we must be and brave we are, even with little choice.

Editorial

Having been asked by Chris to put together this issue of the newsletter, I apologise for the many references to the Gaherty family!

This newsletter will not have come out in time for Christmas, but I hope it will appear early in the new year, and that you will have had a restful and enjoyable festive season. Given that this is the time of year that we all over indulge in food and drink, Morag's reminder about the importance of a healthy diet is a timely one, and you will see there are a good few references to diet in this issue. We know from experience that this is a perennially popular subject with pouch owners.

In the Autumn issue of Spectrum magazine, one person wrote in to say that we are all careful to avoid foods that we know will have adverse effects on our pouch, but made the interesting point that there were times before uc when we would eat something we knew we would pay for later just for the sheer enjoyment of it, so why not have the same attitude with a pouch? Why play safe all the time? He also recommended sweet potato as an excellent "settling" food, and it can be cooked in so many ways. Reaction to foods is highly individual, but we'd love to hear if anyone else finds sweet potato useful in this way.

I hope you enjoy the articles and cartoons in this issue of Roar! and that you will continue to contact us with letters and articles for future issues. Here's to a happy and healthy 1999!

As we start a new year I would like to take the opportunity to say a special thank you to Leona who has done a wonderful job in selling our merchandise to visitors and staff at St. Mark's.

Also in the new year don't forget the **Red Lion Group day** is being held on **Saturday 24th April 1998**, and we plan to repeat the successful format of the last one.

Best wishes for the new year

Brian Gaherty

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* Orange and deep green leafy vegetables, particularly broccoli and carrots (because of their high levels of beta carotene) - these have strong anti-cancer properties. Basically, colour is good, and any of the cruciferous family (spinach, cauliflower, cabbage, kale, brussels sprouts, as well as broccoli) is highly recommended, especially for anyone who has polyps.

* Garlic - it has strong anti cancer properties and improves the blood. It is also sometimes called nature's antiseptic. Other members of the allium family, such as onions, are also effective.

* Oily fish such as salmon, sardines tuna, herrings and mackerel - all have high levels of omega 3, which protects against heart disease

I have mentioned the specific areas in which these foods appear to be powerful, but they are also generally extremely beneficial to your overall health. According to a 1989 study at the German Cancer Research Centre in Heidelberg, increasing your vegetable intake in proportion to the rest of your diet makes your white blood cells more efficient at keeping your immune system healthy - and that's just the kind of news uc sufferers want to hear.

Remember that the healthier a lifestyle you live, the less dependant you will need to be on medication, because you are giving your body a chance to fight back. If you think your diet could do with being improved (and almost everyone's can), speak in the first instance to your hospital dietician for some sensible tips.

There are also plenty of books available for you to read, or nutri tionists for you to see. I can certainly recommend the following three books by Jean Carper, a respected American nutritionist: Food: Your Miracle Medicine, The Food Pharmacy and The Food Pharmacy Cookbook.

THE MILLER'S TALE

In another of our occasional series profiling health care professionals around the country, **Sandy Hyams** keeps an Appointment with a Difference...

It felt very strange to be driving from Norfolk to Cambridge to meet my consultant on a non-medical matter. This time, I would be the one taking notes.

Richard Miller has been the colorectal surgeon at Addenbrooke's for six years, having trained at Bristol and St Mark's. He was on a travelling fellowship in the States when the Cambridge post came up.

"I took over from Mr Everitt," he told me, "a wonderful man and a great surgeon, now thoroughly enjoying a well-deserved retirement."

I asked Mr Miller why he chose surgery as a career.

"That's easy," he said. "I wanted to go into medicine because it was a good combination of science and people. And the decision to go into surgery couldn't have been easier. Some people have an affinity for it. They know instantly that's what they want to do. And fortunately I was one of those. After the first year in the clinical period of being a medical student, I knew immediately that I wanted to do surgery.

"I worked for a chap at Barts when I was a houseman there, called Ian Todd, a marvellous, technically-beautiful surgeon who was a little of a Sir Lancelot Spratt in theatre, very irascible. But he always placed his patients at top priority. He would take time to sit and discuss the ins and outs, even when he was very busy. That's the kind of thing I wanted to emulate."

When I complimented him on his 'needlework' skills, he responded: "I can't sew a turkey very well, something I get asked to do every Christmas!"

I wondered if there were likely to be any changes in pouch surgery technique in the future.
"Probably not. The current techniques of a J or W pouch are good enough to give the patient a good quality of life. I can't see there being any dramatic changes, " was Mr Miller's positive reply. "It's a question of technical surgery. The medical science side of things has got a long way to go because what you want to do is, for example, to treat people with pouchitis better. You want to treat ulcerative colitis better, perhaps not even have to do a pouch procedure in the first place. That's where the improvements are going to be."

Did he agree that surgeons should explain pouch operation procedure in detail to their patients? I asked.

He concurred but pointed out: "You can go on forever explaining all the potential risks and complications of surgery. I think the important points for the patient are that it's their decision, it's not the surgeon's decision. Therefore it's not the surgeon's prerogative to say you will have this operation done, but to explain that there are usually two options. One is an ileostomy that becomes permanent; the other is a pouch. There are pros and cons for both options. An ileostomy is not without its problems. You can have hernias, ileostomy revisions etc. And if, for example, they have an ileostomy created when they are 40 and then go on to get severe arthritis in their 60s and 70s, managing it then becomes exceptionally difficult.

"When you talk about pouches, there are all sorts of pros and cons with those. There are serious complications that can occur during or after surgery. Fortunately those are very few. But the patient still has to know there is a risk of a major problem. That's their right, they have to be aware of the likely outcomes. So what I tend to do is go through the major potential problems - pouchitis, bowel frequency, continence etc. I also get them to see a patient of a similar age and sex who's got a pouch, so they can understand what life with a pouch is like. Then, when they come back for the final interview, I say: what do you want to do?"

Patients often know more about their condition than their GP, I observed. How did he think this situation could be remedied?

Continued on next page

"I don't think you can expect GPs to know about these kinds of operations in enough detail to be able to give accurate advice. I think it's beholden to the hospital doctors and nurses to provide the support for patients once they've left hospital."

I ventured that perhaps it would become more common as the operation became more widespread. "I think it's as widespread as it's going to be, " opined Mr Miller. "If you look at East Anglia, there are lots of good colorectal surgeons. In every major district hospital, there is a surgeon who can construct a pouch perfectly well, and you don't need any more than that. The incidence is there, it's not going up or down. Colitis is there. I think there might be a gradual increase in numbers because there are still pockets of the country where the patients don't have access to specialist advice about whether a pouch is available. I came across one recently who wasn't given the option. Now obviously that situation will change as specialisation continues to improve, and it is improving all the time."

The procedure can be performed in one, two or three stages. I asked Mr Miller which he preferred. "If you're doing an operation for ulcerative colitis, then my preference would be to do what's called a subtotal colectomy - take the colon out but leave the rectum behind. Before a patient who has uc has an operation, they're usually quite ill. The last thing you want to do in those circumstances is to perform a complex reconstructive operation, i.e. a pouch. Those patients need to be taken off steroids gradually, then get their nutrition balanced and correct. They need to get well again. At that stage, I usually then go on to do the operation in one. Now in that regard I'm in a minority. Most surgeons would make a pouch then cover it with another ileostomy. That also has its advantages and disadvantages. The advantage is that if you have a leak from the pouch, the faecal stream is not going through it. But the disadvantage is that it can put more tension on the anastomosis, the join-up of the pouch to the anus. And also, if you look at the literature, there is a 15-20% complication rate of closing an ileostomy. Also, it's a third operation for the patient although it's relatively small compared to the pouch itself."

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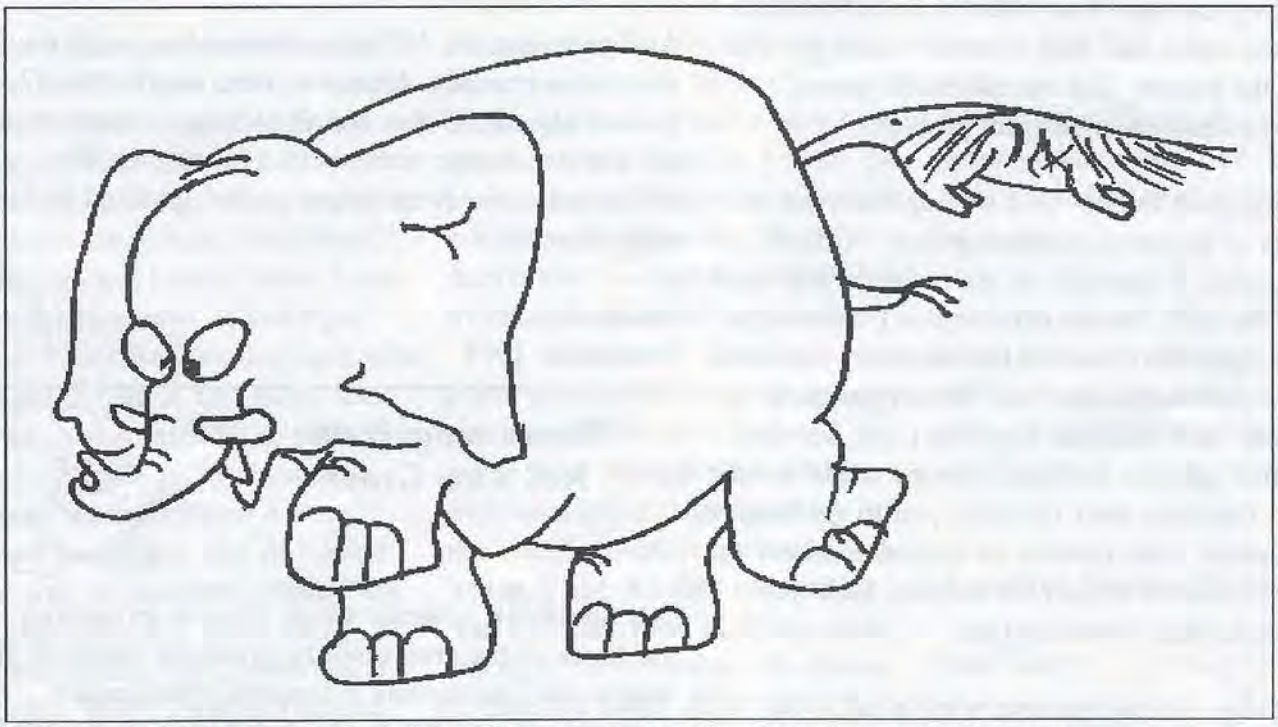

All animals learn by trial and error which foods cannot easily be digested. The anteater is no exception

Mr Miller favours the W pouch, using four loops of the intestine. I was curious why and whether there were any advantages over the J or S.
"The S is definitely a pouch of last resort," stated Mr Miller. "The problem is that it has a short limb from pouch to anus and that often means the patient can't evacuate the pouch spontaneously. They have to empty it with a tube, a catheter. It's not as near normal as we'd want. The reason I choose a W pouch is I can get predictable, good results that way."

He went on to cite examples of early well-functioning results after surgery. Another technique practised by Mr Miller is hand sewing, and I questioned the benefits over stapling.

"Although it's harder work for me, I do it all by hand. I trust my handsewn join-ups, so to speak, my handsewn anastomoses, more than I would a staple. Staples take rather small bites of the bowel wall. They're perfectly fine, I use the stapling technique for rectal cancer all the time. But if I was using a staple gun, I would always tend to cover it with another ileostomy. Surgeons do tend to stick to techniques that work well for them. It's important they should be given the freedom to do operations the way they feel confident in. I started doing them with a staple J. Then I was taught hand sewn. I weighed the two up and thought, well I'm more confident doing it handsewn and my results seem to be better in terms of function. Handsewn pouches can take four hours, whereas a staple J can take two and a half. But it doesn't make any difference to the patient. The anaesthesia is good enough not to make a significant problem."

They say it's good to talk. So I sounded him out on his opinion of the pouch support groups. "I think they're valuable. It depends on the patient's individual approach," he said. "Some patients don't want to go to a group, they don't want to be constantly reminded that they're different in any way. If they get good support from their hospital, they don't feel any need to join. Other patients feel that it's very useful to talk in order to fine-tune their function, just to get support and information from patients or invited speakers or whatever. I think it's horses for courses. Each patient can make their own mind up.

"In Cambridge, we ask patients who've had pouches to counsel pre-operative patients about the pros and cons of surgery," he added. "Our specialist sister has vast experience in the area and therefore can advise in significant detail - on the phone, nine to five, Monday to Friday."

I mentioned the recent pouch symposium held with the aim of creating a federation of support groups. What did he think about this?

"I think that's a good idea. That would be a logical progression to get some sort of national group together, a sensible way forward."
[Ed Note: Mr Miller may not have realised that the Red Lion Group is already a national group!]

Finally, I asked if he had any advice for Roar! readers contemplating pouch surgery.

"First of all, you've got to be referred to an appropriate specialist who can advise you about the ins and outs of it, be prepared to have perhaps two or three interviews beforehand. I think that's probably the most important step," he stressed. "Then you could see a patient or two with a pouch. If you wanted to, you could go to the local pouch group and see loads of patients with pouches. Perhaps you might get a more balanced view because there will obviously be a spectrum of experience. Then you could mull over, with that kind of exposure, whether you wanted to go ahead yourself or not. Some people require very little time; they come in with their mind made up already. You know what they're going to say: I want a pouch."

At Cambridge, Mr Miller performs about eight pouch operations annually. However, next year he has 12 booked already. If they are all satisfied customers like me and two former patients that I met, then Mr Miller will have every reason to feel gratified by his achievements.

Sandy Hyams
November 1998

Please support the Red Lion Group

All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Chairman (Address and telephone number on back page)**

Letters

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A healthy respect

Dear Editor

A few years ago, I went to Inglewood Health Farm with my daughter and I'd recommend it to anybody; it was a real treat. I saw a nurse who told me what I could do and have etc. While I was there, I drank lots and lots of water. I was there for five days. When I got home, I became very tired and went straight to bed. A few hours later, I awoke, had something to eat and then collapsed, so my husband phoned the ambulance. I was rushed to hospital and all I could hear was my husband saying "She has just been to a health farm!" I felt like saying No I haven't, as I felt silly. Well, I was dehydrated and kept in hospital a week. I think it must have been the salt intake.

I did enjoy the health farm - it was first class; but I still laugh at the idea of my husband telling the ambulance men "She's been to a health farm." So just be careful if you ever go.

Blanche Farley, Liverpool

Me too ...

Dear Editor

On reading the letter from the lady in Western Australia in issue 9, I thought I was reading a letter about me. I too was diagnosed some years ago as having uc. I was given treatment and the symptoms disappeared. It was not until 1995, like the lady in Australia, that it reared its ugly head again with a vengeance.

I too had been diagnosed with breast cancer in 1994 and had a lumpectomy in the spring of 1995 followed by radiation treatment. It was towards the end of my treatment that I started having problems with my bowel. It was a very hot summer in 1995 and so I made the journey to the hospital in a hot car every day for 6 weeks. I maybe didn't drink enough to get rid of the toxins caused by the radiation.

I was admitted to hospital and put on steroids then on a drip and given food through a hib line (a tube inserted through an artery in the chest). I went from bad to worse. I had the runs one end and was sick the other. Holding on to my drip, I didn't know which way to face the toilet! After about 4 weeks, the doctor said there was nothing else he could do for me and I had to have an ileostomy. I was devastated. I returned home, only to return to the hospital 2 days later with a deep vein thrombosis in my left leg. I spent another 4 days in hospital and was put on warfarin, a drug to keep my blood thin.

I returned to work three months later. I then waited 2 years before my pouch operation. Just two days after my operation I had to go back to the operating table because I had a hernia. I thought I would never feel well again. But I did get well again and had the last part of the operation to remove the bag and close up my tummy, and I recovered from this part of the op quite quickly.

That was over a year ago now and I am back at work part time. My pouch is not perfect, and I have my off days, but I'm glad I had the op. Thank you Mr Nicholls.

Yvonne Cooper
Surrey

PS I wonder if the lady in Australia doesn't realize that it could have been the radiation that damaged her weak bowel?

Ed note: Do any other pouch patients have any experience of possible connections between radiation therapy and returning bowel problems? If so, do let us know.

Another burning issue

Dear Editor

I have just joined the RLG having had my closure operation in August 1998, performed by our President

John Nicholls. Reading the Autumn issue of Roar!, the letter from Helen Bradshaw struck a loud bell. Like her, I generally feel pretty awful by the evening with a combination of burning bottom, wind pains and general tiredness, and there have been many times when I wondered whether I have done the right thing in going ahead with the pouch.

This is my second attempt at a pouch - the first one was removed because of a persistent abscess - and in between I have had 3 ½ years of an end ileostomy. I have to keep remembering the problems of leakage, wind, noise and bad body image that come with an ileostomy, otherwise my current pain and discomfort would sometimes be too much to bear.

Does anyone have similar experiences? And can you give me hope of real improvement?

Charlotte Barney
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Been there, survived that

Dear Editor

Helen Bradshaw's letter could have been written by me some months ago. I had the reconnection operation on 10 March and until only very recently felt as if I was almost worse off because of the leaking and severe burning and itching. I used to do a lot of long distance walking, but could hardly manage 100 yards before I leaked, and then the irritation started to drive me crazy. I was utterly miserable at night and dreaded having to go to the loo. My husband is a GP and his reassurance that it would all get better in time was not much consolation. The only ointment which soothed it was Germolene. Pelvic floor muscles have helped strengthen the muscles. At least doing them did me good. Washing frequently made it very sore, but Pampers wipes were a good way of keeping clean. It has taken six months since the reconnection for me to sincerely believe the operation was worthwhile. I had the first operation on November 12 1997, having had ulcerative colitis for 25 years, with unmanageable urgency towards the end. Please would you pass on to Helen my assurance that the burning and prickling will get better, and that I, too, thought I was the only one who was suffering so badly after the operation. I would be happy to speak to her if she wishes.

Jessica Drewery
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[Ed note: Jessica has been in touch again since this e-mail to say she is now even better and wishes she had had the pouch done earlier. And she's back on her long walks!]

When in Walsall

Marie Howell writes to tell us about the "Get Up and Go!" club based at the Manor Hospital, Walsall ...

We have now held our first meeting which was attended by 20 pouch patients and some of their partners, together with 2 nurses, Nicola Glennie the dietician, and Mr Stewart the surgeon from Walsall. This made for a very satisfactory turnout for our first official meeting.
The evening was very relaxed and informal, with the main emphasis being on a question and answer session with Mr Stewart and Nicola. The questions to Mr Stewart covered every aspect of both the pouch operation and problems which may arise after the op. He answered them in a very positive and at times amusing manner.

The answers given by Nicola, the dietician, were very helpful for everyone present ..... frequency of meals, foods to avoid or foods to eat more of were all covered extremely well and led to a very interesting general discussion amongst the members there.

A suggestion of an evening out at a restaurant was welcomed but it was decided that such a meal would be too formal, with little chance to talk to anyone other than the people sitting close by. Instead a buffet party was organised for 3 December 1998 in the Post Graduate Centre at the Manor Hospital, which is "Home" to our club.

Marie Howell
01902 756158

RED LION GROUP WEB SITE

You can find our web site at **www.red-lion-group.mcmail.com** It contains a lot of information on areas such as diet, the operation, and links to other useful sites. If you have any ideas on what else you would like to see there, contact any member of the committee.

A DAY IN THE BOG

Red Lion Group member **Anthony Divers** tells us about a recent trip to Southern Ireland, with a few words of advice of particular relevance to other pouch owners.....

No, it is not an article about what you think, but it is an eye-catching title. This is the name of a museum in County Kerry, Southern Ireland, devoted to life in the Irish boglands throughout history.

My wife and I recently spent two wonderful weeks in Tralee, Kerry. The weather was kind to us and the property we stayed in (a Victorian Lodge 50 yards from a beach) was idyllic. We had a great time. We spent the time over there doing all the usual touristy things, but what else would you expect from first time visitors?

I was surprised how quiet the county was as a whole, holidaying in August and being able to drive everywhere and being able to park in all the major towns (very rarely having to pay) without hassle. A pleasant change from the usual British holiday crush.

If you ever consider going to this part of the world, the following excursions are tried and tested:

'Seafari', Kenmare Bay: currently £10 adult/£5 child. Two hour cruise to see wildlife, especially the resident seals (you must book). Tea, coffee and sweeties supplied, use of binoculars and - the real bonus - a toilet on board

Dingle Bay: go and see the resident dolphin 'Fungie'. Boat trips all day. If you don't see him, you don't pay; if you do, it's currently around £5 each. This playful creature is the bay's main attraction, but don't miss out on the 'Oceanarium' in the town - well worth a visit at £6 each. Very well designed and laid out, excellent facilities, coffee shop, toilets etc.

Irish National Folk Theatre, Tralee: £9 a ticket, three different shows during the weekday evenings. A great night out, a sort of mini-Riverdance show.

The above are unmissables in our opinion, but there are other excursions according to personal taste and pocket.

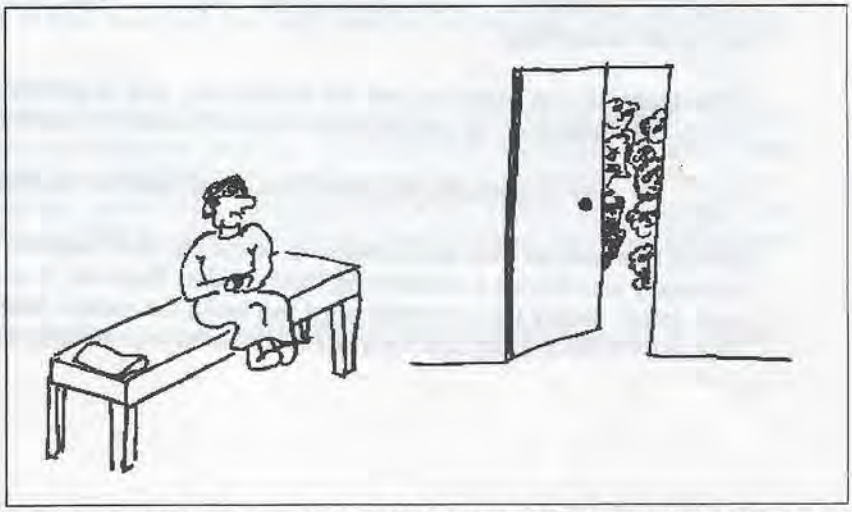
The south of Ireland has stunning scenery, empty beaches, blue/green seas, green fields, mountains - the list is endless. You have to see it to believe it. It has no equivalent on mainland Britain.

To finish, a couple of words of warning: southern Irish drivers are a unique bunch: very polite, courteous, cautious and considerate. But they drive down the middle of the road, they do not signal their intentions (because they "always turn there"), and their road surfaces are best described as 'dreadful'.

The second word of warning is particularly relevant to Red Lion members: public toilets in southern Ireland are few and far between; those you do find vary in quality enormously, e.g. if the loo is Victorian it may have been last cleaned at the turn of the century! Things are getting better and more are appearing. But generally, the rule is: use toilets in local bars, hotels and cafes whenever you stop to buy a drink. If you plan any longish trips, assume the worst on the toilet front and then you will allow for the 'inconvenience' (ouch, sorry about the pun).

To sum up, I would say .... If you ever get the chance to go to Southern Ireland once in your lifetime then go. Do not miss the opportunity, as you will regret doing so.

Anthony Divers



Fred was beginning to discover the downside of having his surgery done at an internationally recognised training hospital

Relationships and your Surgery
Survey Results

The questionnaire accompanying issue 10 (Autumn 1998) of the newsletter was designed to find out how much your pouch surgery and subsequent lifestyle affected your close relationships. It was geared primarily at partner relationships but a number of respondents made the very valid point that children, other relatives and friends are also important relationships in our lives. It is very possible that we will devise other questionnaires in the future to address these different issues.

We had another very good response (74 replies), despite the fact that we put an early deadline on responses. The main reason for doing this was to stop survey results "dribbling in" six months or more after the original questionnaire went out, eg from new members receiving back issues. However, these deadlines are more an indication than a fixed date so we were quite happy to include "late" responses that came in during November. You didn't need to grovel!

Q1 What was your home situation when pouch surgery was first considered?

58 (or 78%) of you were one half of a couple, either married or living together, 6 (8%) of you were single, widowed or divorced, while 5 (7%) lived with family or friends. Of the remaining 5 (7%) that classified themselves as "other", these were largely individuals who were in a close relationship but not actually living together. So the bulk of our respondents were in a close relationship of some sort at the time that surgery was first considered.

Being part of a couple appears to be particularly important if things do not go as planned, as one of our single respondents commented: "I think it is incredibly difficult getting through the emotional problems of having pouch surgery, if things go wrong, if you are single. I found the psychological aspects not dealt with by the hospital [Ed note: a centre of excellence, no less!], and the emotional and physical support in the community, from the local stoma care nurse and my GP, non-existent".

Q2 If one half of a couple, was your partner supportive during this time?

Of the 67 replies we received to this question (some people answered this who had marked themselves in Q1 as alone or living with family, presumably because they were also in a "couple relationship" without living together), the vast majority of you found your partner to be supportive: 64 said yes (96%) against only three answering no (4%). This must be reassuring for those now contemplating pouch surgery, as the last thing you need at such a vulnerable time is the additional fear that your partner will not be there for you, given that the cycle of surgery can take some considerable time.

However, it was clear from many of your replies that there was often a long history of illness to be faced together *before* pouch surgery was even considered, and so your relationships had already been through the mill and survived. After more than 20 years of colitis, in some cases, what are a couple more operations in the scale of things?!

"I had an ileostomy for 3 years prior to pouch surgery – living with the former was (I felt) a much bigger test on my relationship".

"[My husband] was supportive but felt helpless as I was in pain for a long time" wrote one woman, who had the additional blow of needing pouch surgery because of cancer of the colon.

Q3 If your relationship has since broken up, was this anything to do with your illness/surgery?

Eleven relationships have since broken up, and it has to be said that in 9 (82%) of these cases, your illness or surgery was at least a contributing factor to this. However, it was clear that this was generally not the main factor, simply the proverbial straw that broke the camel's back. And again, it was not the surgery as such, but the debilitating effect of years of illness on your lifestyle that caused the problems.

"Relationship shaky to start with. Had my first and last attack of colitis when 3 months pregnant and the ileostomy, the difficult pregnancy, and the pouch and closure ops, plus stress of a young child (that never slept!) added to the strain. Also distracted us from our other marital problems so they were never discussed, and festered".

As can be seen in the answers to Q9, pouch surgery is more likely to allow you to *reclaim* your life from ulcerative colitis than to cause additional problems in your relationships.

Q4 If so, please say why and for whom it was a problem

For those people who had problems in their relationships, they will very often have been a compound of a number of different issues, so there is no point in showing their answers to this question in percentage terms. Instead, I have summarised the information in the table below:

	You	*Partner*		*You*	*Partner*
Stress/unable to cope	3	5	Fear of loss of attractiveness	7	
Depression	8	2	Financial strain	3	4
Unable to share feelings	6	4	Other	3	4
Loss of physical/sexual interest	8	1			

The total number of respondents to this question is low, and therefore it can be dangerous to generalise. However, it would appear that the pouch patients themselves seem more concerned by "inner" problems such as self-esteem issues, whereas their partners may have more difficulty with the communication side of things. And of course, financial worries affect both in the relationship.

Knowing what were the problem areas in other people's relationships at least pinpoints the danger areas that you need to be on the lookout for.

Q5 With hindsight, were there any warning signs of the threat to the relationship and would/could you have done anything different if you had recognised these?

As ever, communication appears to be the key to it all, as the following comments illustrate:

"There were many warning signs which we did not recognise. I wish we had communicated more. I wish we had said to each other, before and during all this, 'how do you feel about what is happening?'"

"I was incredibly anxious to get rid of my temporary loop ileostomy after my pouch surgery as it was constantly leaking.... my only goal in life was getting rid of my bag. I paid no attention to my deteriorating relationship – I was very selfish and totally wrapped up in my own problems. I should have discussed things more".

"[I] could have talked to him sooner. He could have understood me a little better!"

Q6 If you answered Q3, 4 & 5, how long had you been together before your relationship broke up?

The purpose in asking this question was to see whether recent or long-term relationships were more at risk. However, of course, with so few breakups reported (happily), we can draw no statistical conclusions from the answers given. Of the ten people who answered this question, one was a relationship of less than a year's duration (and the respondent was herself only 16 at the time of her surgery, so felt it was "not surprising" that he should have got bored with her restricted life) and the other nine had lasted for between 2 and 21 years.

Q7 If you are in the same relationship as in Q1, what difference has your illness/surgery made?

Happily, the news on this front was very good – of the 57 replies to this question, 54 felt their relationship was no different (24, or 42%) or closer (30, or 53%). Only 3 (5%) now felt less close to their partners than before.

Q8 If you have formed a new relationship since your surgery, what does your new partner know about your pouch?

Of course, the information you give to a new partner about your pouch will depend very much on whether the illness and surgery are part of your history, or whether you have ongoing problems. Of the 13 replies to this question, we had 7 (54%) sharing all the gory details, 5 (38%) telling their partner about the surgery without going into details and 1 (8%) who classed themselves as "other". No-one kept their new partner guessing about what their scar was really for, which reflects the way we are much more likely to share our histories "warts and all" than perhaps we would have done a generation ago.

Q9 Has your surgery enabled you to make relationships that were not possible because of your illness?
Q10 If yes to Q9, please explain why

33 people replied to Q9, of which 23 (70%) said no and 10 (30%) said yes. The main reason was increased fitness which meant for most a new "ability to have a social life" and so "feel more confident".

The question was really intended to find out whether individuals who had previously felt unable to form close relationships (with a partner, eg because of an ileostomy) had been liberated by having a pouch. However, those who answered it in the positive commented on their increased social life or communication with other pouch owners via the Red Lion Group, and so clearly interpreted the term "relationships" in a more general sense than was intended.

In any event, it can be seen from the answers to question 1 that health problems, even of the bowel variety, need not stop anyone from enjoying a couple relationship with another individual. However, a couple of respondents mentioned anxiety about "pouch surgery and how future partners will deal with/view it", particularly with regard to "wind, [toilet] noise...and fear of leakage during the night if in a serious relationship".

Q11 From your own experience, do you have any advice to offer about maintaining successful relationships after pouch surgery?

We asked this question primarily for the benefit of those currently considering pouch surgery or who have recently undergone it, as many of you in this category will not yet have decided how to handle the questions that your operation will naturally prompt.

Mirroring the answers to question 8, none of you recommended ignoring your pouch or surgery completely. 38 of encouraged you to talk about your experiences. 10 suggested talking about it but sparing your partner all the details (such as the Sudocrem!). 40 agreed that you should explain your surgery but then get on with your life. A number of respondents ticked more than one of the options offered here, which is why the numbers are so high.

The general consensus was that it is both good and important to talk, but that you should ensure your partner also gets to talk about their fears and concerns: "Don't be egocentric, listen.." wrote one.

"Marriage is a partnership to share illness as well as health. This includes the Sudocrem!"

A number of people stressed that talking is good, but it should not stop you from getting on with your life: your illness and surgery is "part of who you are, but not all of it". And one person wisely pointed out: "...above all, be able to laugh about things!"

However, a few respondents pointed out that unburdening yourself to friends and in casual relationships is a good way to lose those friendships: "Don't inflict your experiences on others unless they *really* want to know!" said one, while another commented: "I've found that when people ask 'How are you?', all they really want to hear is 'Fine'. If they want to know more they will ask a specific question".

Q12 Do you find yourself completely unaffected by subjects that others are squeamish about, as a result of your surgery (eg volume/consistency of output), and do you ever forget this in conversation?

Not surprisingly, most of us have become inured to what are taboo subjects in the rest of society, as a result of our experiences. However, 56 (77%) of the 73 respondents to this question are careful about what they discuss in front of others, whereas 14 (19%) have no inhibitions about talking about these subjects in front of anyone who cares to listen. 3 (4%) respondents admitted that they are just as squeamish as others and so do not discuss such topics.

Q13 To what extent do your illness, surgery and any ongoing medical problems impact on your life?

Again, this was one of those questions where some respondents ticked more than one answer, and so it is best to present the results in tabular form without percentages:

They don't – it's all past history	12	They don't – I prefer to handle problems on my own	4
I'll tell people if they ask	33	To understand me, you have to understand my medical problems	4
Everyone knows all the details and exactly how I'm currently feeling	8	I would like to talk to people but don't feel I can	3
I talk freely to family/other pouch patients/medical personnel	41	Other	11

Reassuringly, the responses to this question do not indicate large numbers of patients feeling isolated and unable to talk, although there were at least 3 respondents who would appreciate the opportunity to talk about their illness or surgery to others. The problem is worst when you want to share with your partner, who has themselves cut the lines of communication as their own way of dealing with what is going on. Although you can discuss practical pouch problems with your surgeon, it can be very hard to raise emotional issues arising from your illness or surgery with them.

Of course, as a support group, that is exactly what the Red Lion Group is here for. See the separate article in this issue about putting people in touch with each other.

One lady wrote "I can't talk to members of my family [except my husband] about my illness as it occurred very quickly and they couldn't accept it. They think because I no longer have an ileostomy that I am back to normal (nearly) and that I'm fine. However, I suffer from the stress of what I've been through mentally and can get upset about some things very easily…I feel better in myself if I can talk to other pouchies as I feel they can understand how they feel". Her husband took the trouble to get counselling for himself because of the great shock of her sudden illness and operations, and she now rates their relationship as closer than it was before. Full marks to him and perhaps a good idea for other partners to consider if they are having difficulty coming to terms with what is happening.

Positive thinking was advocated by many: "I think it is very important to acknowledge what one has been through but to see surgery as the start of life without uc, not to look on it as an ongoing event".

And finally, one of our members reminds us to put everything in perspective: "Colitis affects patients! Having no colon affects patients! Terminal illness affects loved ones! Summary: At 54 I have had a remarkable illness-free life until now. I am surely grateful for that!".

THE CONTACTS PAGE

Do you want to make new friends, or contact someone you met while you were in Hospital or at a Red Lion meeting or function? Simply send us your name, address, telephone number, or e-mail address. We will then publish them, together with your message. You never know, it might just be the start of a beautiful friendship.

As a matter of policy we never publish postal addresses, except at the author's specific request.

IT'S NOT JUST WALLS THAT HAVE EARS

Members of the Red Lion Group recently attended what we hope is the first in a series of sessions being run to help you to better support people coming to you for a shoulder to lean on .....

Basic Listening and Telephone Skills Training Day

The Pathfinder course for basic listening and telephone skills took place in Rochester, Kent on 24 October. We had planned for 16 members from the Home Counties and Northampton to attend. Unfortunately, due to appalling weather and unavoidable cancellations, only 12 members were able to attend the course.

In brief, the course was a great success, but very condensed. In future, I feel this should be a two day course if possible, perhaps spanning a weekend with a social function on the Saturday night.

All members felt they were now better equipped to face the ever-increasing need to help and support those facing the future with a pouch.

For me, one of the most rewarding parts of the day was sharing the unlimited sense of humour of the course members (literally a laugh a minute), and in particular we thank our very own comedian and comedienne, Phil Elliment and Emma Edwards.

David Irving-James

This course was organised by Dick O'Grady, a member of both the Red Lion Group and the ia, and funded by the Red Lion Group.

If you would like to attend such a session in the future, please let us know by dropping a line to our Liaison Officer, whose address can be found on the back page.

Alternatively speaking .....

In keeping with today's increasing interest in the effects of nutrition on our health, food questionnaires were given to 88,756 women in the Nurses' Health Study. One finding arising from this that may be of particular interest to Red Lion Group members is that long term (more than 15 years) use of multivitamins can reduce the risk of colon cancer by as much as 75%, although short term use did not appear to alter this risk.

One theory is that there may be some protective effect caused by the folate contained in multivitamin preparations (Ann Intern Med, 1998; 129:517-24; reported in vol 9 no 9 of What Doctors Don't Tell You).

LIVING WITH A POUCH

Want to find out more about living with a pouch, from people who know? ***Morag Gaherty*** *has a few ideas about how to go about it.*

If you want to make contact with other members of the Red Lion Group or want to find out more about living with a pouch, here are a few suggestions to get you started:

1. Contact one of our regional reps

Reps' phone numbers are listed at the back of Roar! It may be that they organise get togethers for members in their county, or they may simply be a friendly contact for you to talk to. It depends very much on how many members are in your area, and whether or not they like to get together as a group.

Do not feel you can only contact your local rep. If you would like to talk to a number of people, and there is not much going on in your area - by all means phone other reps listed in Roar! if you wish.

2. Use our "penpal" service

Write to the newsletter editor with a few words (less than 25) about what/who you are looking for, and we will publish your name, e-mail address and phone number in the next edition of Roar! As a matter of policy, we do not print postal addresses - it is up to you to share this information when you speak on the phone, if you want to.

In addition, if you prefer us not to publish your last name, please make this clear when you write to the newsletter editor.

3. Contact the Liaison Officer

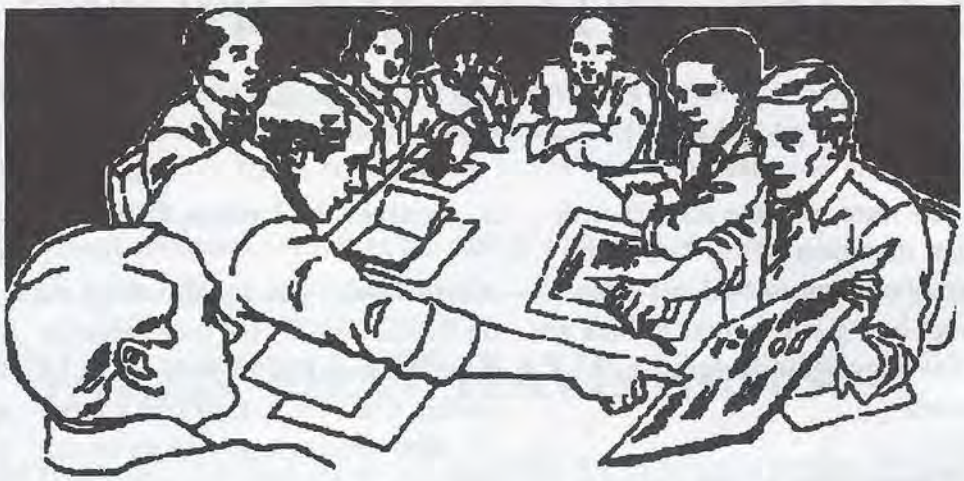
Alternatively, you could contact me on 01622 739034 (or preferably by e-mail at mag1@bakertilly.co.uk), so that I can try to find you a member with similar experiences on our database. I also try to match up age range and gender if possible.

However, please note that all I can do is pass on your details to them - I cannot give their details to you, under the terms of the Data Protection Act - and so I cannot guarantee when (or even if) they will get in touch with you.

4. Speak to the UK's only Clinical Pouch Nurse Specialist

Another alternative is Julia Williams, the clinical nurse specialist at St Marks who deals with pouches. If you are finding it hard talking about your illness or surgery with anyone else, but need support or - especially - medical information, please do contact Julia on 0181-235 4110.

NEWS FROM AROUND THE REGIONS



Kent Regional Group

The most heartening news for this issue is the very successful meeting of the West Kent Group, held on 19 September at Bexleyheath, Kent. The meeting was organised and chaired by Tom Deans, to whom we give our most sincere thanks. The meeting was very well supported and Tom's written report makes very encouraging reading. Many issues were discussed and an amazing amount of interest was generated.

The group's next meeting was again in Bexley on 28 November by popular demand. We hope to have a brief report on this event in the next issue of the newsletter.

Well done West Kent. Hopefully, in the spring, both East and West Kent groups will come together for a joint meeting to discuss the way ahead for county members.

Please note that David Irving-James, RLG Social Secretary and rep for Kent has recently moved home. His new address and tele phone number are listed on the last page.

Northamptonshire Region

On 28 November 1998, the Northamptonshire group met again at their local hospital for a meeting. Unfortunately, with the date being so close to Christmas, only six people were able to attend. However, the discussion, led by the two Northamptonshire reps, David Smith and Cynthia Gunthorpe, was very interesting. Those attending had the opportunity to discuss their pouch experiences with each other, and much practical advice was exchanged.

The next event organised by Cynthia and David is to be a social event in January - Sunday lunch at the Rose and Crown, Yardley Hastings, from around noon on 24 January 1999. So, if you're in the area on that date, make a note in your diary now and call David on 01604 450305 before 17 January, so that he can confirm numbers with the manager. It will be an ideal way to relax after all the stresses of the Christmas season!

Tom Deans provides a report on progress in the North Kent group...

Well, we waited some time for the day to arrive but when it did it was really worth the wait. Fourteen people arrived in Bexleyheath on September 19th and it really was good to see everyone and for everyone to be able to talk so freely with like minded people.

Unlike the other Kent group get-together at a local restaurant, we seemed to prefer being someplace out of the public eye where whoever wanted to speak could do so and say whatever they wanted. We were all in the same boat so we understood one another. We had 11 pouch owners and three partners.

The next meeting was held on 28 November and we hope to have a report on this event in the next issue of the newsletter.

Paw!

Issue 3 • Winter 1998

Welcome to the third issue of *Paw!* For cub members and the children of the Red Lion Group members. Keep sending in the jokes, stories, and puzzles for future issues. The address to write to is shown on the second page, so get writing!!!!

Animal scrambles - Can you unscramble the animal names?

1	ronicosher
2	phentar
3	lethapen
4	ebrave
5	umose
6	ocw
7	ales
8	clame
9	ehn
10	dropale
11	biron
12	frifage
13	konyem
14	derinere
15	rilquers
16	grite
17	ogd
18	braze
19	bitbar

Q Did you hear about the Irish woodworm?
A It was found dead in a brick
From Leanne, aged 9

Q What do you call a violin without a bow?
A. A guitar
From Kerry, aged 7

Q. Why did the skeleton go to the restaurant?
A. To get some spare ribs

Q. Why didn't the skeleton go to the party?
A. Because he had no body to go with

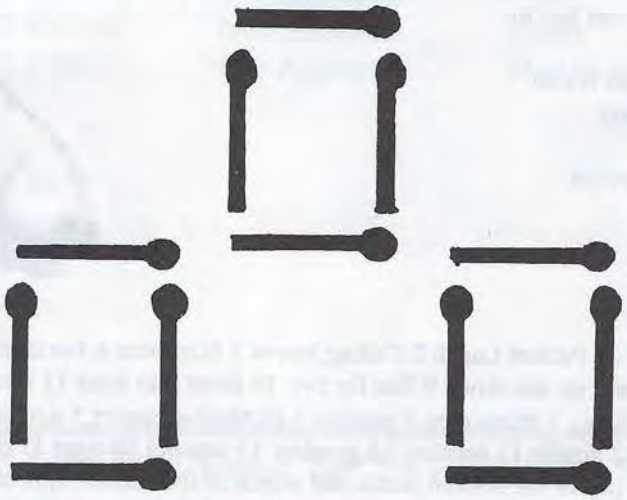
Q. What has a bottom at the top?
A. A leg

Q. Why did the skeleton cross the road?
A. To get to the body shop

Do you know any great Doctor Doctor jokes? Some of our favourites are over the page

Puzzle

How many matches do you have to move to make five squares?



Catchphrases - Can you guess the catchphrase?

1
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH

2
L L L
E E E
A A A
V V V
E E E
S S S

3
SI
ST
ER

4
INSTANT
INSTANT
INSTANT
INSTANT

5
, D

6
WRITE = WRITE

7
OUT OF CHARACTER

8
E P
C A
A C
P E

9
FORE
TEE
FORE

10
TEAR BURST TEAR

11
HEAD
HEEL
HEEL

12
COMMER CIAL

Patient: Doctor, Doctor, everyone keeps ignoring me
Doctor: Next please!

Patient: Doctor, Doctor, I've only got 30 seconds to live
Doctor: Just a minute

Patient: Doctor, Doctor, I keep thinking I am a bridge
Doctor: What's come over you?
Patient: Well so far 2 cars, 3 lorries and a bus

Patient: Doctor, Doctor, I keep thinking I'm a pair of curtains
Doctor: Pull yourself together!

Address

If you want to send us a joke, cartoon, puzzle or story send them with your name, address and age to:

Julia Williams
Specialist Pouch Nurse
Stoma Care Dept.
Level 3
St. Mark's Hospital
Harrow
Middlesex
HA1 3UJ

Remember every letter will win a Red Lion bug and pen ...

Answers

Catchphrases - 1 Packed Lunch 2 Falling leaves 3 Stepsister 4 For instance 5 Comedy 6 Equal rights 7 Out of character 8 Pace up and down 9 Tea for two 10 Burst into tears 11 Head over heels 12 Commercial break
Animal scrambles - 1 rhinoceros 2 panther 3 elephant 4 beaver 5 mouse 6 cow 7 seal 8 camel 9 hen 10 leopard 11 robin 12 giraffe 13 monkey 14 reindeer 15 squirrel 16 tiger 17 dog 18 zebra 19 rabbit 20 dolphin
Puzzle - three (move the bottom horizontal match of the bottom right square to the left so that it forms a square, now move the other two matches to the top left to form another square. With the large square that the four small squares make - you have five in all!!!!)

Catchphrases - Can you guess the catchphrase?

1
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH
LUNCH LUNCH LUNCH

2
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A A A
V V V
E E E
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3
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4
INSTANT
INSTANT
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INSTANT

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6
WRITE = WRITE

7
OUT OF CHARACTER

8
E P
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9
FORE
TEE
FORE

10
TEAR BURST TEAR

11
HEAD
HEEL
HEEL

12
COMMER CIAL

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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

BEDFORDSHIRE
Wendy Gunn — Luton — 01582 423714

BERKSHIRE
Liz Davies — Langley — 01753 586593

CAMBRIDGESHIRE
Rita Deans — St Neots — 01480 403148
Joyce Shotton — P'borough — 01733 706071

CLEVELAND & NORTH YORKSHIRE
Christine Jackson — Saltburn — 01947 840836

CUMBRIA
Jonathan Caton — Kendal — 01539 731985

DEVON
Gill Tomlin — Plymouth — 01752 568643

DYFED
Briony Jones — H'fordwest — 01437 765359
Bruce Dibben — " — 01437 731436

EAST SUSSEX
Kate Bosworth — Brighton — 01273 887102
Lisa Critchley — " — 01273 699286

ESSEX
Peter Zammit — Benfleet — 01268 752808

GWENT
Robert Challenger — Cwmbran — 01633 866320

HAMPSHIRE
Phil Smith — Portsmouth — 01705 426541
Les Willoughby — Winchester — 01962 620012

HERTFORDSHIRE
Carol George — Stevenage — 01438 365707

KENT
David Irving-James — Folkestone — 01303 894614

LANCASHIRE
Joan Whiteley — Clitheroe — 01200 422093

MERSEYSIDE
Blanche Farley — Liverpool — 0151 924 4282

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 — 0181-6901360
Jonathan English — SW12 — 0181-6732518

WEST LONDON
Dee O'Dell-Athill — W10 — 0181-9606726

WEST SUSSEX
Amanda Metcalf — Arundel — 01903 885682

WILTSHIRE & DORSET
Bernadette Monks — Salisbury — 01722 327388

YORKSHIRE
Neil Anderton — Leeds — 0113 258 2740
Sue Appleyard — Huddersfield — 01484 311334

IF YOU would like to be a Red Lion Rep, please contact the Liaison Officer Morag Gaherty (phone number on back page)

Roar! Issue Number • 11 Winter 1998

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Tel (work): 0181-235-4110

FUNDRAISING OFFICER
The position is now vacant
anyone interested in applying
should contact the secretary
Inez Malek (address and
telephone number on this page)

SOCIAL SECRETARY
David Irving-James
6 Gloster Close
Hawkinge
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Kent
CT18 7PP
Tel: 01303 894614

TREASURER
The position is now vacant
anyone interested in applying
should contact the secretary
Inez Malek (address and
telephone number on this page)

JOIN THE RED LION GROUP

* Free quarterly newsletter with all the latest news, views and events
* Membership is £10 (conc £5, free for hardship cases) per annum
* Write to Liaison Officer at the address above for a membership form