ROAR!

ISSUE 57 • SUMMER 2019

Newsletter of the Red Lion Group
St. Mark's Hospital • Watford Road • Harrow • HA1 3UJ

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 regional rep, please contact David Skinner on 01708 455194 or by email at info@pouchsupport.org.

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Sandy
01767 263092

BRISTOL/AVON
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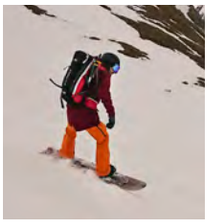
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Please support the Red Lion Group

Registered Charity number 1068124

All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group and send it to: **Red Lion Group Treasurer, Pantiles, Marlow Hill, High Wycombe, HP11 1QL.**

Notes from the editor

Let's start with the highlights. An early spell of spring sunshine, the 25th anniversary of the Red Lion Group, a memorable Information Day and Liverpool FC's triumph in the Champions League (I'm biased of course!). And 2019's lowlights? Need I say more than an enigma disguised as a riddle called Brexit.

But let's stay with the highlights. Were you one of the lucky 90 or so who were warmly serenaded by our chorus of eloquent speakers at this April's Information Day? I was and I haven't recovered!

Eloquence, intelligence, expertise. It was all there and that was just the audience! In fact, the whole of St Mark's Hospital's Himsworth Hall reverberated with enthusiasm, expectation, ideas, medical wisdom and the pithiest of questions and answers about topical issues.

Self-created sun

But there was no sun! It must be a first – every Information Day I have been to in the past 24 years has been bathed in welcoming sunlight. Until this year. Luckily there was an alternative.

Our sunny dispositions were restored by a delightful review of Red Lion Group and how it was created by Dr Martin Peters, the group's first chairman, who literally flew from his Spanish home and postponed his own wedding anniversary to launch the 27 April event.

Another metaphorical ray of sunshine was cast by founder-member Tim Rogers, the first editor and current designer of *Roar!* and still active on the committee, who gave us an inspired appraisal of some of the colourful personalities and events that led to the group's founding in 1994.

Talking points

By now thoroughly uplifted, we were ready for the talks and learning about such diverse topics as biofeedback and pelvic floor mastery; drugs and the importance of taking your daily dose; the benefits of a healthy diet and the secrets and inner workings of the ileoanal pouch. You can read all about them on pages 12-28.

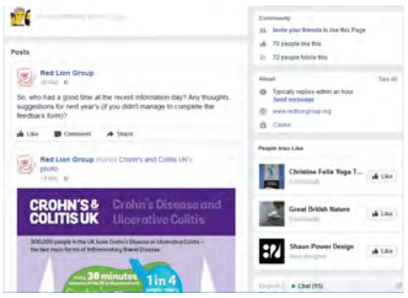
But back to those highlights again. It's been a year of them for Red Lion Group. A record attendance at Information Day, a steadily growing membership, new link-ups with hospitals, charities and other UK support groups and recent success in our search for a new treasurer.

Jim Symington, who owns and runs his own computer consultancy, has taken over the role that has been so staunchly overseen by committee member Peter White for the past three years. Jim is joined on the committee by Michelle Martin (initially as a co-optee). Michelle's skills in PR, marketing and fundraising will certainly enliven our ambitions for a bigger, better and more beneficial support group.

Enjoy *Roar!* and I and the committee wish you a very healthy and happy 2019!

As a little footnote, and if you haven't already done so, please fill out the Gift Aid form on this issue's back cover so Red Lion Group can reap the benefits of a few more tax rebates!

CHRISTOPHER BROWNE



Find us on Facebook

www.facebook.com/theredliongroup/

Visit our website

pouchsupport.org

Browse nearly every copy of *Roar!* that has ever been published (including issue 1 from 1994) at pouchsupport.org/resources/roar-archive/

For online support, advice and tips on life with a pouch, please visit our Frequently Asked Questions (FAQs) page on the website at:

pouchsupport.org/faqs/

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Chairman Davies's annual review

Red Lion Group is 25 years old this year and we gave the group a rousing send-off for our next 25 at the 2019 Information Day on 23 April. The event which was held at St Marks Hospital's Education Centre was attended by over 90 people, a record attendance and a further sign that our efforts to increase our profile are paying dividends.

We had a commemorative sash on the banner (thanks to Chris B) and a sumptuous 25th anniversary cake – in fact TWO cakes (with thanks to Susan Burrows, who arranged all the catering on the day).

It was a delight to welcome on to the podium, Dr Martin Peters, who flew in especially from southern Spain where he now lives. For those who do not know, Dr Peters was one of the earliest people to have the pouch operation and was the first chairman of the Red Lion Group, helping to set it up with Tim Rogers, who is still on the committee 25 years later, and several others.

Many of the committee are long-term pouchees with an extensive history of service to the Red Lion Group and our members, and I thank them all on your behalf for their dedication and hard work. Dr Peters opened the agenda with an engaging speech in which he reminisced about the founding of Red Lion Group and said the current committee and group "continues to go from strength to strength".

Tim Rogers, who has had a pouch for more than 30 years, provided an amusing, personal insight into his pouch experience. He said he continues to enjoy very good outcomes which is heartening news for all of us.

Suitably uplifted we moved on to the AGM which was attended by 38 members plus nine committee members. The audience included seven potential pouches who are either waiting to have surgery or wanting to find out more about it before making a decision. I encouraged them to use the Day to find out as much as they could by chatting to pouchees, potential pouchees, families and friends in the breaks between the talks and workshops.

Acting treasurer Peter White presented the 2017-2018 accounts which showed income of £3,863 for 2018 compared with £3,395 in 2017. The balance for the year was a "small but healthy" £5,008. This was despite several one-off expenses such as the website and a new Red Lion Group banner. We have also made a £350 donation towards pouch-related research in 2019.

It was a real pleasure to see Paul Mulot, our former treasurer who had to stand down through illness three years ago, in the audience.

> Delegates relished the chance to resolve some thorny issues with the experts.

There was an excellent series of talks on pharmacy, diet, biofeedback and developments with the pouch. The feedback we received for all four presentations was extremely good and the question-and-answer sessions after each presentation were busy indeed as delegates relished the chance to resolve some thorny issues with the experts.

Aside from the presentations, there were also the workshops for male pouchees, for female pouchees and for families and friends. I was in the male group and can faithfully report a very successful session, with much discussion about avoiding night-time leaks, frequency, sphincter strength, efficient emptying, the use of a medina catheter, vitamin deficiencies, annual blood testing, diet, medication and sex!

A particular feature of the session, which was expertly chaired by Chris Browne with excellent inputs from Gary Bronziet, was that every single person spoke at one stage or another and we had the extra edge of advising two potential pouchees on what life is like with a pouch. I heard similarly laudatory comments from

David Davies

the female pouch and friends and family groups.

Red Lion Group continues to grow from strength to strength and the 90 plus registrations on the Day are the highest ever. Indeed next year we might need to hold the event in a larger and more modern facility if the growth in registrations continues.

What is driving this growth? The committee is energised and enthusiastic to do a great job on behalf of you, the members. The website is a fantastic internet platform and there have been a number of communication developments, with *Roar!* available electronically, the online forum which has been well used of late and efficient and effective email communications using mailchimp. With thanks to Gary Bronziet who has driven these initiatives. It was interesting to see how many people at the Information Day were happy to receive all Red Lion Group postings by email in future, which is cheaper and quicker than sending out paper-based messages.

Another gratifying sign is the interest of others to become involved on the committee and we have had three people expressing interest in getting involved during the past few months.

Money is scrupulously managed by the committee and until now by Peter White in particular as the recent treasurer. Our income is limited and is an inevitable constraint on what we are able to achieve on your behalf. We have taken the collective decision to keep the subscription at the same price for another year, which represents extremely good value for money and we hope is not

a disincentive to anyone wanting to join the group.

However, if anyone has a few extra sheckles they would like to donate to Red Lion Group to facilitate our good work, then please feel free. We are now registered with the onsite donation platform, JustGiving, which enables secure, online donations and organises the automatic processing of a 25% uplift on eligible donations via gift aid on our behalf. Many members will have used JustGiving in the past for other charities and fundraising events. The service

Peter White and Jim Symington

is now offered free which enables charities like Red Lion Group to sign up. Note the "donate here" button on the website – and there is an invitation to sponsor my partner, Bev, and me as we cycle the 127 miles of the Leeds-Liverpool canal on Raleigh Choppers (remember them?) this summer for Red Lion Group (see article on page 29).

In his three years of steering the finances, Peter White has done a superb job, introducing initiatives such as changing the signatories on the banking mandate and documenting our financial processes to improve our governance.

In the last few days Peter has completed the handover arrangements to a new Treasurer Jim Symington, who we warmly welcome as a new trustee on the committee. Jim has a background in senior management and IT in particular and his skills will be much appreciated as we continue to manage the finances efficiently.

We have also dusted off the group's constitution, which was unchanged for 25 years, though still as relevant and pertinent today as when Martin Peters and colleagues put it together all those years ago.

An essential update was necessary, however, and Theresa Parr has driven this initiative to produce a sparkling new constitution, which was approved by members at the AGM. There are no material changes to the document, but as a precaution I presented a summary of the main changes at the AGM prior to the vote. Any member can see these in the powerpoint slide set on the website (pouchsupport.org).

> We have a vision to reach more pouchees in the more remote UK areas.

We have a vision to reach more pouchees in the more remote UK areas where this operation might only have been carried out on a couple of patients and there is little or no local infrastructure for support. There is an opportunity to collaborate with other groups – especially those with a national infrastructure – to see if we can extend the support being offered by Red Lion Group to pouchees everywhere.

St Mark's is a worldwide centre of excellence for surgical interventions of the digestive tract and the fact that we enjoy the benefits of a pouch is all down to the pioneers who developed this procedure in the early days at St Mark's and at a few other centres around the world. That legacy lives on with the outstanding surgical and medical work being carried out by the hospital's current team.

But what we also see at Information Day are the many and varied specialists who provide the support to assist the surgical teams and give outstanding specialist care for pouchees, when we need them most and to ease our successful transition to life with a pouch.

My very best wishes to all of you for a healthy and successful 2019-2020.

Letter to the editor

Dear Red Lion Group

I found the article about air fresheners on the website "Let us spray..." very interesting. I use either Neutradol, PooPourri or a similar one called VIPoo by Airwick – the latter two consisting of essential oils I believe – when I am at home.

I have even filled one of the bottles with my own mix of essential oils from Amazon which is much more cost-effective. You need a carrier like witch hazel, then a few drops of such oils as lemon grass, anything citrus, bergamot and frankincense. It works a treat!

In my handbag I carry a small canister of Limone Ostomy Spray which neutralises odours when I'm away from home. This was originally prescribed when I first had my ileostomy 31 years ago, with my pouch being formed two years later. I can still get this on prescription.

Here is the essential oils spray I refer to above (as shown on Pinterest):

- 20 drops of lemon grass essential oil
- 20 drops of grapefruit essential oil
- 20 drops bergamot essential oil
- 2 oz witch hazel
- 2 oz dark glass spray bottle

Kind regards

Jane Humphries

ED: All comments and suggestions on Jane's letter are very welcome

Dysplasia: the pros and cons of surgery

A recent survey led by St Mark's Hospital's Dr Misha Kabir produced some interesting findings

Dr Misha Kabir

Decisions, decisions, decisions! Sound familiar? If you're a potential pouchee one of the biggest decisions you may have to face is whether to have surgery after a bout of dysplasia – pre-cancerous cell changes that can lead to cancer if they are not removed.

In most cases dysplasia can be taken out during a colonoscopy (an examination of the large bowel and part of the small one using a flexible tube known as an endoscope). If this process doesn't work, most medical professionals recommend surgery to remove the large bowel and the fitting of fit a pouch or stoma.

In a recent St Mark's Hospital survey, which polled 113 responses, (see the December 2018 *Roar!* page 14) almost two-thirds of patients (64%) diagnosed with dysplasia opted to have surgery while 36% decided not to do so and have regular monitoring instead.

However, 35% of those who had never been diagnosed with dysplasia chose the surgical option, 30% preferred regular monitoring and a further 35% were uncertain about what they would decide to do.

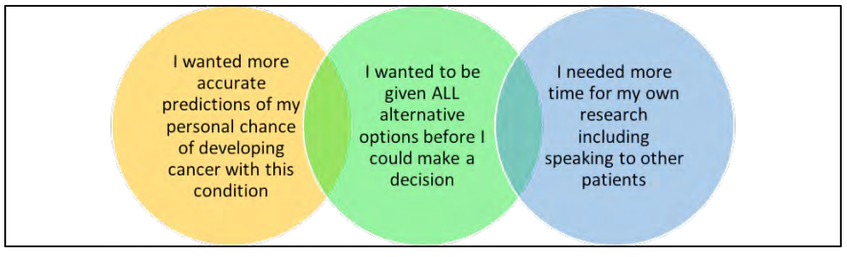
The reasons respondents gave when considering treatment are shown in Box 1 (below):

Survey leader Dr Misha Kabir, Clinical Research Fellow in IBD and Endoscopy at St Mark's Hospital, told *Roar!*: "The respondents who preferred surgery were more likely to think that dysplasia progressed to cancer within a year and that colonoscopy surveillance alone would probably not prevent cancer developing in the future.

"Three-quarters of the 47 respondents who had previously been diagnosed with dysplasia felt well informed by their medical teams about the risk of cancer associated with a dysplasia diagnosis and the management options available to them.

"The majority also did not regret the final decision they made to have surgery – or not – for the dysplasia. They also completed a quality-of-life score which on average was the same for the patients who had surgery and those who had not done so."

The reasons for not feeling well informed are highlighted in Box 2 below:



Dr Kabir added: "We hope to address the issues raised in Box 2 and to improve the information and the support we give to patients making these decisions in the future. As always we are grateful for the invaluable role that support groups like Red Lion Group continue to provide to patients making decisions about surgery."

The high life – a snowboarder's secrets of success

If you're looking for thrills – and spills – snowboarding or boarding is today's snow-lover's favourite. For those seeking the X-factor splitboarding – when the board divides into two to cope with tricky slopes and rough terrain – is the ultimate experience. Red Lion Group member ADAM BRAMLEY reports

Slippery slope or route to success: Adam Bramley on Courchevel

A spell of unexpectedly warm weather in the French Alps earlier this year proved a double bonus for snowboarder and pouchee Adam Bramley.

His health suddenly changed for the better and his passion to get back on the slopes was almost instantly rekindled. "Having had my take-down in October 2018 at the end of a three-stage surgical process I was absolutely desperate to get back on the snow," says Adam, who had his operations at the Queen's Medical Centre in Nottingham.

The intrepid boarder, who was staying in the famous French ski resort of Courchevel with his 'touring buddy' Valentina, adds: "The improvement continued throughout February, March and early April this year. And with some decent piste-skiing under my belt and a good few kilograms back on my frame, courtesy of copious amounts of excellent French cheese, I started looking towards bigger challenges."

As many snow enthusiasts know, one of the key features of the French Alps is its refuges – places where people can stay varying in size from simple mountain huts to small hotels with hot food and showers. "We decided that a hut-to-hut route would give me the opportunity to get out into the mountains for a few days, making our way across untracked snow and getting in some good descents."

On the first day the pair stood excitedly at the foot of Courchevel 1650 (the number marks the mountain's height in metres) with 30 litres of kit on their backs and "looking nervously up at the 1,000 metres plus of ascent we'd planned for the start of our adventure," says Adam.

"Our three-day adventure passed in a blur. Hut-to-hut touring is a challenging undertaking at the best of times. You have to carry all your food and equipment, manage the weather, snow conditions and avalanche risk, navigate through tricky terrain, climb using nothing more than your own leg power, descend steep slopes in variable snow

conditions and finally heat the hut where you are staying at the end of each day.

As well as the physical challenges, Adam had bravely decided to give his six-month-old J-pouch a trial run without the security of any traditional back-up support or facilities.

And the highlights were spectacular. Each day the pair watched as the sun climbed over the mountains and the snow turned golden yellow in the pre-dawn morning light. On another day they had the thrill of descending a perfectly even 600m-long 45° slope "all the way into the valley" and during one lunch-break they were even approached by an alpine fox. Two other unforgettable moments were lying on a rock and watching as a series of avalanches poured off the upper Alpine slopes in the afternoon sun and the "feelings of fear we experienced when stuck and exposed on a bitterly windswept ridge turning to absolute exhilaration moments later as we charged off it into a late April powder-field," says Adam.

So how did Adam's pouch fare during his Alpine adventure? "Physically I didn't feel too bad. There's still a big weakness in my core and I've got another 10kg to gain before I'm back to my previous weight – including a lot of work to do on my abs before I can truly trust them again. The pouch was OK. It started off great, but by the end of the second day I was feeling a bit gripey, which I'm blaming on a combination of much greater physical effort than I'd done previously and a sudden change of diet. It worked though and this adventure has stoked the fires for bigger trips next time," he says.

Adam Bramley and his 'touring buddy' Valentina

"What I have gained is the confidence that one day I'm going to get back to something pretty close to normal – something I wasn't 100 per cent confident about beforehand. I've definitely still got a lot of healing and learning to do and my next step is going to be to take six months back at home focusing on my health. Come next winter though I'm confident that I'll be back in my snowboard instructor's uniform.

Next year, after a long period of unbroken recovery, Adam plans to finish his International Snowboard Teacher Diploma (ISTD) exams - which he began before his spell of ulcerative colitis – and become a fully-fledged snowboard instructor.

"It's often stated that pouches continue to improve for 10 years – and I'm pleased with where mine is after only six months," says Adam.

A visionary professor and a wonderful colleague

World-renowned gastroenterologist and consultant physician at St Mark's Hospital for 37 years, Professor John Lennard Jones, died on 29 March 2019 at the age of 92.

Prof Lennard Jones's achievements in gastroenterology and his visionary work in such fields as nutrition, digestive disorders, intestinal failure and psychotherapy during his St Mark's career from 1965 to 1992 read like an entry in Who's Who.

St Mark's former clinical director and the co-founder of the pouch, Professor John Nicholls, told *Roar!*: "Professor Lennard Jones was one of the world's leading gastroenterologists during a period when gastroenterology emerged as a speciality. When he started, the medical treatment of ulcerative colitis and Crohn's disease was beginning to become standardised and Professor Lennard Jones contributed greatly to this.

"His work on cancer in patients with inflammatory bowel disease defined the risk of this developing through the painstaking follow-up of patients over many years. He introduced parenteral nutrition at St Mark's and developed the department – now the Lennard Jones Intestinal Failure Unit – to become one of just two nationally-funded units specialising in intestinal failure.

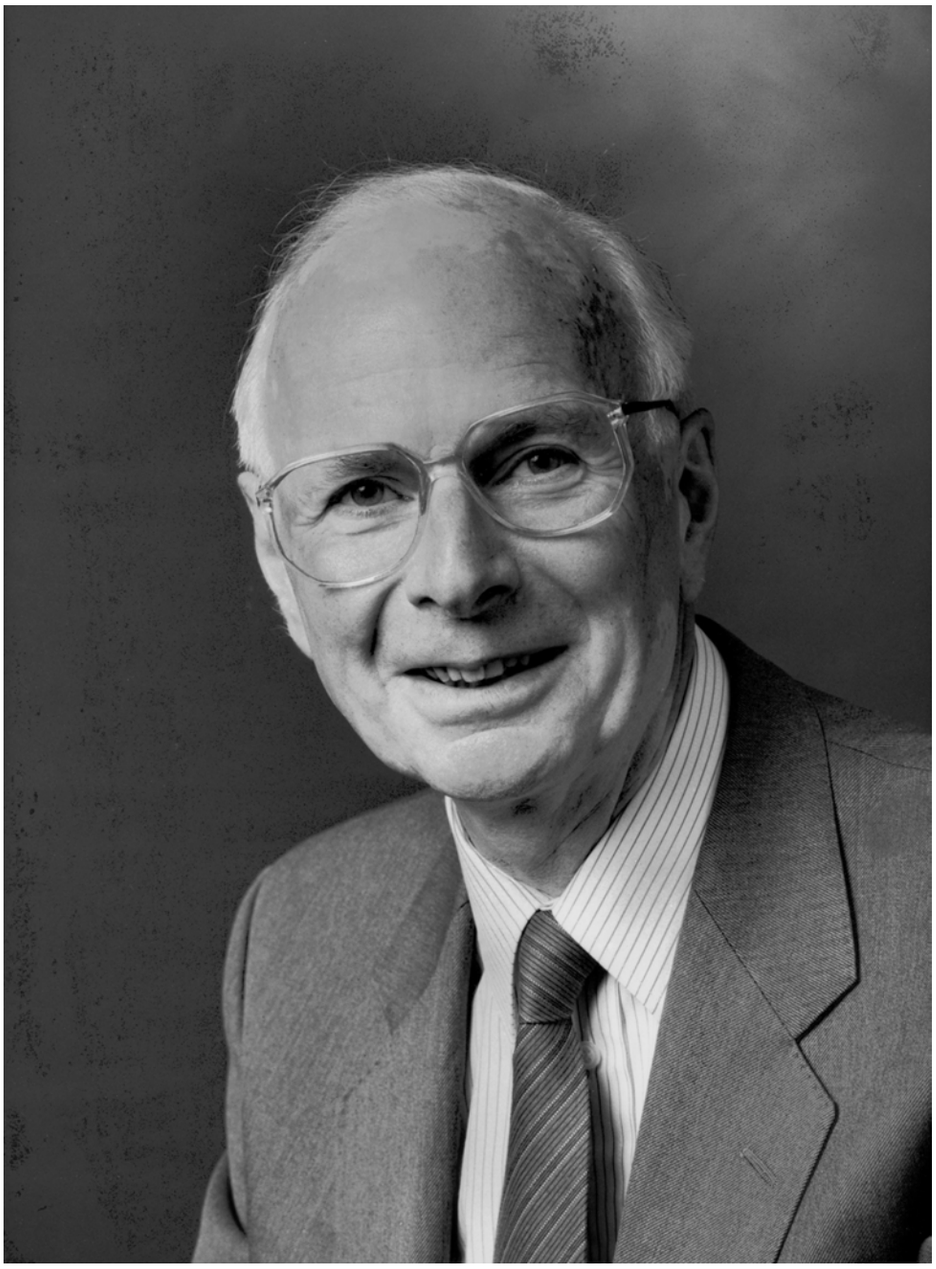
"He made important contributions to exceedingly common disorders of intestinal function including constipation and irritable bowel syndrome. Through the appointment of Dr Alexis Brook he also introduced psychotherapy for patients severely affected with functional bowel disorders."

Among his many medical distinctions, Prof Lennard Jones was President of the British Society of Gastroenterology (BSG), President of the Digestive Disorders Foundation, which became Guts UK, and Chairman of the British Association for Parental and Enteral Nutrition (BAPEN). He also co-founded the charity Crohns and Colitis UK.

"Professor Lennard Jones was a deeply moral person and a devoted and conscientious doctor. His Saturday mornings were often spent in the hospital to allow him to see his patients in a more leisurely manner than the weekdays permitted," said Prof Nicholls.

"He was a wonderful colleague and displayed wisdom at all times, but this quality was particularly valuable during his chairmanship of the medical committee at St Mark's which coincided with a period of threat and uncertainty to the institution. He succeeded in serving his patients to the highest degree while advancing the understanding of disease and its treatment through research.

"Professor Lennard Jones was a rare person who will be missed and remembered for all that he achieved for the benefit of mankind," added Prof Nicholls, who is patron of the Red Lion Group.



Professor John Lennard Jones

Zoey joins the J-pouch set

Intrepid bodybuilder Zoey Wright who was crowned world champion fitness model while wearing a stoma-bag at the recent Pure Elite Pro World Championships has taken the next step and had a J-pouch fitted in April this year.

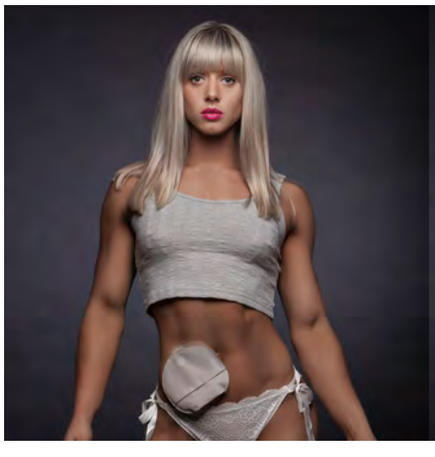
The Red Lion Group offer Zoey our warmest congratulations for her bravery and decision to opt for a J-pouch. Our thoughts are also with her during her post-op recovery period.

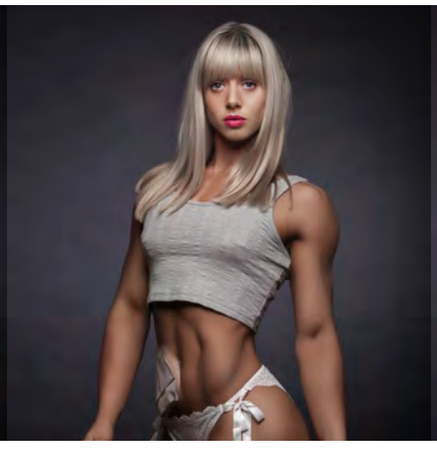
Despite more than four years of serious uc issues and frequent visits to hospital, Zoey, as many *Roar!* and *pouchsupport.org* readers know, decided to continue her bodybuilding and fitness model career while wearing a stoma-bag. Her success with an ileostomy in the world championships is probably a first in the worlds of sport and fitness.

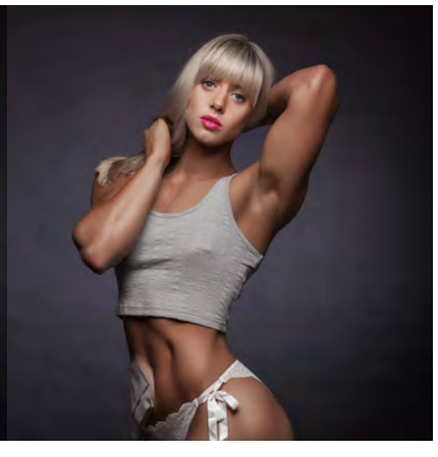
27-year-old Zoey told *Roar!*: "At the end of April I said goodbye to my stoma and hello to my J-pouch. I lived with my stoma for over four years and so it is taking some time adjusting to the new 'plumbing', but I'm extremely happy with how my recovery is going so far.

"My surgeon and his team at Truro's Royal Cornwall Hospital have been amazing and there to answer any questions big or small! I'm looking forward to getting back into weightlifting and fitness instructing very soon and hopefully go from strength to strength with my J-pouch!"

You can keep up with Zoey's progress on www.zoeywright.com, Twitter (@zoeywrightx) and www.instagram.com/zoeyfitness.





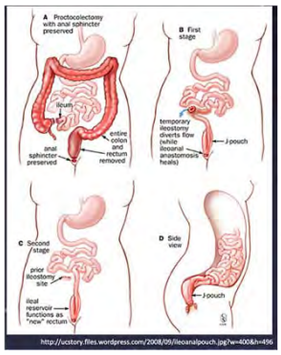


Information Day 2019 Photos

Top dietary tips for pouchees

St Mark's Hos[pital's Dietitian GABRIELA POUFROU highlights the dos and don'ts for pouchees before and after surgery

Pouch Formation

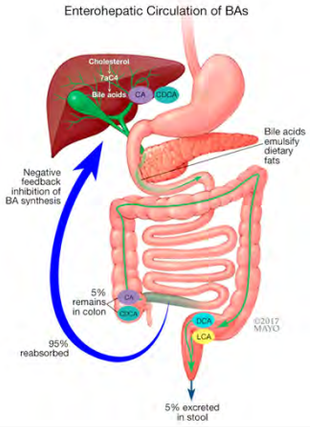


- Loss of large bowel
- Large bowel responsible for reabsorbing water and salt
  - More liquid stool
  - ↑ volume of stool
- Pouch formed from last 30-60cm of terminal ileum
- -Terminal ileum absorbs B12 and bile salts

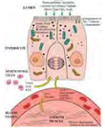
Nutritional implications of pouch formation

- Vitamin B12 malabsorption (M'Koma 1992)
- Bile acid/salt malabsorption
  - ? fat malabsorption/ gallstones (no evidence for ↑ risk of gall stones)
- Dehydration
  - —>First 6-8 weeks of surgery large losses of fluid and salts 1.2L-2.0L/day

Enterohepatic Circulation of BAs



Adaptation



- Kidneys adapt and reserve more water/salts
- Small bowel adapts and ↑absorption of nutrients
- Pouch empties 3-7 times/day
- ~650g stool/day (mushy consistency) (Pearson 2008 chapter 14 (210-232) in Stoma Care (J Wiley)
- Bowel movements similar throughout years ~ 6-7 x 24 hours (night frequency 1-2x) Bullard et al. Dis Col Rect 2002

Dietary support for patients

- Identify malnourished patients
  - Before and after surgery
  - Identify those **at risk** of malnutrition
  - Use Nutrition Screening Tools
  - Monitor for weight loss
  - Check for food restrictions
- Supporting patients reintroducing foods post-operatively
- Supporting a healthy diet in the long term (varied and balanced)
  - Prevent nutritional deficiencies
  - Maintain good pouch function
  - Maintain a healthy weight
- Ensure well hydrated -fluid and salt
- Monitor

The New patient
What to eat after surgery

- Introduce a soft, low fibre diet to avoid
  - Blockages
  - Delay healing of the wound

Avoid:

Nuts	Seeds	Pips
Pith	Fruit/Veg skins	Peas
Raw Vegs	Salad	Sweetcorn
Mushroom	Celery	Dried fruit
Coconut	Pineapple	Mango

For how long?

- 6-8 weeks after your ileostomy is formed
- 2-4 weeks after your pouch is formed

What about after?

- Reintroduce these foods in small quantities
- one at a time for 2-3 days/1 week
- Eat slowly and Chew well

019 Information Day talks

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The New patient
What to eat after surgery

Choose high protein/energy diet
- **Promotes wound healing**
- **Speeds up recovery**
- **Stops weight loss**

- Choose **nutritious balanced meals**
  - include **protein** e.g. meat, fish, cheese, eggs, milk, yogurt or pulses
  - include **carbohydrate** e.g. cereals, bread, rice, pasta, potato
  - Include **healthy fats and Calcium rich dairy products (or lactose free alternatives)** e.g. olive oil, milk puddings, petit filou, custard, blancmanges, yogurt, cheese and biscuits
- Choose **nutritious snacks**
  - e.g. sandwiches, cereal, milky drinks, cold puddings
- Supplement **meals with energy dense ingredients (fortify)**
  - e.g. olive oil, rapeseed oil, butter, margarine, cream, sugar, jam, honey, marmalade, sweets, chocolate, biscuits, cakes, ice-cream, crisps
- Introduce **oral supplements**

The New patient
What to drink after surgery

Take enough fluids and salt to stop dehydration
- Aim for 1.5-2.0 litres (3-4 pints or 8-10 cups) of fluid per day

-water, tea, coffee, unsweetened fruit juices or sugar free squashes

- Add extra salt to your meals.

- ½ - 1 teaspoon a day

- If your output is ↑ ; you may need anti-diarrhoeal medication (loperamide) and rehydration solution e.g St. Marks electrolyte mix
- 30-60 minutes before meals

The Established patient

Alcohol

- Promotion of drinking in moderation
  - 21 Units a week for men
  - 14 units a week for women
  - 1-2 alcohol free days a week
  - 1 unit
    - ½ pint beer
    - Pub measure spirit
    - Small glass wine

Individual foods and pouch function

- You are Unique!
- Individual tolerances
- Follow a varied, balanced diet – only avoid foods which cause unacceptable pouch function
- Tolerance to certain foods may change over time
- Food and symptom diaries can be useful
- Introduce one food at a time

Food affecting pouch function

Symptoms	Associated foods
Foods that thicken the stools	– Bananas – Rice – Bread – Potatoes – Tapioca – Pasta – Instant mash – Jelly babies/marshmallow – Psyllium husk/oats
• Foods that loosen the stools 	– Chocolate – Raw fruit/vegetable – Highly spiced foods – Greasy foods – Sugary foods – Fruit juice – Leafy green vegetables

Foods frequently associated with symptoms

Symptoms	Associated foods
Increased stool output	Fibrous foods, spicy foods, alcohol, milk, caffeinated drinks, fried food, chocolate
Decreased stool output	Bread , rice, pasta, bananas
Anal irritation	Spicy foods, nuts, seeds coconut, citrus fruit, raw fruit & vegetables
Increased wind	Broccoli, sprouts, cabbage, cauliflower, onion, garlic, leeks, asparagus, beans, spicy foods, beer, milk, fizzy drinks, minimise swallowing air
Increased stool odour	Fish. Onions, garlic, eggs

Wind consists of gases produced during digestion from 2 sources:
→**air swallowed** with food
→**bacterial fermentation** of carbohydrate rich food leaving residue in the pouch

- **Wind can be reduced by:**
  - Eating **small regular** meals
  - Eating **slowly** and **chewing food well**
  - Avoiding smoking, sugar free gum, taking drinks through a straw, fizzy drinks
  - Reducing **fiber** intake (white bread, rice, pasta, refined cereals, small portions fruit and vegetables but avoiding skins, pith, seeds, pips)
  - Reducing intake of **pulses** (beans, peas, lentils)
  - Reducing intake of **fructans** (garlic, leeks, onions, artichoke, chicory)
  - Reducing intake of **brassicas** (cabbage, sprouts, broccoli, cauliflower)
  - Reducing intake of **resistant starches** (pre-heated pizza, dry pasta, reheating starchy foods i.e. cold potato)
  - Trial a period of lactose free dairy – check for **lactose intolerance**

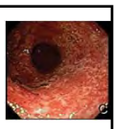
Eating patterns and pouch function

- Study of 69 people showed
  - Pouch opened 5-8 times a day (51 pts)
  - Bowel frequency with no. of meals
  - Pouch opened ½ - 4hrs after a meal (28pts ½ - 2hrs after a meal
  - Stool output greatest after main meal of day (48 pts)

- To *improve function*
  - No more than 3x meals a day
  - Experiment with timing and size of meals
  - Keep a diary to evaluate meal and pouch pattern
  - Eat last meal at > 2 hours before bedtime
  - You are Unique. Check your own bowel habit to determine how long after a meal you can leave home
  - Food choices based on your tolerance
  - Avoid unnecessary restrictions
  - Try one new food at a time
  - Use food and symptom diary
  - Tolerance changes with time- re try
  - Eat slowly/Chew food well /Mindful eating

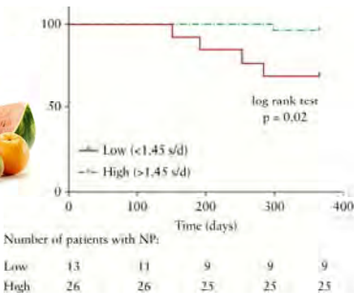
?Radar key/ Toilet urgency card

Pouchitis



- Probiotics
  - Specific strains used (i.e.lactobacillus, acidophilus bifidobacteria)
  - Vivomixx preparation (**previously known as VSL#3**) 1-2 sachets/1-4 capsules (3-6g a day)
  - ↓Pouchitis developement (Gionchetti et al (2003), Gosselink et al (2004)
  - ↓ Pouchitis recurrence (Mimura et al (2004), Sator (2004)

Association between fruit consumption and the development of pouchitis within one year.



Number of patients with NP:

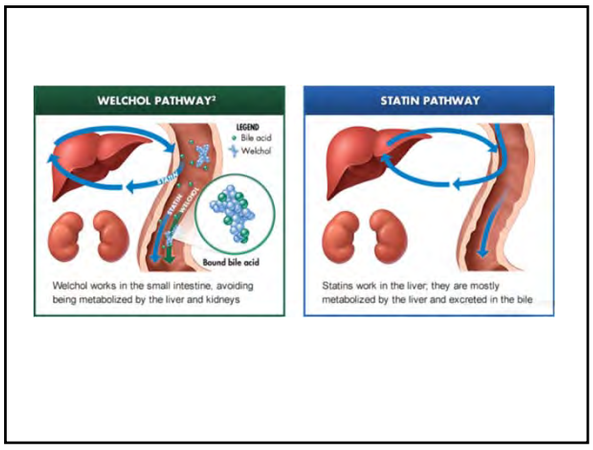
Low	13	11	9	9	9
High	26	26	25	25	25

Journal of Crohn's and Colitis, jjz053, https://doi.org/10.1093/ecco-jcc/jjz053
Published **4/3/19**. NP=Normal Pouch All patients [n = 39] 30% vs 3.8%

OXFORD UNIVERSITY PRESS

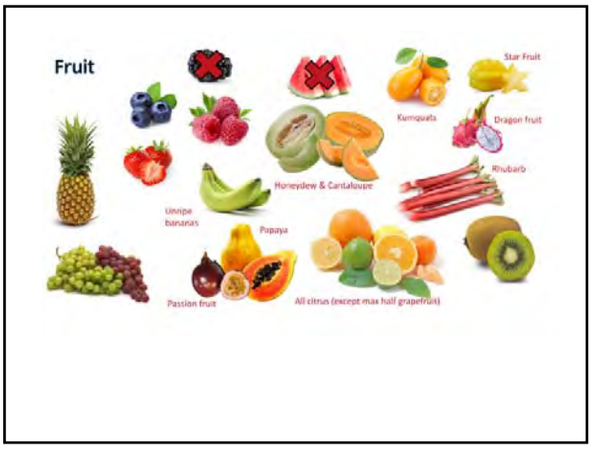
Summary

- After surgery take a soft low fibre diet, eat slowly and chew well for 2-4 weeks to stop blockages at the ileostomy closure site
- Long term aim to promote a balanced diet
- Prevent nutritional deficiencies
- Little and often approach
- Experiment with size and timing of meals
- Take enough fluids and salt
- Maintain a healthy weight
- Intolerances to certain foods will vary between individuals
- Avoid unnecessary restrictions
- Specific symptoms may be reduced by avoiding specific foods
- Seek advice if needed


WELCHOL PATHWAY²
LEGEND
Bile acid
Welchol
Bound bile acid
Welchol works in the small intestine, avoiding being metabolized by the liver and kidneys
STATIN PATHWAY
Statins work in the liver; they are mostly metabolized by the liver and excreted in the bile

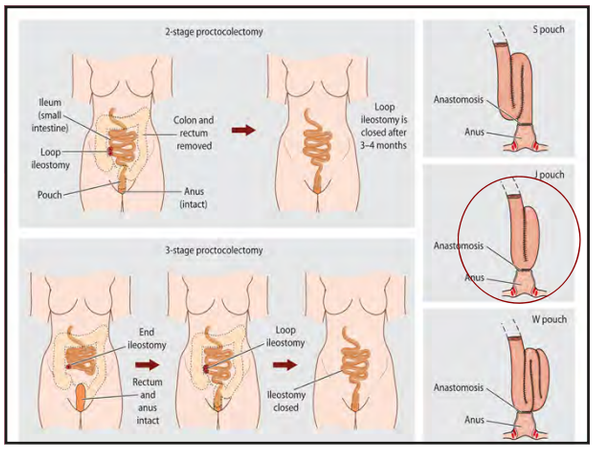

Support
https://patientwebinars.co.uk/ibs/
https://www.j-pouch.org/pages/diet
https://www.ostomy.org/
https://www.crohnsandcolitis.org.uk/
BDA
Food Fact Sheet

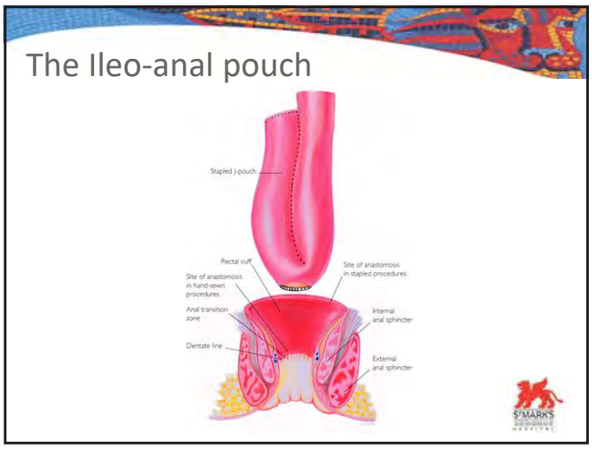

Vegetables


Fruit
Star Fruit
Kumquats
Dragon fruit
Rhubarb
Honeydew & Cantaloupe
Unripe bananas
Papaya
Passion fruit
All citrus (except max half grapefruit)

The ileoanal pouch and how it works

St Mark's Hospital's Clinical Nurse Specialist LISA ALLISON gives the lowdown on pouch function





Normal pouch function

- Normal pouch function : 4-6 times in 24hrs, occasionally one nocturnal motion
- Loose stool (porridge consistency)
- Ability to defer defaecation for up to 1 hour
- No faecal leakage in the day, may occur at night
- Very individual

When to start investigating

- Increased pouch frequency
- Urgency
- Bleeding
- Abdominal pain
- Bloating
- Fever/night sweats
- Lethargy
- Ineffective emptying of pouch
- Nausea/vomiting
- Incontinence
- Leakage
- Symptoms of fistulae (sepsis, vaginal/perianal discharge

Initial investigations

- Abdominal examination
- Digital exam- check for narrowing
- Rigid pouchoscopy- limited views
- Flexible pouchoscopy with biopsies - can exclude or confirm pouchitis, cuffitis, dysplasia, pre-pouch ileitis, strictures, Crohn's. Can also balloon dilate strictures in mid pouch
- Bloods: FBC, U&Es, LFTs, Vitamin B12, Vitamin D, ferritin, folate, Coeliac screen

Inflammatory pouch problems

Most common:

- Pouchitis
- Cuffitis (retained rectum)

What is pouchitis?

- Pouchitis is an inflammatory response to changes within the pouch, aetiology is unknown
- It is thought to be triggered by changes in the intra-luminal bacteria within the pouch
- 20-50% of patients will suffer from pouchitis at some time Moskowitz et al 1986; Nassar et al 2006

Possible causes/theories of pouchitis

- Multi-factorial
- Imbalance of bacteria in the pouch
- Immunological factors
- Excessive bile acid production
- ?Genetics – increased incidence in patients with Primary Sclerosing Cholangitis (PSC)

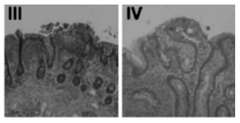
Common symptoms

- Frequency
- Loose stool – no change with diet or Loperamide
- Abdominal pain/cramping
- Generally feeling under the weather
- Possibly fever
- Possibly bleeding
- Symptoms not getting any better, progressively getting worse

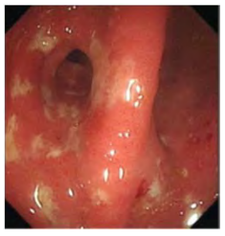
Pouchitis

Diagnosis based on:

- Compatible symptoms
- Endoscopy
- Histology



Clinical
Stool frequency
Faecal urgency or abdominal cramps
Rectal bleeding
Fever



Pouchoscopy

- Simple pouchitis (acute) one episode per year
  - antibiotic responsive
- Complex pouchitis (chronic) – more than 3 episodes per year
  - antibiotic responsive
  - antibiotic dependent
  - antibiotic resistant

Most common treatment

- 14 day course of Ciprofloxacin – 500mg twice a day
- If does not resolve or patient has a rapid relapse then needs a 28 day course of Ciprofloxacin 500mg twice a day alongside Metronizadole 400mg three times a day

Cuffitis symptoms

- Frequency
- Urgency
- Bleeding
- Feeling of 'something up there'
- Anal pain

Treatment of cuffitis

- Mesalazine suppositories 500mg PR bd for 6 weeks
- Predsol suppositories 5mg bd for 6 weeks
- Pouch revision surgery if rectal cuff is long

Non inflammatory pouch problems

Common:

- Ineffective emptying of pouch
- Pouch anal anastomotic narrowing

Symptoms of ineffective emptying

- Multiple visits to the toilet in a short space of time
- Knowingly not emptying effectively
- Straining
- Struggling with loose stool and porridge like consistency
- Leakage
- ? Narrowing of the pouch anal anastomosis

Strictures in pouches

- Develop above, in or below the pouch
- Most commonly at pouch anal anastomosis
- If there is a narrowing at the pouch anal anastomosis patient will require an EUA and dilatation
- Post theatre some patients will be taught how to use a Hegar dilator to help maintain anastomosis

Hegar dilators

- If no narrowing of the pouch anal anastomosis found then go through pouch emptying techniques
- Correct positioning on the toilet
- Standing up, sitting down
- Wiggling hips

Defaecating pouchogram

Medena/ileostomy catheters

Biofeedback

- Non surgical and non invasive
- Behavioural /holistic approach
- Learning through reinforcement
- Involves advanced assessment, patient education, bowel and muscle retraining
- Practical techniques are taught to control and improve bowel symptoms and function
- Dietary advice

- Loperamide and/or Fybogel usage
- Anal skin care
- Pouch training
- Improving anal sphincter tone and pelvic floor muscles
- Renew Inserts
- Irrigation
- Psychological support
- Follow ups every 4-6 weeks for 5 appointments

Qufora and Renew Insert

Follow up at St Mark's

- All patients who have had a pouch for ulcerative colitis
- Information about what to expect with the pouch is reiterated in detail when patient is on the ward following closure
- A date is made before discharge for the patient to come to clinic in 6 weeks

- Assess how patient is managing their pouch at 6 weeks, 3 months, 6 months and 12 months
- Cleveland Global Quality of Life score is used
- Can use to judge against previous visit/review
- Pouch functional score – symptoms
- Pouch functional score - restrictions

- Diet, lifestyle, routine, discuss any concerns
- Check stoma closure site for healing
- Digital examination of pouch anal anastomosis if deemed necessary
- Pouch nurses can liase with surgical/medical teams if needed
- Point of contact between clinic appointments

Patients who can be discharged

- If patients with a history of UC are well at 1 year following closure then discharged
- Can continue to make contact with pouch nurses via phone and email if needed

Patients who are not discharged

- Patients with FAP are followed up by the Polyposis team but can contact us at anytime
- Pouchoscopy annually for patients with a history with dysplasia or cancer when they underwent colectomy
- Annual clinic review for patients with a history of chronic pouchitis and possible pouchoscopy depending on circumstances
- Patients with Primary Sclerosing Cholangitis (PSC) need to remain under gastroenterologist

Routine follow up

Blood tests required annually:

- Full blood count
- Urea and electrolytes
- Liver function tests
- Calcium
- Vitamin D

- Vitamin B12
- Patients who are deficient will require 3 monthly vitamin B12 injections
- Folate
- Ferritin

Conclusion

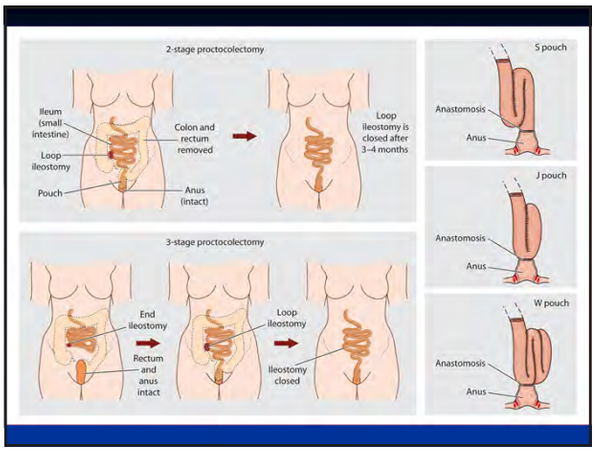
- Patients need to be fully informed before proceeding with pouch surgery
- Pouches can have complications – the majority can be investigated and treated
- Supporting the patient needs to be a multidisciplinary effort
- Some patients with pouches will never be discharged
- All patients with a pouch require annual blood tests

Pelvic floors, biofeedback and daily control

Some top technical tips from ELLIE BRADSHAW, St Mark's Hospital's Lead Biofeedback Nurse

Pelvic Floor Perfection and the Importance of Emptying

Ellie Bradshaw Lead Nurse
Biofeedback



What is Biofeedback?

- Behavioural Therapy
- Bowel and muscle retraining including pelvic floor muscles (continence and support of the pouch)
- Widely advocated as a first line non invasive treatment for constipation, evacuation disorders and faecal incontinence

What Does Biofeedback Involve?

- Advanced assessment
- Patient education
- Bowel and muscle retraining
- The teaching of practical techniques to control and improve bowel symptoms
- Psychological support

How Does This Relate to Pouch Function?

- Literature shows that a "good pouch function" is often related to aspects such as: lower frequency of pouch emptying, ease of evacuation and faecal continence
- Conversely, pouch "dysfunction" can be said to include increased frequency of pouch emptying, evacuatory problems and faecal/ mucus incontinence (or leakage)

Pouch Dysfunction

- Pouch Frequency – Loperamide useage, anal skincare, dietary advice, pouch training
- Evacuatory Dysfunction – evacuatory positioning and techniques, use of Medina catheters and water irrigation
- Faecal/ Mucus Incontinence – improving external anal sphincter tone and pelvic floor muscles, prevention using anal plugs

Pouch Frequency

- Pharmacotherapy- Loperamide, Codeine, Cholestyramine
- Skin protectants - barrier creams, diltiazem, lignocaine
- Dietary advice/ modification- Low fibre, exclusion diets, FODMAP

Pouch Training

- Urge Deferral – Training to improve pouch capacity and behavioural response
- Understanding of continence mechanisms
- Insight into brain/bowel signals with visual Biofeedback

Evacuatory Techniques

- Humans are designed to open their bowels squatting – this makes complete evacuation anatomically and gravitationally easier
- The position can be emulated using a low foot stool, with elbows on knees and back straight
- Standing up for 10-20 seconds and sitting down again can be useful

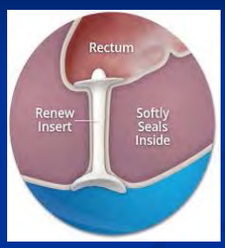
Irrigation to Empty

Pelvic Floor and Sphincter Exercises

- Teaching isolation of the External Anal Sphincter and the Pelvic Floor Muscles as a group
- Using exercise programmes to promote strength, endurance and fast response of the muscles
- These exercises may also act as a preventative for future problems with compromised continence

- "Nonrelaxing Pelvic Floor Dysfunction Is an Underestimated Complication of Ileal Pouch–Anal Anastomosis" Quinn et al Clinical Gastroenterology and Hepatology 2017;15:1242–1247

Prevention of Leakage



- "Acceptability, effectiveness and safety of a Renew® anal insert in patients who have undergone restorative proctocolectomy with ileal pouch–anal anastomosis"
- J. P. Segal et al, 2018

- "Incontinence following restorative proctocolectomy occurs in up to 25% of patients overnight."
- In a small study, the Renew® insert can be both acceptable and effective and is also associated with few safety concerns. It is also associated with significant reductions in night-time seepage.

Key Points

- Literature shows that a "good pouch function" is often related to aspects such as: lower frequency of pouch emptying, ease of evacuation and faecal continence
- There are many different techniques and strategies for optimising pouch function so don't be afraid to ask!

For fuller versions of these Information Day talks, visit the website pouchsupport.org

Why it's vital to take your daily dose

Key advice on drugs and medication and when to use them by UCHU MEADE, St Mark's Hospital's Lead Clinical Pharmacist

Pharmacokinetics

ADME

1 Absorption → 2 Distribution → 3 Metabolism → 4 Elimination

Pharmacokinetic

Why is this important for pouch patients?

The most common route of medication administration is the oral route: Tablets, Capsules and Liquids

A = Absorption from the GI tract

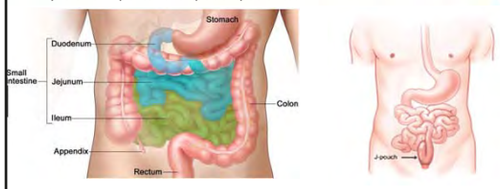
The majority of medications are absorbed from the jejunum

Oral Bioavailability

- The amount of medication that reaches the systemic circulation
- Based on healthy individuals

Pharmacokinetic

Why is this important for pouch patients?

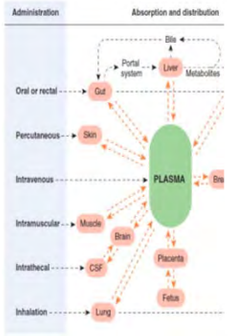


A = Absorption

- ✓ The amount of medication that reaches the systemic circulation
- ✓ Oral Bioavailability
- ✓ Sufficient amounts of an active form of the medication reach the site of action to elicit a pharmacological response

Caution- preparations designed to release medication in the colon
Important to explain your GI anatomy to anyone prescribing you medication

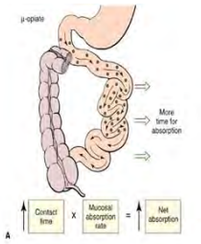
The Main Routes of Drug Administration



Prescription Only Medications (POMs)

Can only be prescribed by a healthcare professional with the relevant qualifications

Loperamide and Codeine: How do they work?



Acts on gut receptors

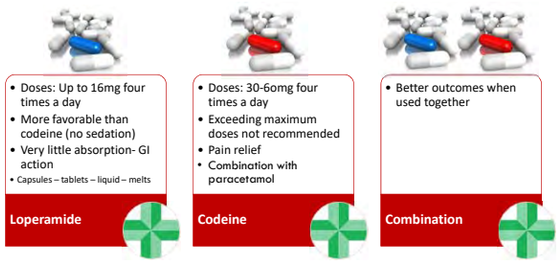
To reduce bowel movement

Allowing more contact time

So increasing absorption

Resulting in:
Reduces bowel frequency & quantity

Loperamide & Codeine



Loperamide	Codeine	Combination
• Doses: Up to 16mg four times a day • More favorable than codeine (no sedation) • Very little absorption- GI action • Capsules – tablets – liquid – melts	• Doses: 30-6omg four times a day • Exceeding maximum doses not recommended • Pain relief • Combination with paracetamol	• Better outcomes when used together

Loperamide and Codeine: how to take

- How to take
  - 30minutes to 1 hour before meals
  - Allows drugs to work before eating
- Side effects
  - Balance with higher doses
  - Loperamide: abdominal pain, bloating, nausea, flatulence
  - Codeine: drowsiness, headaches, low blood pressure, nausea & vomiting

Loperamide- 8 in 24hrs label- not for you ☺

Vitamin B12
Cyanocobalamin

A = Absorption from the end of the ileum

So need to give via an intramuscular injection

1mg every 1-3 months from GP or hospital

Vitamin D

A = Absorption form the jejunum

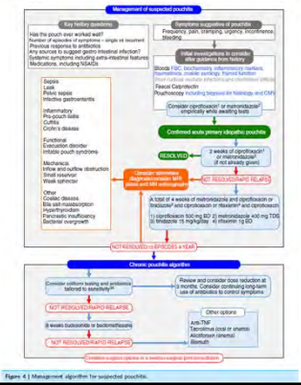
Oral: Colecalciferol 800-1000 units once a day
intramuscular injection: Ergocalciferol 300 000 units 1-3 months from GP or hospital

Levels to monitor absorption of the drug

Pouchitis

1st line
Ciprofloxacin
Metronidazole
2 weeks

2nd line
Tinidazole
Rifaximin
4 weeks



How to take

- Take regularly
- Take at the same time each day
- Ensure the timing fits in with your lifestyle
- Don't misses doses – even if you are feeling better
- Finish your course

- To avoid antimicrobial resistance and relapse
- Which could lead to treatment escalation

Ciprofloxacin

Driving: May impair performance of skilled tasks (e.g. driving); effects enhanced by alcohol
Absorption of ciprofloxacin reduced by oral antacids, calcium, iron, zinc salts, dairy products (give at least 2 hours before or 4 hours after ciprofloxacin)

Metronidazole

Avoid alcohol during course and for 5 days after stopping

Tinidazole

Same family of medication as metronidazole
Possible interaction with alcohol

Rifaximin

Action in the GI tract very little aborption

Probiotics: VSL#3®

- No longer available on prescription via the GP
  - Can buy from Pharmacies and Health food stores

Powder:

containing 8 strains of live, freeze-dried, lactic acid bacteria

Contains traces of soya, gluten, and lactose

Other POMs used

- Amitriptyline
- Ispaghula husk
- Steroids
- Nitrofurantoin and Colistin
- Mesalazine
- Glyceryl trinitrate and Diltiazem
- Paracetamol
- Buscopan
- Dioralyte and St Mark's electrolyte mix
- Colestyramin and colesevelam

Prescription charges

http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx

1st April 2019

£9 per item

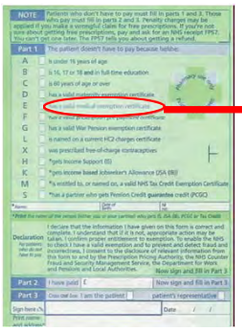
The same item e.g. drug, strength and formulation

Local and hospital pharmacies

Who is exempt?

have a specified medical condition and have a valid medical exemption certificate (MedEx)

Medical exemptions



- **Permanent fistula (colostomy, ileostomy, laryngostomy) which requires continuous appliances**
- Diabetes inspidus
- Diabetes mellitus
- Hypoparathyroidism
- Myasthenia gravis
- Myoedema (hypothyroidism)
- Epilepsy requiring continuous therapy
- Continuing physical disability which means person cannot go out without help. (Temporary disabilities are not included if they last several months)
- Cancer (recently included)

What about other chronic conditions requiring regular medications?

Prepayment cards

Prescription Prepayment Certificates (PPC)

- ✓ 3 months: £29.10 (saves £ if you require 4 items or more in 3 months)
- ✓ 12 months: £104.00 (saves £ if you require 12 or more items per year)
- Available from community pharmacies, GP surgeries, online and by phone
- 12 month PPC - 10 monthly direct debit instalment payments

Over the counter medication (OTC)

No prescription needed

Pharmacy only (P)

Must be sold under the supervision of a pharmacist

General Sales List (GSL)

No pharmacist supervision needed

Indication of use and pack size tend to be restricted

Over the counter medication (OTC) sales 2016

OTC Sales 2016

Over The Counter (OTC) medication

Pain Relief – 6m
- Topical
- Oral

Coughs, colds and sore throats – 5m
- Liquids
- Decongestants

Skin - 4.5m
- Infections
- Dry skin conditions

Vitamins, minerals and antitiredness - 3.6m
- Iron levels
- Absorption

Gastrointestinal – 2.9m
- Indigestion remedies
- Laxatives
- Diarrhoea treatments

Can cause ulceration in the pouch with potential bleeding

Pregnancy and Breastfeeding

Safety data: Pregnancy and Breastfeeding

- No clinical trials (ethical issues)
- Animal data
  - Sometimes hard to apply to human models
  - Many factors to be taken into consideration
- Use general and basic pharmacology principals
- Look at your condition and prognosis
- Help you make the right choice

Where to find information

- Patient Information Leaflets (PILs)
  - Found inside the medicine box
- Doctors, Nurses and Pharmacists
- On line – NHS sites
- Charities

Thank you for listening

David and Bev's chopper ride

What do a pair of Choppers, the UK's longest canal and two energetic cyclists have in common? Raising funds for Red Lion Group, of course. Our hardy chairman David Davies and his partner Bev enjoyed a weekend break at the end of June – cycling more than 100 miles on tiny Choppers!

Red Lion Group chair David Davies and his partner Bev dutifully hoiked their Raleigh Choppers out of the bike-shed one June summer's day and pedalled up the road – for 127 miles!!

Though the original Chopper, which was launched in 1969 and known as "The Hot One", was designed to go on trips to the shops of up to 500 yards, the doughty pair were using theirs for a two-day marathon along the bumpy banks of the Leeds to Liverpool canal. And their aim couldn't have been more commendable – to raise money for the Red Lion Group.

They set off in bright Saturday sunshine from Liverpool's famous Albert Dock and managed to cover the 62 miles to Blackburn, Lancashire (it sounds like a verse from a Beatles' song) in almost 10 hours with just a couple of snack stops en route.

"There was abundant wildlife, with swans, geese and ducks all raising their broods; herons still as statues, fish and dragon flies in abundance," says David. "There was also lots and lots of litter. We made good time and negotiated the ramps and bridges with no problems. The Choppers were working well and there were plenty of walkers along the canalside to try and avoid – crucial tip, make sure to have a cycle bell on your bike," says David.

All very straightforward you might have thought. But the next day proved far more testing! After a fish-and-chip supper and an overnight stay in a B&B, the pair set off at 5.30am and stopped almost immediately for an emergency supply of Vaseline from an all-night garage! "Then it was just heads down and keep pedaling into the wind, mile after mile, bridge after bridge, lock after lock," on their iconic mini-cycles at speeds of seven to nine mph depending on the wind – or lack of it.

"Choppers are not built for off-road riding and, because of their small front wheels, we felt every bump and divot, of which there were many. The canal also has distance markers every half mile, which was a

The sign that says it all (as if any proof were needed, of course)

useful progress marker, though after a while it seemed to take longer and longer to tick them off," says David.

Their next milestone was Shipley where they paused for a fortifying bag of chips. Then on to Keighley, through Saltburn and Bradford and, ultimately, the canal's basin in Leeds, their final destination where they were greeted by Bev's children and a large bottle of bubbly.

"The bikes held up magnificently and were a constant source of amusement for people we passed along the way," says David. "The only issues were my mudguard became loose and I had two punctures, one to each lung (old joke). By the end of our endeavours we were mighty weary but we were delighted to reach the finish."

The doughty duo have expressed their heartfelt thanks to you and everyone else who supported them and donated money for the Red Lion Group. Their final tally came to an impressive £250 for Red Lion Group.

Dynamic duo: a triumphant David and Bev compare Choppers at the finish of their marathon

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Join the Red Lion Group

- Newsletter twice a year with all the latest news, views and events
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(July 2019)

To: The Treasurer

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