

Roar!



Issue number 13 • Summer 1999

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

Pouch Owners Relieved!

The problem with public conveniences is that they are rapidly becoming inconvenient – there seem to be fewer and fewer of them around.

For most people, the lack of public toilets is a bit of a drag, but for pouch owners it can be a serious problem. Many of us have had to dash in to use the loo at a restaurant, shop or hotel, with no chance to explain why the matter is so pressing (literally!). Some even find they hardly dare go out, in case they are caught short. Crouching behind a bush is just not an option when you have an ileo-anal pouch.

Well, help is at hand, thanks to one of our members.

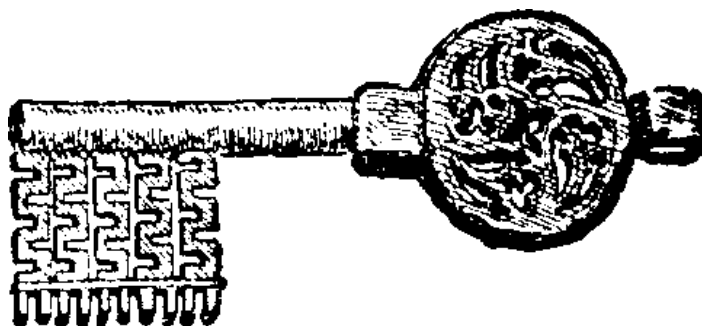
At this year's AGM, John Drasar mentioned that he has a key to gain access to the country's disabled toilets. This is because he is registered disabled, but he suggested we contact RADAR (who issue the keys) to explain that many people with an ileo-anal pouch would benefit greatly from being able to use these toilets.

So I wrote to RADAR a few days after the AGM. I sent them a copy of our leaflet with a couple of back copies of the newsletter, and explained our situation: that some pouch owners may need to use a toilet urgently, and many others would certainly benefit from having a bit more privacy to "do their worst" than your average toilet cubicle offers.

The director, Mr Massie, was most interested to hear of our work, and asked a few more questions, so that he had enough information to take to his co-directors, to enable

them to make a decision. For a few weeks, we waited on tenterhooks, but that decision has now been made.

Mr Massie writes: "I can see no



reason why your members should not have access to the National Key Scheme, and the toilets to which it provides access."

Point 4 of the NKS Code of Practice says: "Please note that it is not just wheelchair users who would need/could benefit from access to an NKS toilet. People who can walk but who have difficulties with stairs, people who have continence problems, people who may need to be assisted by a partner of the opposite sex, (and who therefore could not use 'ordinary' single sex toilets) such as someone with Alzheimer's Disease, and people who have visual difficulties (and who might find the cleanliness and extra space of great help) are just some examples".

So there you go. Official permission for pouch owners to obtain a key to use the disabled toilets. Of course, pouch owners should bear in mind that other users of these toilets may have priority on the basis of disability – pouch owners can use ordinary loos, whereas many registered disabled people cannot.

Keys can be obtained from some local authorities and also from RA-

DAR at 12 City Forum, 250 City Road, London EC1V 8AF. Mr Massie advises: "In the case of your members obtaining keys from RADAR it is important when they write to us

and send us their cheque that they enclose a note certifying that they are disabled. If they do not do so we are obliged to charge VAT."

Keys cost £2.50 with this declaration (or £2.94 if no declaration is made). There is also a guide listing over 4,000 toilets in the UK fitted with the NKS locks

which costs, £5. You must send your payment with your order, cheques made payable to RADAR.

So thanks to John Drasar for suggesting such a sensible idea – if you can think of any other matters we can take up on behalf of all pouch owners, please let me know.

Brian Gaherty

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Contact

Please send your replies to the person you wish to write to at the Liaison Officer's address (details on back page), quoting the reference number given on your envelope. Letters will be forwarded unopened.

I am looking for people (male or female) of around my own age (25) or in the London area who have a pouch and would like to talk or write to me. Please write to me in the first instance. Gillian Appleby, reference 0699/01.

I am willing to meet or talk to any people considering having pouch surgery. Jo Driver, reference number 0699/02 or telephone me on 0181 778 8216.

I would be happy to talk to anyone thinking about having the pouch operation. I know I have always found it useful to hear other people's experiences. Lorraine Howell, reference number 0699/03 or telephone 0181-723 4801.

I would like to make contact with any penfriends around my age (20-30

years) male or female, who have had the pouch operation. Jane Folkes, reference number 0699/04.

I would very much like to be a contact number for anyone wishing to speak to a fellow 'poucher', although I work too many unsociable hours to be a regional rep. Louise Marson, reference 0699/05 or mobile phone number 0421 358984.

CAN YOU HELP? I'm a female pouch owner hoping to have a baby. I would like to speak to any pouch owners who have had a post-pouch baby themselves about their experiences, including any difficulties in getting pregnant. Any tips you have about pregnancy or delivery will be gratefully received! Rebecca Davies, reference 0699/06.



Gala Auction 2000

Comments from some of the contributors so far

"I wish you every success with the event" - Claire Rayner, our very own Patron

"All good wishes" - artist Graham Clarke

"I can't imagine that you will be able to retire on the proceeds of such a souvenir, but I hope it might be of some help. Good luck with your event." - Piers Morgan, editor of The Mirror

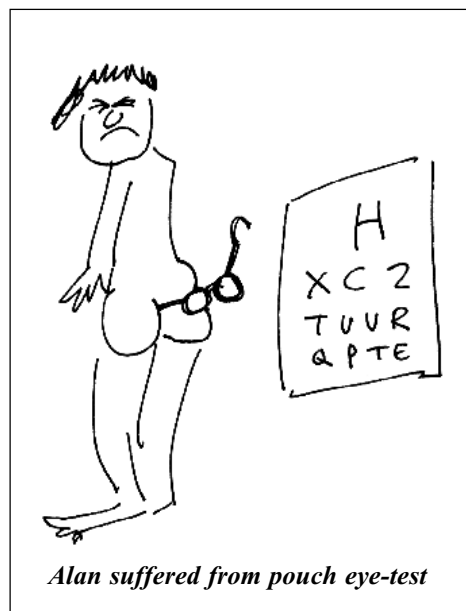
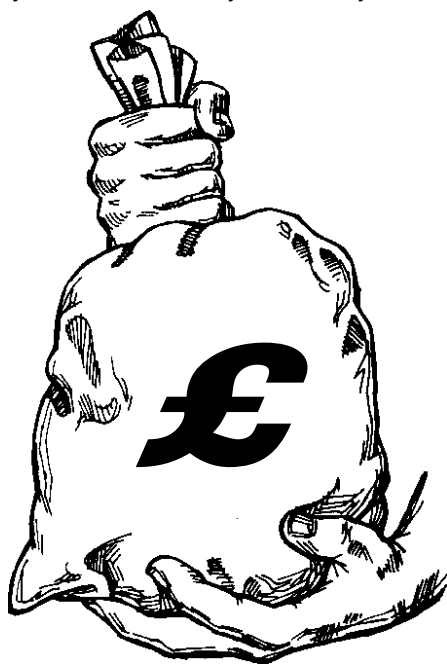
"[Mr Hague] read with interest the information about the work of the Red Lion

Group and sincerely hopes that you will be successful in raising considerable funds to further the work of

your charity, thereby helping those whose lives are enriched by it." - Tina Stowell, assistant private secretary to William Hague, leader of the Opposition

"I wish your association all the very best. When my father was 70 he underwent an operation for cancer of the colon which was, mercifully, ex-

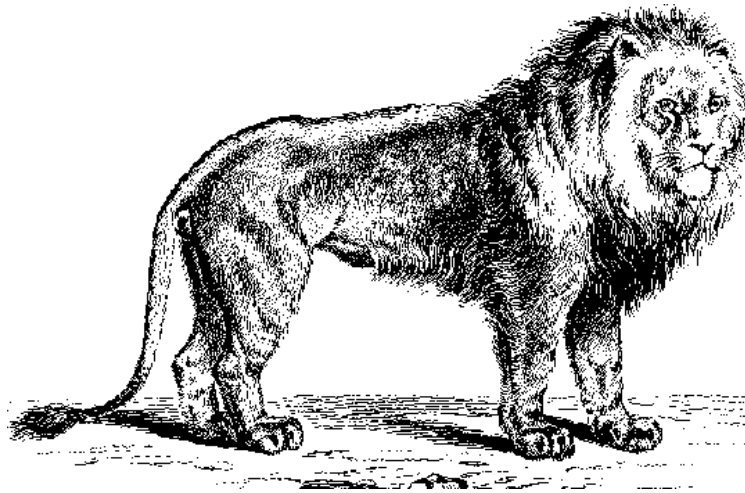
tremely successful. I therefore have a particular interest in your work and I do hope that all goes well for



you." - Ann Widdecombe, MP

"Lord Bath hopes that your auction will be a huge success" - secretary to the Marquess of Bath, Longleat House

We also have signed Red Lion logos from Tony Blair and Paddy Ashdown, making a hat trick of the three current party leaders!



Editorial

The 1999 AGM and information day was once again a great success, and thanks are due in particular to David Irving-James and Julia Williams, who worked so hard on the logistics. All the speakers were entertaining and interesting, and I am sure everyone learned a great deal. Thank you to everyone who contributed to the success of the day, in whatever capacity.

I certainly know more about toilet plumbing now than I did before 25 April, and I hope that the Lu-Fan will soon be available once more to make life more pleasant for pouch owners. For those who missed Margaret Ward's talk, you can find out more about the Lu-Fan on page 6.

There were only two logistical issues that we need to address for future years. The first is the number of people who booked places but did not turn up on the day. David Irving-James's article on page 4 has more to say about how we will solve this one next year. The other one is the question of toilets.

It is true to say that where two or three pouch owners are gathered in one place, the toilet facilities will be well used. When you have a whole convention ..., well you get the gist! Next year, a plan of the relevant area of the hospital will be included in the pre-AGM issue of *Roar!*, with WC facilities clearly marked, plus signposting on the day. Please do try to spread yourselves around a bit, to reduce the burden on the

plumbing!

I must offer an apology to members that the diet survey results did not come out with the last newsletter. We received so much information, that it was impossible to analyse it all in time. As you will see from the results from page 9 onwards, there is no one answer – what works for some does not work for others. But by being informed, you can work out what foods work best for you. Please also take the time to complete and return the survey on steroids included with this newsletter. Even if you do not use steroids, we would like to hear from you.

Scarring is a highly relevant subject for pouch owners, and we have not one but two articles on this topic this quarter, one reproduced from the Sunday Times Style section, and one summarising an article in another publication, What Doctors Don't Tell You. This latter article has some suggestions on how to reduce your scarring – we can't promise it works, but if this is important to you, you might like to give it a try.

There is so much in this issue of the newsletter, that I do not have space here to mention it all. I suggest you get reading, and find everything for yourself. However, here are a few pointers.

We have at last got a Contacts page up and running, as you can see on page 2. Please do write in if you would like to put something in this

section.

Whilst on the subject of writing in, let me remind you that you can get hold of me via e-mail at gaherty@cwcom.net. We will soon be storing e-mail addresses on the database, as this is a popular method of communication, so do e-mail me with your details. I know there are a lot of internet users out there, which is why we have started a section listing useful-looking internet sites for you to visit.

My favourite is the Creative Couple's Colitis Cookbook site (with a book available for order). We have obtained permission to reproduce recipes from the website in future issues of the newsletter. I do hope you enjoy these.

We get many positive comments about *Roar!* from stoma nurses and other pouch support groups, for which we are very grateful. However, we are always keen to hear from you, because it is your newsletter. Tell us what you would like to see more of (or less of), and take the time to write something for the newsletter: an article about your experience, a letter, a poem, a cartoon – whatever. Or maybe you have found an interesting piece that we could reproduce or précis – cut it out and send it to me.

To those who have told us how much you enjoy *Roar!*, thank you. It is important to us that the newsletter is both interesting and fun – worthy but dull is not our style!

Morag Gaherty

Scar Issues

Dr Roger Henderson gives the low-down on scars.

Reproduced with kind permission from On Call with Dr Roger Henderson, Sunday Times style Section 2 May 1999.

If we injure our skin it will scar. This is completely normal and the severity of the scar depends on the initial trauma, although most tend to fade over a period of about two years. However, it is very important to remember that scars are for ever. The skin will never be quite the same again and hair follicles and sweat glands are not replaced.

Of the many types, hypertrophic (red and raised) scars are among the most visible and are most common in younger people. Keloid scars are similar but commoner in people with dark skin, although anyone can suffer from this type of scarring. In both types, the problem is the altered production of the protein collagen that is used by the body in healing. The scar therefore becomes

red or dark, raised and may be intensely itchy. If you are prone to this, your doctor should be told before you have injections or any sur-



gical procedures. Both differ from the usual pale, flat scars that occur when the body heals normally, although, initially, these can be red and raised as well.

There are many possible treatments for scars now compared with

20 years ago; however, nothing can permanently remove them. Keloid and hypertrophic scars sometimes respond well to courses of steroid injections, which flatten and soften them. Laser treatment is sometimes used to reduce a scar's colouring, but evidence of its efficacy is anecdotal, as few good long-term studies have been done.

Collagen injections are becoming rather fashionable, but the effect of these is only temporary and there is a risk of allergic reactions. Silicone gel sheets are available at pharmacies and claim to reduce scar size and redness after a period of two to four months. They may have a place in medical treatment, but seek medical advice first. If you have a scar that distresses you, ask for help – you are not alone.

The Scar Information Service, PO Box 2003, Hull HU3 4DJ (0845 120 0022)

Who Claire Wins

David Irving-James points out that for the annual general meeting it's not just quality – quantity matters too.

"The best all round Day so far and I'm a veteran of AGMs. Well Done. Lunch was most sensible this year. Claire Rayner should be a permanent fixture on question time."

And

"Thanks to all the Committee for another stimulating, interesting and educational day."

These were just two of the comments about the day. There were many others in the same vein, for which I am sincerely grateful. The day was a great success, however it is with great disappointment that I have to write on the following subject:

Out of the 134 members and guests who indicated they would be attending, only 85 turned up on the day. 49, or 36%, of our members and guests failed to attend. Most of these did not contact any member

of the Committee to inform us of their change of plan, whether in advance or in retrospect. I do not know whether some were put off by the tube problems earlier in the day.

Organising such an event is enjoyable and rewarding, but it is not as easy as some might think. Knowing the accurate number of those attending is crucial. This allows us to organise the venue to its best advantage, but above all else, it allows us to accurately forecast our feeding requirements. It might surprise some of you to know that the sum of £12 per head was charged for tea/coffee and the meal. This was kindly paid for by Dansac, who support the Red Lion Group's AGM and information day.

Although the invitation did not expressly state that cancellations should be notified (which it cer-

tainly will do next year!), it is both courteous and customary to do so. Even 48 hours' notice would have allowed us to adjust the catering accordingly, and this would have saved Dansac a staggering £588 (12 x 49). Although we are not ourselves paying, we will soon lose the support of Dansac if we continue to abuse their generosity in this way. Quite apart from the cost, the food left over was simply wasted.

And of course, being so tight on (booked) numbers, we had to turn away people who desperately wanted to come. Those people could have come, if we had known what would happen. I was particularly disappointed at the couple who made such a fuss about insisting on coming, when we were already over numbers, who then did not turn up, even though we had made arrange-

Letters



Roar! Letters Page

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Dear Newsletter Editor

I suffered with all of the symptoms that Donna Swift from Portsmouth is suffering, as you printed in your last newsletter. I was advised to try 'Comfeel Barrier Cream' after every visit to the toilet and 'Anusol' cream at bedtime (both of these I get on free prescription). They worked very well for me.

Anonymous

Dear Newsletter Editor

Having read Donna Swift's letter about how she has problems having the pouch, I find myself hav-

ing every sympathy with her. I also seem to walk about most days half asleep and all washed out through rushing back and forth to the toilet at all times of the day and night. I sometimes wonder if I'd had the bag instead of the pouch my lifestyle would have been a lot better. I took the pouch because I couldn't face having a stoma sticking out from my body so when I was told about the pouch I jumped at it. I'd also like to find out if any of your readers had the pouch fitted all in one go, as I've often wondered if that's the reason for my discomfort during the days and nights since my operation in Edinburgh Royal Infirmary in 1994.

George Scott
Perth

Ed: According to Julia Williams at St Marks, all the literature indicates that there is no difference in function between one stage and multiple stage operations. Problems are more commonly related to the choice of design of the pouch itself. Having said that, of the members on our database who have reported ongoing problems, many of these had pouches made in one stage. The experience of the surgeon is, of course, also a factor to be taken into account.

Dear Newsletter Editor

In reply to Donna Swift (Spring Roar!), I do sympathise. I have had a very rough time since my reconnection in August 98, but now, in May 99, I am beginning to feel that it has been worth it. I still have bad days, especially with trapped wind and the attendant soreness from

going to the loo too often in an attempt to free said wind, but looking back I can genuinely say that I am getting better at last. It sounds as though Donna may never have had an ileostomy, so has nothing to compare the pouch with. Yes, I felt very well with an ileostomy, but it is depressing to look forward to a lifetime of kneeling in front of dubious loos, and to a permanent disfigurement/disability. My advice to Donna (the same as other people have given me when I was desperate) is be brave, slap on the barrier cream, take the painkillers and believe that it will get better - though nowhere near as quickly as you thought it would before the operation!

Charlotte Barney
charlotte@duntish89.freemove.co.uk

Dear Editor

Please can anyone help? I have just completed a degree course and am now faced with job applications. How does a pouch patient write about their medical condition and its requirements (loo access) on a CV, without putting off a prospective employer at the outset?

Yours sincerely
Sarah Robinson
Doncaster

Ed: We are planning to do an article in a future newsletter about this very topic, and would welcome comments from any pouch owners about their experiences and views. Contact me direct, and I will pass on any tips and letters to Sarah, so that she can get on with her job hunting in earnest. Best of luck, Sarah!

ments for two members of the committee to vacate the theatre to make way for them.

I believe that part of the problem stems from the fact that we do not charge for the AGM, as this would put the day out of reach of the pocket of some members, what with travel and parking costs. However, in view of what has happened, the following procedure will be in

operation next year:

You will be asked to send a returnable deposit of £12 per person when booking your place at the AGM/information day. Your cheque will not be cashed but will be returned to you when you check in. If you give 48 hours' notice (or a good reason for non-attendance without notice), it will be returned to you by post. Anyone who fails to

turn up and has not warned us of this will have their cheque cashed, so that Dansac can be reimbursed for the wasted food.

I am sorry to have to have to do this, but this is the fairest way I can devise without asking people to pay.

To those who did attend, it was lovely to see you. The efforts of the Committee were greatly rewarded by the fact you enjoyed the day.

How we got rid of the Smell Problem

Margaret Ward's life has been transformed by a little piece of gadgetry



In the early '90s, when we had not even heard of ulcerative colitis, my husband spotted an advertisement in one of those through-the-door magazines.

It was for a piece of gadgetry which would sit inside a WC cistern and remove noxious smells from the loo or bathroom.

He had come across one such in Austria and had been very impressed, so we ordered one and fitted it.

We found that our Lu-Fan was as useful for what it did not do as for what it did do: it removed smells from the WC pan, but it did not remove the centrally-heated air from our bathroom. A smell-free, always-warm-in-winter bathroom – splendid!

This happy state of affairs continued for about eighteen months when the fan became less effective. Inspection revealed that a small rubber flap-valve had become hardened. It was intended to cover and seal a hole while the fan was not operating, and was no longer re-seating itself properly.

My husband found an alternative material for the rubber, fitted a new flap, and it has worked without any further trouble since.

In 1997, UC struck. It very quickly became apparent that one loo was no longer enough – especially as it was in the bathroom. So we installed a second one with a Saniflo system in a bedroom corner, boxed in to make an en-suite loo. Needless to say, we fitted another Lu-Fan (with modified flap-valve) and have been very satisfied with the result.

We now enjoy a more pleasant atmosphere, and can entertain visitors – staying briefly or for a longer period – without a second thought.

The Maxview Lu-Fan: Practical Details

Fitting

1. A competent DIY person, or a plumber/electrician is needed.
2. You will need the following tools: junior hacksaw, bradawl, screwdrivers (terminal and Phillips), Stanley knife, fine sandpaper, pencil.
3. Full instructions and guarantee included.
4. Fan operates at 10 volts.
5. The voltage-transformer (supplied) can be fitted in an adjacent airing cupboard or bedroom

room where there is a mains supply.

6. If fitted, the cistern's ball valve needs to be replaced by a quiet valve (eg Torbeck, Armitage Shanks) to make room for the Lu-Fan.

Cost

1. Initial cost in 1992, approx £50 including a Torbeck quiet valve, bought separately.
2. Running cost approx £8 per year, assuming 10 visits per day at ½ hour per visit.

Other

1. The Lu-Fan is fitted inside a low-level cistern and takes air from the pan up the water pipe into the cistern. From there, it goes out of the overflow pipe to the open air.
2. We extended the overflow pipe from our second cistern to an outside wall and piped both the overflow and the breather pipe from the Saniflow unit into it.
3. The unit is invisible except for the touch-switch, mounted on the external wall of the cistern.
4. The fan runs for approx 4 minutes, then switches itself off; it can be switched on again immediately if required.
5. We converted our touch-switches to toggle/rocker switches to give continuous running.

The Lu-Fan is reasonably quiet – barely audible outside a loo or bathroom.

The company making the Lu-Fan has them in stock, but they need to modify the valves before offering them again for sale. They are in the process of making and testing trial valves, and hope to have the product back on the market soon..

Enquiries should be made to Peter Johnson, Maxview Ltd, Setchley, Kings Lynn, Norfolk (tel 01553 810376), mentioning this article.

Better the Demon You Know...

Tony Turtle shares a few tips about life as spouse-of-pouch

As experienced pouch-pairs will know only too well, the first few months of coping with the new addition can be sheer hell. This food goes straight through, that foods slows it all up too much. And as for beer... Ha!!!! For someone as stubborn as my wife Sally (her description, not mine), it is a big change having to restrict the diet. For someone as adventurous in the kitchen as I am (and he is a good cook - Sally) it's the biggest challenge possible.

The change from being brought up knowing when you need to go to the loo to suddenly

needing "Nappies" just in case can be downright degrading. Soiling the bed or your clothes, without having felt the need to go, can bring the Demon Depression flying out of its hiding place!

That's the Demon, creeping up behind you and jumping out just when you didn't expect it and it does not just aim itself at the pouch owner but targets the spouse-of-pouch as well. Still, as Sally keeps reminding me in the long gaps between the Demon's appearances -

"It lives with you, not you with it!"

Still, having got the Demon firmly put into it's rightful place (buried about two miles deep on the surface of Pluto preferably), you



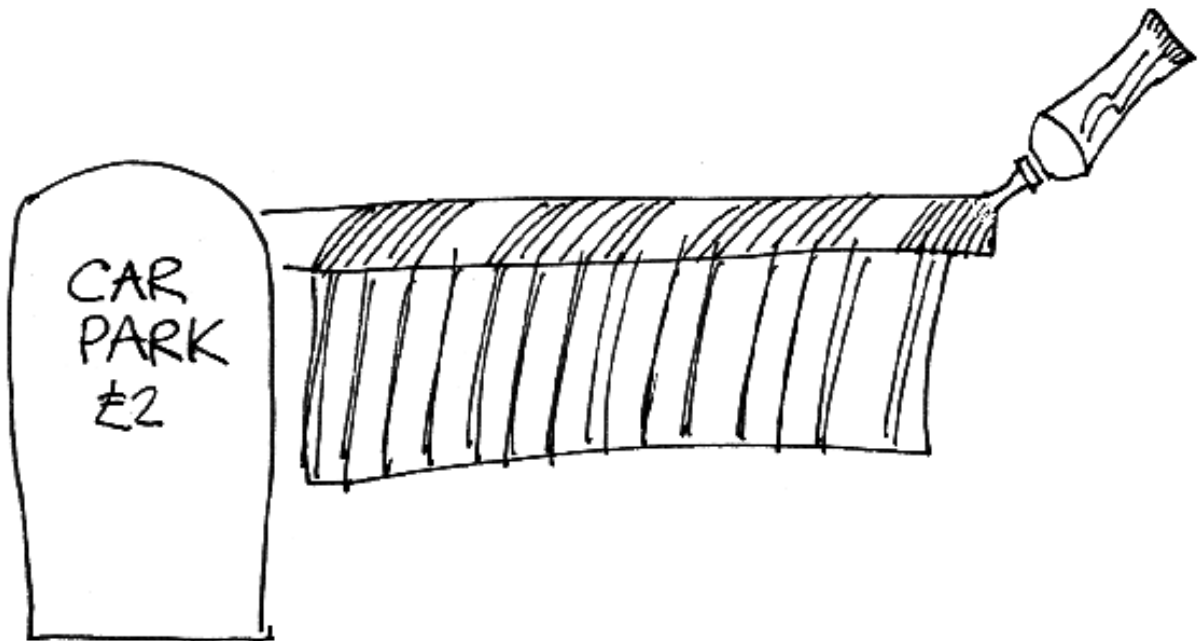
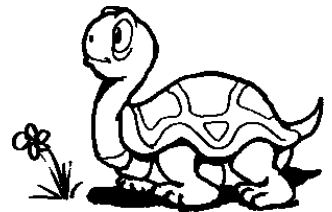
then have to look into feeding the pouch. I am sure that many of you will have discovered that "pouch" actually stands for Permanently Open Unfillable Constant Hunger, because of the little but often method of feeding needed to satisfy this creature seldom encountered out of the tight-knit social group in which it lives.

First, take a very minimalistic

shopping budget (as I am now on incapacity benefit, thanks to arthritis aggravated by pushing her around the hills of Hastings in a wheelchair for six weeks!) and a greatly reduced shopping list (take a chair into the supermarket to sit on while you read the contents lists to avoid the no-no items). Then it's a case of trying out a variety of meals (one at a time!).

While I am talking of food, a bed of boiled white rice topped with some plain fried minced beef or lamb into which a large quantity of ketchup had been mixed was, and still is, our staple emergency meal.

If the owner of the "little f(r)iend" liked spicy foods before the op - sorry, but it may take a long time to slowly build up to something they can handle. "Slow and Steady wins the day" as the Turtle said to the Hare!



John was seriously considering changing his brand of barrier cream

Tips from members

Some of these comments come from your membership forms, as these give us a great deal of information which could be of value to other members. So you may recognise your name and not remember writing to Morag!

- Colpernin capsules worked wonders for my cramps. (Alistair Laird)

- When I was pregnant with my second child [before having a pouch], the ante-natal people were very ill-informed about colitis and steroids and gave me conflicting advice. I don't know if they would be any better informed about pouch surgery, and whether they would understand what care would be necessary. Also, my skin gets very sore, but I use "Comfeel" prescribed by my GP, which helps. (Dawn Lanham)

I started having trouble after

my third operation. It took us two years to discover that the pouch had fallen and formed a kink in the works. Now I use a catheter to release wind and stool. (Alison Lawford)

- Suspect irritants for me include milk, fizzy drinks, chocolate, spicy foods, raw veg, citrus fruits, beans, peas and cabbage. I also find Orabase cream ideal for treating affected skin. I also drink plenty of fresh water. (Robert Mitchell)

- I have found that taking charcoal tablets really does help with the problem of painful wind. (Glenis Plumridge)



Internet News

If you have access to the internet, check out some of the information you can get – and if you know of any sites worth visiting, drop the newsletter editor an e-mail on gaherty@cwcom.net.

www.MedicineNet.com

"A network of doctors who produce comprehensive, up-to-date health information for the public. We strive to bring a doctor's perspective to important medical issues. Our goal is to be comprehensive, easy to use, and responsive to our viewer's needs.

We invite your participation. Interact with us often, and don't forget to bookmark us."

Editor's comment – very comprehensive and easy to navigate, without too many graphics to slow things down. There is a forum page for each topic, hotlinking through to relevant topics plus a huge medical dictionary.

www.j-pouch.org/diet.html

Dietary guidelines from the J-Pouch website. Very detailed – suggestions about foods at different

stages of surgery, what may irritate, what may cause gas and odour, what may increase output etc. Worth a look. The J-pouch site is particularly aimed at pouch owners with (not surprisingly) a J-pouch, but the diet tips are useful to all pouch owners.

www.colitiscookbook.com

Ross and Denise Weale, professional chefs, have written a cookbook especially for the kinds of diets many of us contend with. Ross himself suffers from ulcerative colitis, which was why they wrote the cookbook. The site includes 14 recipes on line, plus an index listing of the cookbook which you can send off for. There is also a quarterly e-zine with regular recipes. And all the fan e-mail they have posted indicates their recipes are indeed delicious.

Recipe Corner

Pink Grapefruit Sorbet

Serves six

1½ cups sugar

1¾ cups water

1 tbs grated grapefruit zest

1¼ cups freshly squeezed pink grapefruit juice

¼ cup lemon juice

1 egg white

Combine sugar, grapefruit zest and water in a medium sauce pan and bring to a boil. Remove from the heat when the sugar has dissolved. Add the pink grapefruit juice and lemon juice.

Transfer sorbet mix to a storage container and refrigerate for six hours. Add lightly beaten egg white to mixture and combine thoroughly.

Freeze sorbet mixture in a ice cream maker according to manufacturer's instructions. Place sorbet in a sealable container and put in the freezer for 2 hours before serving.

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

Diet Survey Results

As expected, this survey produced an avalanche of replies – 131, to be precise. In fact, there was so much information that it was not possible to analyse it all in time for the last newsletter. Some of the helpful suggestions received will be included in the Autumn 1999 Tips from Members section of the newsletter.

The Diet Survey comprises effectively two sections: the first deals with what foods help or hinder your pouch, while the second deals with how healthy your diet is on the whole. The following analysis deals with the first aspect only, as the second needs a much more thorough computer-based analysis if we are to derive any themes relevant to pouch owners from it. That is a project for another day and will appear in a future issue of Roar.

Before moving on to the results of the survey, I should also like to mention that there will be an excellent article on regaining good bowel control in the next newsletter, reproduced from the newsletter of the University of Texas MD Anderson Cancer Centre. It is clear that some of you have learned to accept a relatively poor quality of life in terms of bowel function, and I strongly recommend considering following the programme outlined in that article, with the assistance of your healthcare professional. The author writes: "There is all the reason in the world to believe that your bowels can be managed after colorectal surgery". You may not believe her now, but read what she has to say with an open mind.

If you cannot wait for the next newsletter, please contact me with an SAE and I will send you a copy of the article in question, so that you can get cracking. One pouch owner who has tried it went from 10 visits every 24 hours to 7 every 24 hours in just one week.

And so back to the survey. To start, I must thank the contributor who inadvertently provided light relief with the words: "I have tried eating my maid at midday, but there

were no noticeable effects." Either the mind was too far ahead of the pen, or one of our members has a very unusual diet.

The most important thing that came out of the responses was that – aside from a few general themes – there is no one approach that works for everyone. Everyone's reaction to foods is highly individual, and just because one person finds something causes them trouble (or helps them) does not mean another will have find the same effect. Different people have different sensitivities.

It is all trial and error, and the longer you have your pouch, the more you will learn about how it works for you. This article can give you a few ideas about areas to explore, but should not in any way be taken as a list of Do's and Don'ts. Also, you will find as the years go on that your pouch function improves, and so foods that were impossible six months after surgery may well be perfectly OK two years down the line.

What you must try to do is to eat a balanced diet and not become too restrictive about what you eat. One of our members eats a diet heavily influenced by crackers and marshmallows, but has no idea what effect this has on pouch function, because it was something adopted almost from day 1. This sort of restrictiveness, on the whole, is not a recommended approach, even though I understand the desire to stick with a formula that works.

Joy Notter's survey on quality of life issues some time ago found a shocking level of acceptance of a mediocre or even poor quality of life by many pouch patients. Please do not be fobbed off by healthcare professionals who tell you that this is what you must accept (and we know they exist). There are many possibilities to explore before you should consider your output beyond improvement.

Q1 What was your original illness?

As expected, the bulk of respondents had a pouch as a result of

ulcerative colitis (115 replies), with the next largest group (7 replies) being polyposis patients. Other illnesses mentioned were rectal cancer, colon cancer, rectal ulcers, proctitis, Crohn's and EB virus.

Q 2 When you first saw your GP regarding your illness, were dietary considerations discussed at all?

Sadly, but not surprisingly, 109 (or 83%) or you replied No to this, with only 20 (15%) replying Yes. Two respondents did not answer this question. It will be a long time before GPs start to think in terms of mitigating illness by optimising diets unless more on nutrition is added to their own medical training.

Having said that, during the course of the survey, a few respondents made comments such as: "I eat smallish portions but find tiredness plays a bigger part than food."

Q 3 Have you been able to control your medical condition/reduce your dependence on medication at all using dietary factors alone?

25 (or 19%) of replies answered Yes to this, with 88 (67%) No's and 18 (14%) left blank. Clearly, diet alone is not the solution in all cases. However, as mentioned earlier, bowel control after colorectal surgery can be relearned in many cases, and so pouch owners should not assume that they will be dependent on medication for ever onwards. Once bowel control has been regained, diet certainly can help you regulate the amount of fibre etc that you need to keep pouch function optimal.

Q 4 Have you discussed your medical condition with the hospital dietician or other nutritionist?

Knowing how pouch patients love to discuss their diets, it does not surprise me at all that 61 (47%) of you have taken the trouble to talk about nutrition with a qualified professional, and that initiative should be applauded.

However, 66 (50%) of you have not and a further 4 made no comment, which implies that they have not either. This being the case, how

can 88 of you say you have not been able to reduce your dependency on medication using diet (Q2)? You won't know until you find out, so I recommend you talk to your hospital dietician or other nutritionist as soon as is convenient. They are there to help you, so use them.

Q 5 Have you consciously looked into dietary factors affecting your medical condition?

89 (68%) have looked into the link between pouch function and diet, while 41 (31%) have not. Bearing in mind the answers to Q3, most of this research must have been conducted on a trial and error basis. Hopefully, this article will go some way towards pointing you towards potentially rewarding avenues, by letting you know just what has and has not worked for others.

Q 6 Do you eat regular meals?

We received many comments to the effect that pouch function is best improved by keeping to a regular mealtime routine, and the proof of the pudding is that a whopping 122 (93%) of you do eat regular meals, and only 9 (7%) do not.

Q 7 Do you drink fizzy drinks with your meals?

Most (95 or 72%) of you prefer to avoid the combination of fizzy drinks and meals. As we shall see, a lot of you suffer from more liquid output or wind from drinking fizzy drinks in particular. 36 (or 28%) do combine food and fizzy drinks at least occasionally, and I assume that these people do not find a strong reaction, for the most part.

Q 8 Since your operation, have you experimented with food that you previously avoided due to your condition? If so, please identify the foods/drink in question and what has changed

This question could provide the basis of a survey all on its own, and we will look at the comments made by people in this connection in a future issue of Roar. 59 (45%) of you answered Yes, while 50 (or 38%) said No. 22 (17%) gave no answer at all.

The No's (and those who did not complete this question at all) fall into two categories: those that did avoid foods pre-operatively and

have chosen not to experiment post-operatively, and those that never avoided any foods pre-operatively anyway.

Results were very mixed. Many people noted that they are able to eat foods post-operatively that caused them problems before. Others found that foods which previously gave them no trouble suddenly caused a new reaction.

The best advice is to experiment and – if the first attempt at reintroduction does not go well – to leave it for a few months and then to have another go.

A second attempt may well have a very different result, especially if the pouch is new, and so continually improving. Also, of course, if wanting to try something like spicy food, it makes sense to introduce it gradually, not to have a huge portion the first few times.

And so onto the questions you will be most interested in: the causes of liquid output, irritation and wind, foods that don't digest well and foods that settle the pouch

The answers given depend on the kind of diet you have (one, for instance, was very specific on the effects of jelly babies, chocolate and other sweets!). Also, some of the comments made are very specific whereas others may be very general: eg one person might write "broccoli, cabbage, cauliflower" whereas another might just write "green vegetables". Additionally, of course, the person who only mentions one food might well suffer similar effects from a related food, but does not know this because they have not tried it.

You should also bear in mind the fact that, a particular food may get a disproportionate number of mentions in that if it is mentioned (for example) as causing anal irritation, it will normally also cause pouch irritation and maybe wind as well.

For these reasons, therefore, it is not appropriate to analyse the number of times a food is mentioned in percentage terms. Instead, I will indicate common themes by detailing foods that cropped up frequently. I will also list the "oddballs"

- items mentioned by only one or two individuals, but which might be ideas worth trying.

You should also remember that what is understood to be "good" varies – if you are prone to blockages, a more liquid output may be welcome, whereas most pouch owners are interested in how to thicken their stool.

A number of people commented that smaller meals are best, and that large meals seem to cause bloatedness, cramps or wind. Routine and moderation in food matters, on the whole, seem to suit a large number of pouch owners.

Finally, a number of respondents were clear about what was actually best for their pouch function, but were either unable or unwilling to follow such a diet regimen. The best time to eat, for instance, may not fit in with your pattern of employment.

Q 9a Passing undigested food

Undigested food on the whole results in one of two things: it either goes straight through, or it causes blockages. The second of these is generally more serious, as a bad blockage can result in hospitalisation.

Small things, chiefly nuts, sweetcorn, peas and mushrooms; also seeds, sultanas, rice, currants, raisins, pulses tomato skins, potato skins and apple peel. However, the main culprit with these is not the fact that they are small but the fact that most people do not chew properly. Try to sit down at the table in order to eat in an unhurried manner, making sure to chew properly.

High fibre low starch foods, mainly salads such as lettuce, peppers, beansprouts, celery, carrots, tomato and beetroot; also bran

New pouch owners should also be aware that beetroot passes through the system very quickly (1½ hours noted by one pouch owner) and your output turns an alarming shade of red, which is all too easily confused with blood!

Less commonly mentioned were:

Raw or undercooked vegetables

Bean family: broad beans, green beans, beans in general

Other vegetables: broccoli, aubergine, cabbage, onion and spinach

"Oddballs": chips, fish, meat, prawns, anything stringy, anything solid, some Chinese food, some foods not chewed well and Guiness

Q 9b Anal irritation

Spicy foods such as curry, spices and chilli

Nuts, peppercorns, seed, pips and pulse skins

Less commonly mentioned were:

Tomatoes (probably the seeds)

Red wine

Fruit juice, particularly orange or grapefruit; fruits, in particular citrus fruits but also strawberries

Rich foods: chocolate, Christmas food, rich sauces, sweet things, cheese and too many fatty things

Fibre: wheat cereals, bread with wheatgerm, too much roughage, cereals, high fibre cereals and wholemeal bread

Vegetables: asparagus, onion, cabbage, broccoli, garlic, mushrooms, salad and sweetcorn. It is important that vegetables are sufficiently well cooked, so that they digest easily in the body.

"Oddballs": alcohol, beer, garlic bread, fish, tinned fish, prawns, soya meals, crisps, fizzy drinks, some medications, coconut and acidic foods.

One of our respondents writes: "Re anal irritation - my best guess is marginal imbalances in alcohol levels or foods which perhaps slow down movement too much without absorption can cause higher acidity levels in stool which burns. May be related to mild infection." Another found that "anal irritation is usually caused by wind."

The person who listed prawns, coconut, pineapple and asparagus as culprits for anal irritation clearly has a more varied diet than most of our members!

Irritation from vegetables usually seems to be related to excess consumption, or undercooking. A longer cooking time also fits in with latest theory about digestion being better if foods are cooked longer, because this breaks down cell walls.

Bearing in mind the lack of colon, part of whose function is to break foods down, this would seem to be particularly relevant to pouch owners.

Q 9c Thickened stool

Starchy foods: bananas, potatoes, rice, porridge, pasta and marshmallows were mentioned most frequently. One pouch owner eats 10 marshmallows before going to bed as she finds this prevents or at least lessens night time leakage. Another respondent has a banana after lunch every day. Also: mashed potatoes, chips, bread (some specify white, some specify brown), noodles, polenta, pastry, Yorkshire pudding, semolina, rice cakes and stodgy puddings.

Less commonly mentioned were:

Vegetables, particularly if well cooked: parsnips, spinach, cabbage, carrots, sweet potato, globe artichoke (with the comment "excellent"), swede, sprouts and cauliflower.

Fibre: oat flapjacks, oatcakes, shredded wheat, cereal, peanut butter and oats

"Oddballs": lentils, mushy peas, gravy (!), jelly babies, jellies, drink with meal, some medication, well balanced meals, large meals, meat, red meat, roast dinners, chicken, fish, boiled eggs, fennel, alcohol, plain cake, cheese, fruit

Q 9d More liquid output produced

Liquids: fruit juices, soup, drinking with meals, alcohol, liquid food, more than 3 pts liquid daily, fizzy drinks, beer, (red) wine, spirits, gravy, lager, coffee, Guinness, tea, coke and orange juice were all given as examples

Chocolate

Less commonly mentioned were:

Fatty foods (possibly dairy products): butter, cream, milk intolerance, sauces, mayonnaise, fried food, cakes, biscuits and pastry

Fruit: rhubarb, raisins, sultanas, if eaten without other food, melon, oranges, grapes, watery fruit, citrus fruits or excess consumption

Vegetables and especially salads: onion, raw or undercooked veg-

etables, lettuce, tomatoes, greens

Protein foods: pork, chicken, minced beef, roasts, ham, fish, hering, mackerel, boiled eggs, cheese

"Oddballs": dairy products, picking between meals, lots of exercise, skipping meals, nuts, indigestible food on an empty stomach

Q 9e Pouch function slowed/decreased urgency

The information listed here largely mirrors that given for thickening stool.

Starchy foods: pasta, rice, bananas, potato, marshmallows, bread. Also: porridge, mash, chips, cream crackers and sandwiches were listed

Controlling the way you eat: not much eaten, long gaps between meals, light meals, proper meals not fast food, reduce liquid intake, mild or plain food, plain boiled food, well balanced regular meals were all suggestions made

"Oddballs": vegetables, some root vegetables, cooked carrots, aloe vera, milky drinks, cheese, thick yoghurt, eggs, alcohol (*), red wine, spirits, Chinese curry with fried rice, cereal, "low residue cereal products", roast dinners, fatty foods, fish, meat, fruit, jelly babies, jellies and wine gums

(*) Well this is one justification for drinking more than 28 units a week, as one of the pouch owners who listed this does!

Q 9f Pouch function speeded up/increased urgency

The information given here largely mirrors that given in respect of more liquid output.

Liquids: Too much liquid, alcohol, lager, wine, red wine, beer, bitter, tea, caffeine, strong coffee, fizzy drinks, fruit juice, orange juice, soups, vegetable soup, gravy

Vegetables and salad: potatoes, root vegetables, cooked vegetables, excess consumption, green or leafy vegetables, cabbage, raw or undercooked vegetables, garlic, "delicate" vegetables, tomatoes, peas (especially), cauliflower, sweetcorn, beans, baked beans and onions (especially) were all specifically listed

Less commonly mentioned were:

Protein foods: spicy foods, curries, stews, beef, red meat, fish, textured vegetable protein

Fibre or starch: high fibre foods, bran, wheat, flapjacks, porridge, muesli, wholemeal bread, brown rice

Fruit: raisins, sultanas, grapes, mixed fruit, red/blackcurrants, citrus fruits, oranges, too much fruit

How you eat: eaten a lot, snacks between meals, eating often

Fatty foods: chocolate, fast foods, cake, fried foods, fats, rich foods with sauces, oily salad dressing

Dairy products: cheese, milk, cream, ice cream, sauces

"oddballs": spices, spicy or salty foods, acidic food eg pickles, sweets, exercise

One person finds that urgency increases as the day goes on, regardless of eating habits. This may be related to increased stress as the day progresses.

Q 9g Pouch settled

How you eat: plain foods, regular meals, balanced meals of bulky food, small portions, general balanced diet, moderation and eating starchy foods, not eating were all suggested

Starchy foods: rice, pasta, porridge, potatoes, boiled potatoes, mash, cereals, banana, cornflakes, cream crackers, white bread

Less commonly mentioned were:

Protein foods: white meat, ham, chicken, roasts, fish and chips, fish

Fluids: lots to drink, water, mint tea, scotch

Dairy products: yoghurt, cheese, cooked cheese, milk, skimmed milk

"Oddballs": apples, no vegetables, stir fry vegetables, bedrest, white wine, jellies, ginger, fennel, globe artichoke

As a general rule, it seems that plain starchy foods are the most likely to be effective in settling your pouch, with white meat and fish being better than red meat.

Q 9h Irritated pouch

Spicy foods and spices: curry, Chinese, monosodium glutamate, spices, vinegar

Fatty foods: fried food, processed food, rich sauces, fatty meat

Vegetables: onions (especially), broccoli, garlic, lettuce, cabbage, green vegetables, beans

Small things: nuts, black peppers, sweetcorn, peas, lentils, potato skins, mushrooms, coconut, muesli, some salad skins

Liquids: alcohol (especially), fizzy drinks, excessive drinking, red wines

Less commonly mentioned were:

Dairy products: chocolate, ice cream, cream, milk, cheese

Fruits: acidic fruits, fruit juice, apples, pears, raspberries, citrus fruits, oranges, rich fruit products

"Oddballs": red wine sauces, irregular meals, missed meals, having a cold (2 respondents), fruit cake, mince pies, wheat, oats, barley, rye

One person mentioned that curry irritates his or her pouch, but not if yoghurt is added.

One (obviously female) respondent blamed her irritated pouch on her menstrual cycle. Then she admitted the real culprit, which she craves at this time of the month: chocolate!

Q 9i Wind increased

Liquids: fizzy drinks (especially), alcohol, fizzy lemonade, liquid with meals, red wine, water

Vegetables: beans, onions, cabbage, green vegetables, peas (all these five especially), sprouts, cauliflower, baked beans, broccoli, garlic, pulses, sweetcorn, potatoes, parsnips, carrots, pickled onions, kidney beans, green beans, lettuce, salad, chick peas, lentils, mushrooms

Less commonly mentioned were:

Dairy products: cheese (especially), eggs, full cream milk, semi skimmed milk, milk, chocolate

Protein foods: curries, hot spicy foods, fish, red meat, lamb, soya meals

Fatty foods: very processed foods, rich foods

How you eat: missing meals, too long between meals, eating too much

"Oddballs": acidic food, pickled onions, nuts, fruit, apples, spices, popcorn, fibre, wheatflakes, pizza

One pouch owner finds full

cream and semi skimmed milks increase wind, but uses skimmed milk to decrease it. Another finds that red wine increases wind, but still drinks more than 28 units a week, so clearly finds it a price worth paying. Whether his family would agree is a different matter!

Q 9j Wind decreased

Starchy foods: potatoes, pasta, bread, rice, stodgy foods, crispbread, cornflakes

Avoiding vegetables: sprouts, onions, cauliflower, green vegetables, beans, pulses, cabbage, potatoes, chips, salad. Many of these are known wind producers even for non pouch owners.

Less commonly mentioned were:

Liquids: skimmed milk, hot sugar water, excess alcohol (drinking not avoiding), bland drinks such as milky tea, peppermint tea, avoiding fizzy drinks

Low fibre food

How you eat: small amounts of plain foods frequently, eating little, plain or bland foods

"Oddballs": yoghurt, low fat cottage cheese, chicken, avoid fatty foods

All of the above should give you a few ideas to consider what foods to try and what foods may be the cause of your discomfort if you have not already identified these.

As I have said, it is important not to fall into a restricted diet simply because you assume you will not be able to eat certain things: there are no fixed rules, and you must find out how your own body reacts to different foods, and then you should revisit occasionally those you have avoided, in case things have changed since you last ate them. One swallow does not a summer make, and one bad curry experience does not mean you will never be able to eat one again.

To close on a positive note, many pouch owners follow advice similar to that given by one member:

"I have never let food control me since the ops. I would rather eat what I like (and I do) and suffer a bit of wind etc afterwards. I'm in control of the illness – not it in control of me."

Polyposis People

Most Red Lion Group members have ulcerative colitis, but a significant minority have polyposis. John Roberts is one, and he has offered to run a regular polyposis section in *Roar!* Please contact him with feedback, contributions and ideas about what topics you want him to cover.

John D. Roberts,
21, Clinton Street,
DERBY, DE21 6DH,
Telephone 01332 361234

It is now approximately 15 years since I came across Familial Polyposis Coli. It has made a great change in my life, but it has been very difficult to find reliable information on the problem. For several years I was able to obtain an American Hereditary Polyposis Newsletter, which I found helpful.

I feel that there may be a need in this country for a network of FPC people to offer support and encouragement to each other. And this section within *Roar* can give an introduction to the illness in general, articles on ongoing research or how Registries work by a professional, and probably personal experiences sent in by readers.

My Own Experience

My family history is as follows. My mother died of bowel cancer in 1970. I developed a phobia about cancer and read a lot about it. I found that it was mainly lifestyle and environmental, so I altered my diet and got on with life. I got married in 1979 and in the summer of 1985 my wife Fran was expecting our son George.

Also in the summer of 1985 my brother Edwin was found to have polyps in his large bowel. It was thought that it was FPC so I was checked the day after his operation and given the all clear, with the suggestion that if I was clear, our child would be as well. So again we got on with life.

In the spring of 1992 we realised that George was poorly. The symptoms were similar to a virus. At the third visit by the GP George was admitted to the Derby Children's Hospital, where he was diagnosed within 2 hours as having a tumour

of some type.

George went on to have chemotherapy, which shrank the tumour. However, they were unable to do the required operation to remove the tumour from the liver at Nottingham Queens Medical. The next port of call was Birmingham Children's Hospital where he had a liver transplant in October 1993. This was considered a success but George became tired and began having back pain September 1997, which was put down to carrying his school bag.

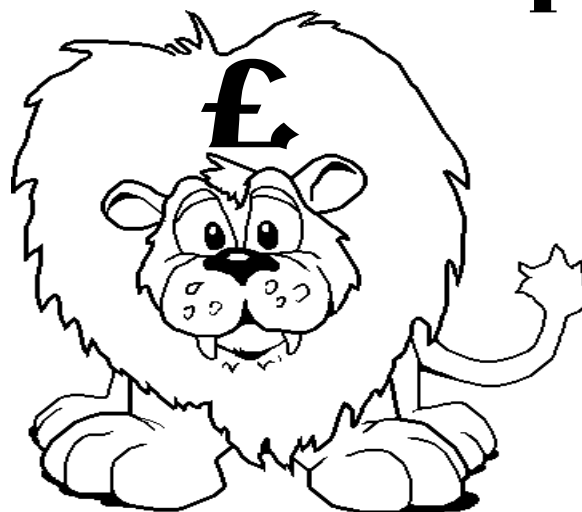
In January of 1998 it was realised he had secondary tumours in his chest. After a failed attempt at chemotherapy, we brought him home at the beginning of May. We

had a week's holiday at Burnham-on-Sea, courtesy of the James MacDonald Cancer Trust. George was still keeping us busy collecting Doctor Who books, and we visited Legoland at Windsor. At the beginning of July we had a week at Aberystwyth with the Christian Lewis Trust. By now, he was slowing down but enjoyed buying and reading four new Star Wars books. George died on Friday 24 July 1998.

You may not be aware but the children of FPC parents have a higher risk of developing hepatoblastoma (children's liver cancer) than the general population, although it is very rare. This, it turns out, is what George had.

Continued on next page...

Please support the Red Lion Group



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

...continued from previous page

When George was at Birmingham Children's Hospital for assessment, the doctors - being aware of my family history - said that I should be investigated, as this suggested I had FPC too, despite the results of the earlier tests. They took blood tests, looked at the pigment at the back of my eye and suggested flexible sigmoidoscopy, an inspection of my large bowel.

I behaved like an ostrich with its head in the sand and put this off for as long as possible. Two months after George's liver transplant, I had to undergo the bowel inspection. The FPC had been missed at my earlier screening. In February 1993 I

I had a mental aberration at work and broke my left femur in October 1997.

had an operation to remove my large bowel and had an ileo-anal pouch installed.

It has not been perfect in operation as the operation was done in one stage. The problem for FPC pouch owners, as I see it, is that you go into hospital a healthy person. No matter how positive you are about it, your body and function are changed; you will never be the same again.

Initially with the bowel on strike after the operation, I was feeling well. On the fifth day the bowel did start. An hour later, I was hoping it would stop. But it was at least 48 hours before there was any respite.

I was still very positive and after 12 days got back home. I was still going to the loo 25 times every 24 hours (it seemed mostly at night!). After 3 months I reached a plateau of 10 times a day, where I seem to have stuck. The stress of all that happened about George has contributed to this higher rate of loo visits.

As I was a three shift worker, I was taken off the night shift, but working two afternoon shifts and one morning shift every three weeks, has not contributed to giving one's life a regular rhythm. I get very tired. I still cannot work out cause

and effect where food is concerned. Just to make things even more stressful, I had a mental aberration at work and broke my left femur in October 1997.

An Introduction to Familial Polyposis Coli (also known as Familial Adenomatous Polyposis, or FAP)

Basically, Familial Polyposis Coli is when large numbers of polyps are found in the large bowel or rectum. A hundred pre-cancerous polyps (but there can be thousands) seems to be the point at which it will be referred to as probably being FPC rather than polyps. The other indicator is if your family has a history of bowel cancer.

The polyps themselves are benign, but, at some stage one of them will become cancerous. It is a question of when, rather than if. These polyps can also happen in other organs.

It is your DNA, your genes, that determines what happens, and this may be inherited from one of your parents, or it can also happen as a non-related event, a mutation.

Once this has happened to a person, each time one has a child there will be a 50% chance that the child will eventually develop FPC. But if that child is clear then its children will also be clear. If the child has inherited the damaged gene, the polyps will appear at puberty.

It must be said that FPC is very rare. In South Derbyshire, there are only about three families with the problem. An even rarer possibility is childhood liver cancer, although children with FPC have a higher risk of developing this than other children do.

What do the medical profession do about FPC? If there is a family history of the problem then examination using endoscopy is carried out regularly from puberty. If blood tests of the person with FPC have enabled the DNA problem to be identified, then blood tests of his or her offspring could allow early identification of other family members with FPC.

The surgeons have a procedure to prevent cancer developing, which

is to remove the whole of the large bowel. There are then 3 alternatives:

- Connect the small intestine directly to the rectum.
- Construct an ileostomy and use an external appliance to collect the stool.
- Construct an internal pouch using part of the small intestine and connect it to the rectum. The ileo-anal pouch procedure can be done in one, two or three operations, depending on the health of the candidate.

Glossary

Taken from the John Hopkins Guide referred to in the Publications list.

Desmoid tumours

A Benign connective tissue (fibrous) growth that may occur in the abdomen or abdominal wall. It may enlarge and may cause pressure on or encircle the bowel, stomach and other organs.

Gardner syndrome

A hereditary disorder with intestinal polyposis, soft-tissue tumours of the skin, jaw lesions, and other abnormalities.

Publications

My favourite is the *John Hopkins Guide for Patients & Families: Familial Adenomatous Polyposis*. This is well presented, though some of the American terms are a bit rich: for example, the idea of the "pull through" when referring to the ileo-anal pouch perhaps tests the imagination.

The glossary is useful, and the items on Desmoid tumours and Gardner Syndrome are an example.

The booklet can be obtained from:

*John Hopkins Polyposis Registry
The Johns Hopkins Hospital
600 North Wolfe Street
Baltimore, MD 21287-4922
USA*

Contact the suppliers of the publications listed for prices and/or mailing charges before ordering.

I have discovered that the Polyposis Registry at St Marks is planning a newsletter, and will report on that in due course. They also have a nice booklet on FAP.

ScarTactics

Morag Gaherty finds out more about scar reduction methods

In a recent issue of *Roar!*, we drew to your attention the fact that Boots now sell silicone sheeting which is designed to reduce scarring. As yet, no-one has contacted us to tell us if they have tried it, perhaps because at £35 it is rather an expensive idea to try.

However, the latest issue of *What Doctors Don't Tell You* contains an article on precisely this topic. The most important points in that article are reproduced below:

The use of silicone sheeting in order to reduce scarring is a relatively new and non-invasive procedure. The idea is that the individual wears a thick sheet of gel impregnated with silicone for at least 12 hours a day.

According to the medical research (*Aesthetic Plas Surg*, 1994; 18:307-13), silicone sheeting has certainly come out as one of the best ways to deal with fresh and chronic scars. It can also be used on older scars, although results are more variable with these.

There are occasionally cases where use of the gel has resulted in minor skin rashes, but these are temporary and disappear once use of the sheeting is discontinued. The silicone does not appear to enter the wound site, which would be the main cause for concern with the use of silicone.

All the research that has so far

been done indicates that silicone gel sheeting is both painless and effective, particularly on fresh scars. (*Cutis*, 1995; 56: 65-7). 12 - 24 hours' daily use for two months immediately after surgery appears to get



the best results.

However, what no-one has yet been able to say is precisely why it works.

There are a few studies which indicate it is not the silicone itself which is the active ingredient, as

other types of sheeting showed improvements in the scarring as well (*Dermatol Surg*, 1996; 22: 955-9. *Adv Wound Care*, 1998; 11: 40-3. *Br J Plast Surg*, 1992; 45: 599-603). The authors of the last of the three studies referred to concluded that the therapeutic action of this method must be due to the hydration and covering up of the scarred tissue.

The Cica-Care sheeting sold in Boots is easily adhesive and more comfortable than other silicone sheeting with which it has been compared in trials (Burns, 1994: 20: 163-7). However, it is also very expensive, as noted above.

What Doctors Don't Tell You comments: "While the gel is perhaps more pleasant to use, it's not likely to be any more effective than an occlusive dressing with silicone cream, though it will be more effective than cream simply applied to the skin (*Br J Plast Surg*, 1990; 43: 683-8). Keeping the scar hydrated for long periods of time is what appears to improve the appearance of scar tissue."

We would recommend that you show this article to your stoma nurse and discuss with her ways in which you could hydrate and cover up your scar, to see if this helps reduce its prominence, particularly if you have only recently had surgery. Please also keep us informed as to how you get on with this.

These Boots Were Made For...

Since her recent letter to *Roar!*, Jessica Drewery's pouch has improved so much, she has been able to take up long distance walking once more

I set off to walk the Wealdway one evening recently. We started from the Tollgate and got lost immediately because the Channel rail link works were in the way! However, walking through Kent orchards at this time of year was lovely.

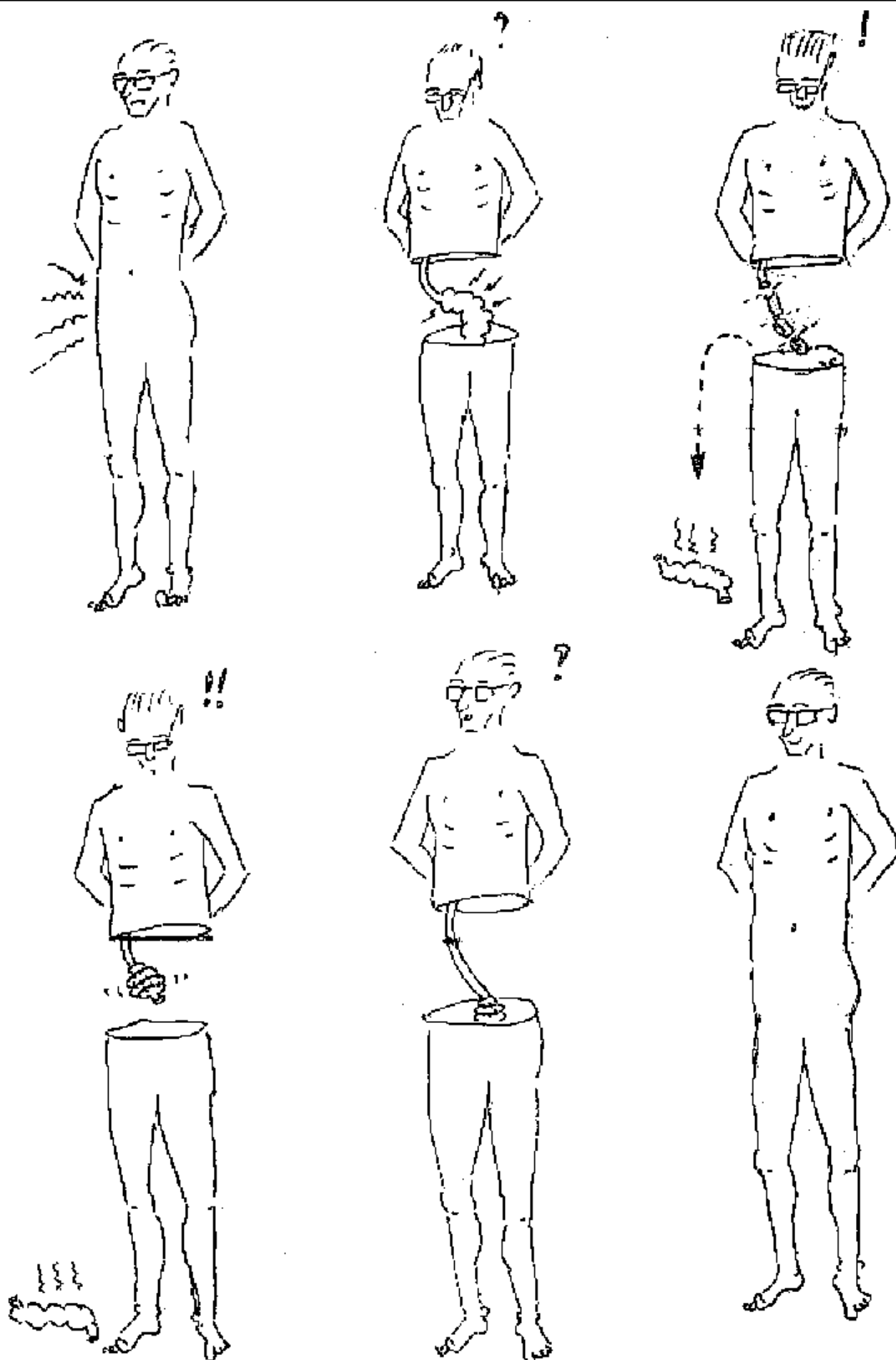
We camped along the way and rarely met any other walkers, until Ashdown Forest. Sadly, most of the

village shops had closed down, but the pubs kept us fed and watered.

My friend's feet became horribly blistered, she had a plaster on every toe, her soles and heels. My dog strained a muscle and got awful diarrhoea on the last day. I was the only non-casualty! But that may have something to do with the fact that I upped the dose of loperamide

just in case, and had recourse to the hip flask to boost flagging morale at the end of the day.





Do-It-Yourself Guide to an Ileo-Anal Anastomosis and Pouch Construction in Five Easy Steps, after a Total Colectomy

Three Ops and a Baby

Jo Driver found that ulcerative colitis was an unexpected precursor to motherhood

I was ten weeks' pregnant when I had my first – and last – attack of colitis. Not content with having the usual morning sickness, indigestion, backache etc, I decided to be more dramatic!

However, having the colitis and the subsequent sub-total colectomy and ileostomy (at 12 weeks' pregnant!) certainly prepared me for motherhood. Getting up numerous times in the night to go to the toilet was good training for the sleepless nights to come. Emptying my bag made changing nappies seem like child's play.

There were other advantages, too. Of course, I had no piles or constipation to worry about. Plus I avoided the condescending pats on the stomach, because people were too afraid to touch something embarrassing! And no messy "accidents" at the birth, no worry afterwards about straining and bursting my stitches (mothers will know what I'm talking about here). I was also complimented on how clean my stitches were – strange, that!

Of course, there were some disadvantages: having to wear a garish, patterned pink, gold and green maternity swimming costume to "hide" my bag; having to have an indecently long stoma so that I could see it over my bump (I felt like a hermaphrodite!); best of all was having a bowel obstruction at 7 months' pregnant, and being told I was in premature labour! I have to say, labour was less painful. Still, they gave me lots of entonox for the pain – highly recommended, or should I say a recommended high?! Obstetricians, midwives, delivery suite, scans – I don't know – all that fuss for baby muesli..... Premature labour, my foot.

Anyway, back to my attack of colitis at ten weeks' pregnant. To avoid puncturing my colon, it was decided after two weeks that I should have the operation. I christened my stoma George. The nurses were pleased at his arrival – they

were all starting to get severe RSI from writing details on my stool chart.

George was very well behaved, unlike the stoma I had after my next op, the temporary loop ileostomy and formation of my pouch. I called him George II, although I think George III would have been more appropriate, as he was completely mad.

He would have outbursts in public – he didn't care where: backs of taxis, barbecues, friends' sofas, an Indian restaurant. That last one was the best – I had already used up my spare bag and I was miles from home. I decided that to avoid needing a skin graft, I'd better get to the nearest A&E (which, in my case, stands for Accidents and Effluence). Of course, I wasn't really a priority on a busy Saturday night and resorted to sitting on a pile of magazines to soak up my "homemade curry" (I sat on a pile of Hello! magazines, on the grounds that what was coming out of my stoma would blend in nicely...).

Eventually, after a few hours (ouch!), I was taken to a room and shown a range of bags. I'd pull the curtain and try one on – no good, next please and what about shoes to match? They were all colostomy bags, but better than nothing. My poor husband had to drive from Enfield to Penge in the middle of the night, stopping off at shops on the way for bottles of water – he needed them to dilute his alcohol content, because he hadn't planned on driving, and I don't need to tell you what I needed them for. Poor George, it wasn't his fault – he was just a funny shape and very close to my skin. And of course, it was all worth it in the end. But I must admit, I started making so many deposits, I thought I'd been reincarnated as a pigeon.

Conversely, my pouch has been impeccably behaved. Apart from getting an infection after its forma-



tion, and therefore not leaving St Marks until Christmas Eve – I'll go to any lengths to get my husband to cook Christmas dinner! – my pouch has been wonderful. As are Mr Nicholls and his team; all the stoma nurses that looked after me; Mr Swift and Mr Hurley, and their teams from the Mayday in Croyden, and Mr Theodossi and his team from the same hospital. Oh, and of course Mr Clarkson, my obstetrician, who must have spent a few nerve-wracking hours overseeing my colectomy.

Yes, I'm glad I didn't decide to become an eternal ostomist. OK, so I need soundproofing on my bathroom walls; my homemade curry results in "Poucho Marks" on the sheets (so strictly for when I'm on my own), and I'm buying shares in Sudocrem. But I made the right choice.

So if having an ileostomy isn't your bag and you want to start using those bendy bag closures as freezer bag ties (very handy), go for it if you can. You don't have anything to lose, apart from a few months off work! Blast the resulting itchiness BOTTOMS UP!

By the way, my pregnancy went smoothly after my blip at 7 months and I gave birth naturally to a beautiful baby girl (naturally to a girl – they're stronger in the womb!). She's now five and a half, with gorgeous red curly hair and blue grey eyes. Sally Louise, you were worth every bit of my story, and thank God for making you so strong....

The Demon Goes on Holiday

Tips from the Turtle...

Start by making lists - buy a notebook specially for the purpose; you will need:

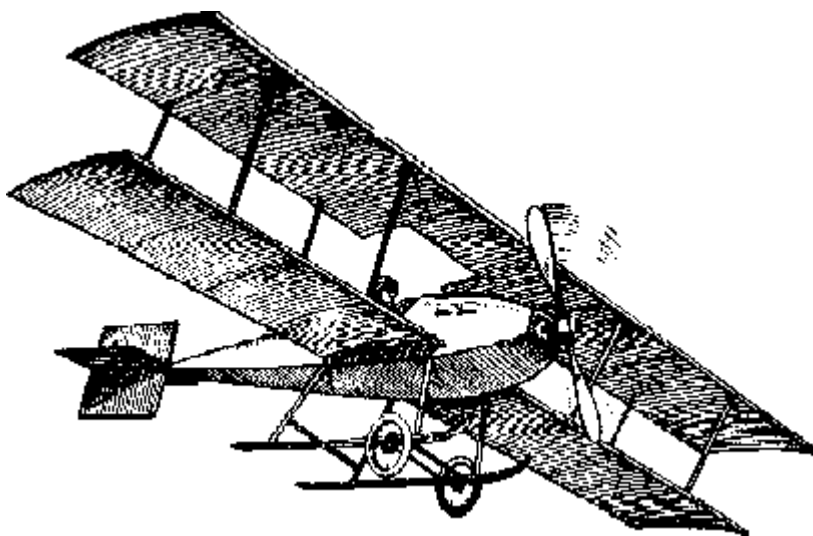
- A list of all medicines prescribed to the family
- A list of all the packing to do
- A list of all the things to be taken care of before you leave for the airport, including the passports being placed in a sensible place on your person or in your hand luggage.

Try and pack no more than the basic minimum. Remember that most modern fabrics can be hand-washed in the bath in your room if need be. Make sure that Inco-pads and "nappies" are included, if you use these (one piece of airline-standard hand luggage can take 2 packs of Tena Comfort Plus).

If possible, go self catering - there are fewer problems with drying clothes in the apartment than in a hotel. Better still, if you will be going back, make friends with any expatriate Brits (or with the locals, if you speak the language). They may be able to help on future trips.

Remember to get more medica-

tion than you need for the amount of time you are on holiday - you may meet a delay on the return trip or come back to a weekend or Bank Holiday.



Try and find out a little about the area you are visiting before leaving - for instance, all Spanish cafes must, by law, provide toilet facilities that anyone may use; you don't have to buy anything.

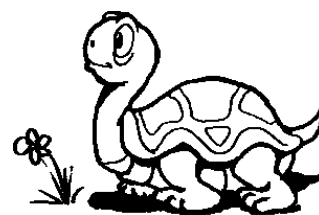
In some parts of the continent, there are large groups of expatriate Brits. Some of these groups may have organisations like the Royal British Legion that may be able to help with any problems you encounter, such as translation prob-

lems.

If one of you tends to worry about the unforeseen, try and arrange for any possibility before leaving. This includes ensuring that your

travel insurance includes emergency air-ambulance cover. Remember Murphy's Law - "Any eventuality sufficiently well planned for never happens!"

But above all - remember the Imodium and Dioralyte. Don't forget that annoying two-hour wait in the airport, and the journeys to and from it. Once you have mastered the planning stages, you should about be ready to join the Army Logistics Unit - so ENJOY YOUR HOLIDAY. We have had two since the op, and Sally coped with both.



NAPG News

Well it's happened! We've finally got the National Association of Pouch Groups (NAPG) up and running. It was launched at the Pouch Open Day in Birmingham on 10th April.

Professor Chris Brannigan addressed the 222 delegates present, explaining the reasons for the formation of NAPG. We had previously circulated the proposed constitution of NAPG and the proposed National Committee to run the as-



sociation.

Chris asked those present if they wished NAPG to be the umbrella association for all the internal pouch support groups in the UK. This was unanimously agreed and the nominated national committee were also

unanimously accepted as well:

Chair - Angie Perrin;
Chair Elect - Julia Williams;
Secretary - Dick O'Grady;
Treasurer - Morag Gaherty.

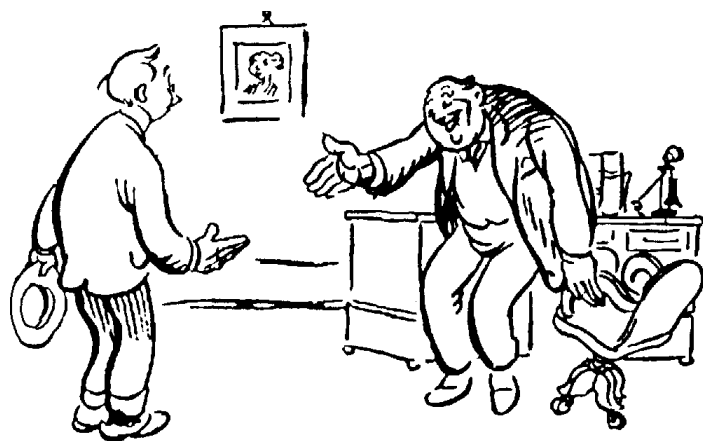
The elected representatives were: Claire Rowsell; Liz Cheshire; Marica Pilkington; Jonathan Keeley; Karen Dixon; John Noble and Dee O'Dell-Athill.

We have since held our first committee meeting and I was asked to circulate a newsletter to all known pouch owners and clinical nurse

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).



BEDFORDSHIRE

Wendy Gunn Luton 01582 423714

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CAMBRIDGESHIRE

Joyce Shotton Peterborough 01733 706071

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Bernadette Monks Salisbury 01722 327388

YORKSHIRE

Neil Anderton Leeds 0113 258 2740

Sue Appleyard Huddersfield 01484 311334

specialists. This I am in the process of compiling. At the moment its up to 4 A4 pages and I've still got to put in articles from other committee members, so please be patient, you will get a copy.

My reason for writing this short article is not only to let you know that NAPG is alive and kicking but also to ask your permission on one topic which came up at the committee meeting:

It was agreed by all present that although NAPG does not in any way wish to swallow up the individual support groups, it should act

on their behalf providing a central hub from which the individual pouch owner, the local support groups, the person about to have a pouch, their partners and families can draw on information.

To provide such a service and avoid duplication of information being circulated, plus cutting costs in printing, postage etc., it was agreed by the committee that the National Secretary of NAPG should hold a central database of all known internal pouch members from each of the different support groups, so that individuals would not be con-

tacted more than once if they belong to more than one support group.

The Red Lion Group database details will therefore shortly be made available to me for this purpose only.

It is assumed that you have no objection to your details being passed on in this way, unless you write to me stating that you do not want your details recorded on the NAPG central database.

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FUNDRAISING OFFICER

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

* contributions to the newsletter should be sent to Morag Gaherty

PRESIDENT

Professor John Nicholls

PATRON

Claire Rayner

Join the Red Lion Group

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

Write for Roar!

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

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

Perhaps you've taken up a new hobby since having your pouch operation? Or are there any clever lit-

tle tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

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

You'll get the satisfaction of seeing your name in print and you may give hundreds of fellow pouch people an insight into an aspect of their

condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

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

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

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