



# ROAR!

***It's all in the mind. Or is it?  
See pages 13 to 17***

ISSUE 60 • CHRISTMAS 2020

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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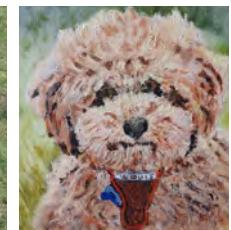
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**Please support the Red Lion Group**  
**Registered Charity number 1068124**



# RED LION

## Pouch Support

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

Have you joined the Zoom revolution? Of course you have – and so have I. And even if you haven't, you've certainly heard all about it from the RLG alerts about our lively summer series of speakers and the much-praised monthly members' workshops.

It's the second best news event of the year! The best is the vaccine, of course. Though Christmas is a little different this year, our spirits have certainly been raised by the ingenuity of the pharmaceutical companies. Who'd have thought it three months ago?

Then there's *Roar!*. At first glance, it looks like a very serious magazine because its main theme is mental health. But mental health is not just serious, it is much more important than that.

It is now seen as a vital part of our personal make-up hence the number of initiatives by governments, public bodies, hospitals and individuals so I'm delighted to include some inspiring stories from four lovely Red Lions about how they coped and a professional overview from our new patron Janindra Warusitavane on pages 13 to 17.

Talking of enterprise and initiatives, I think you'll enjoy reading about the exploits of J-pouchee and rock-climber Michael Teanby on pages 7 to 8. It's just another example of somebody who has made the most of his talents and used his inner strength to help recover from a tricky spell.

But mental health is not just serious, it is much more important than that.

And just to remind you of those lazy, crazy days of summer, family holidays, alluring scenery and the habitats of some of the world's most exotic animals including the red lion

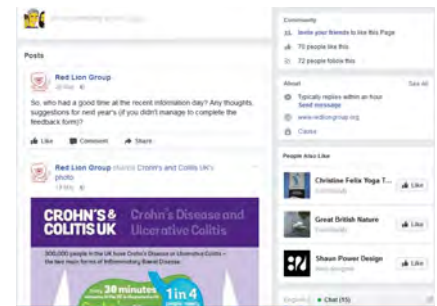
(yes, I kid you not!), you can savour the adventures of Red Lion member Susan Burrows during a pre-lockdown trip to Kenya on pages 9 to 11.

Talking of exotic, do you remember the last time you enjoyed a plate of mushrooms? Mere memories for some of us! But not any more thanks to Theresa "Mrs Versatility" Parr. Try her delicious recipe for mushroom soup on page 6. It's as good as the original – better actually – and without the digestive snags.

And no December *Roar!* would be complete without a seasonal scoop. Did you know that the UK's top rugby union referee Nigel Owens MBE who has just overseen his 100th international – more than any other global referee – has ulcerative colitis. Read about his successes, struggles and secrets on page 6.

Meanwhile the RLG committee and I wish you a very happy Covid-aware Christmas and New Year.

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/](http://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/](http://pouchsupport.org/faqs/)

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## A message from the chair

**A**s I sit down to write my chairman's report for Roar! my very first concern is to hope that you are all well and that you and your families have escaped the worst of the pandemic so far. Hopefully by the next Roar! the situation will be under control and we will have an approved vaccine, which will confer long-term protection from this awful virus.

Mental health has been drawn in to sharp focus during the pandemic, with communities and individuals feeling vulnerable and isolated and social interactions drastically reduced due to the risk of infection. This issue of *Roar!* looks at various aspects of mental health for pouchees and the editor Christopher Browne has elicited some highly personal stories and reflections from the membership.

It is becoming clearer that the pouch journey, from critical illness (for some) through the stomach stage to the challenges of confluent but challenging "normal" bowel function can have more profound effects on our psyche than was originally thought. Attendees at recent Information Days will recall the fantastic presentations by Dr Yoram Inspector, head of the psychological medicine unit at St Mark's Hospital, and his entertaining insights into the psyche of bowel disease (recordings of his presentations, along with others, are available on the RLG website at [www.pouchsupport.org](http://www.pouchsupport.org)).

Technologies to facilitate communication have become popular and "Zoom" is now a new word in most people's vocabularies. This online meeting platform technology has risen from relative obscurity one year ago to universal familiarity thanks to Covid's social restrictions and the need to work from home. Your committee acted with great haste to provide Zoom-based webinars to keep members informed of the latest pouch developments in



the summer (as reported previously) and we have continued this inspired initiative with an ongoing series of interactive meetings for pouchees to get together and discuss pouch-related topics from the luxury of your own sofas.

We have hosted five such events to date and they have proved to be increasingly popular

We have hosted five such events to date and they have proved to be increasingly popular, with participants feeling suitably relaxed and comfortable to share their comments, concerns, tips and questions in a supportive and friendly forum with fellow pouchees and potential pouchees. Pouch longevity ranges from just six weeks all the way up to 43 years, with the eighth and ninth people to have pouches in the UK joining for a chat.

These monthly events have proved very popular and will continue for the foreseeable future. They

are free for members to join and all the details can be found at <https://pouchsupport.org/attend-red-lion-group-internal-pouch-zoom-forum/>. The forums are held on the first Monday of every month and it looks like we will be continuing them well into 2021. Please remember to register beforehand to receive your dial-in instructions.

I offer my thanks to Gary Bronziet (Membership Secretary and IT guru) for hosting the events and to Theresa Parr (Minutes Secretary) and Christopher Browne (Roar! Ed) respectively for chairing the ladies and gents breakout sessions.

The RLG committee has been a very stable community of approximately 10 people over recent years – and there are a few changes to report. Susan Burrows (Membership Secretary) and Sarah Bowes-Phipps (Secretary) stood down during the Summer after many years of loyal and very active service to RLG and they will be greatly missed. While Lisa Allison, pouch nurse specialist at St Mark's, an ever-present on committee for many years and chairman of RLG for 5 years prior to me, has taken on a new role as IBD nurse specialist at London's Royal Free Hospital and has therefore stepped down from her role in RLG.

Lisa has been a long-standing stalwart and supporter of RLG and

worked tirelessly alongside her very demanding professional workload to provide real pouch nursing experience from the front line of the NHS. We are very sad to see her go and we wish her very well in her new role.

I am delighted to say that a modest recruitment campaign led to an avalanche of excellent candidates

I am delighted to say that a modest recruitment campaign led to an avalanche of excellent candidates, and so it is with great pleasure that I am able to announce the following people, who will be seconded on to the committee for now and, hopefully, in due course, the membership will vote for them to become full trustees at the next AGM:

- Laura Dunn – chair of the Kangaroo Club, a “sister” charity to RLG, providing similar support to people with pouches created by surgeons at Oxford’s John Radcliffe Hospital
- Sinead MacDonald – she has a track record of voluntary support for social causes and is a grateful pouchee who is keen to give something back
- One of the team of clinical nurse specialists at St Mark’s Hospital who will attend committee meetings on a rotational basis

Please join me in welcoming Laura, Sinead and the St Mark’s specialists to the committee. I would like to thank all of the candidates who put themselves forward on your behalf, with commiserations to those who were not successful. As you can see from the above, it was a very strong field.

Enjoy this latest version of *Roar!* and please tell your fellow pouchees, your friends and family about us as we would be delighted to have more members in this friendly and supportive pouch community.

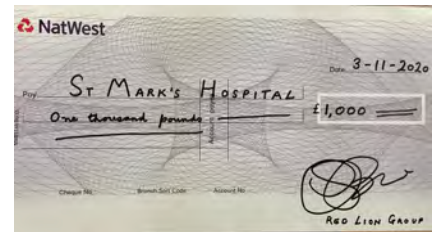
DAVID DAVIES

## RLG donation for pouch research



Jason Bacon, CEO of the St Mark’s Hospital Foundation, receives a cheque for £1,000 from Christopher Browne, RLG committee member and *Roar!* editor (right), at St Mark’s Hospital, Harrow.

The money, which was donated by the Red Lion Group, will help fund key pouch-related research at St Mark’s Hospital. Mr Bacon commented: “Medical research is



expensive and we rely greatly on donations such as this to continue our world-class projects.”

## RLG’s new membership secretary

IT guru Gary Bronziet is the Red Lion Group’s new membership secretary.

He recently took on the role from Susan Burrows who did a sterling job liaising and looking after new and established members for almost eight years.

Gary or “Gazzer”, who was a computer software developer for many years, has managed the website and RLG’s IT and social media activities for almost four years. He also oversaw a recent overhaul of the website and handles the hosting and alerts for our latest Zoom talks and forums.

“I hope you are enjoying the new website which, after its recent revamp, now comes high in the



Google rankings for people looking for pouch-related help and support,” says Gary.

**Do we have your email address?**

**Gary has overseen a healthy rise in new RLG members however he says the database still has more than 50 members without email addresses. “If you are currently receiving emails from us – for example notifications of new articles on the website – then we have your address. If you are not sure, then please email me at membership@pouchsupport.org and I will check and add your email to our database if necessary,” says Gary.**

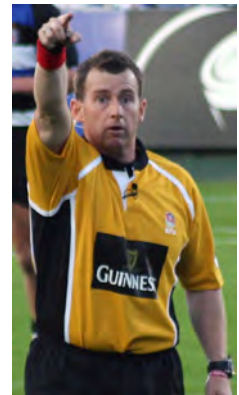
## A man for all seasons

During his distinguished career the Rugby World Cup referee **Nigel Owens** has faced several personal and health issues. One of them is ulcerative colitis

If you're a rugby lover you've undoubtedly watched highlights of recent world cups and caught a few glimpses of the hyper-active men-in-charge – referees like Nigel Owens. The 49-year-old Welshman is not only rated as probably the world's finest referee by both players and the public but as an articulate pundit who is better known than many of the internationals he oversees. Just ask his 374,000 Twitter followers. But there's a less glamorous side to Nigel's success. Take bulimia. It took Nigel many years to admit he suffered from this debilitating condition. Then in 2007 he faced another personal, potentially career-threatening, dilemma. He bravely decided to come out as gay. But what his fellow referees and rugby-loving public didn't realise is that he had another secret. For many years, Nigel has faced spells of

ulcerative colitis, one bout almost forcing him to pull out of the 2019 World Cup in Japan. "I've had UC on and off for 20 years, there's no cure as such for it at the moment. Very occasionally it will flare up, whether through stress, feeling tired, having a few beers, spicy food – no one can be certain," he told the [www.walesonline.co.uk](http://www.walesonline.co.uk) website. "Different things trigger it, but when it does happen there is a kind of uncomfortable pain in the stomach area and the feeling of a need to go to the toilet the whole time. You feel you need to go there and then, or an embarrassing accident might happen," he said. During the 2019 World Cup he was admitted to hospital in Tokyo where, he says, "they looked after me superbly and gave me some tablets and medication to settle it down.

So there I was, on a bed in a side ward, watching Wales's win over France on my mobile phone." Fortunately he recovered in time to referee the spectacular semi-final between England and the All Blacks which England won. Yet despite all these setbacks Nigel's reputation for fairness and on-field discipline has continued to burgeon – as well as his sense of humour. He told one player during a recent international: "I don't think we've met before. I'm the referee." We wish Nigel all the very best with his health and future career.



## Mushroom soup – a recipe for success

Many of us have had to ignore our dinner-time favourites since our pouch ops. But RLG's notes secretary **Theresa Parr** has come up with an answer

Happily, over time, I've found that I can eat most foods - apart from mushrooms! And, boy, do I really miss garlic mushrooms," says Theresa.

"I've tried various recipes for mushroom soup but few have that intensely mushroomy taste," she says. "However, after quite a bit of experimenting, this is my alternative version which seems to be closest to the flavour of garlic mushrooms without the digestive problems."

### Ingredients

- 50g dried porcini mushrooms
- 25g butter plus a large glug of oil (you can use all oil if preferred)
- 400g chestnut mushrooms, sliced
- 1 onion, finely chopped
- 1-2 garlic cloves
- 1 potato, finely diced
- 1½ pints of stock (I like to use strong beef stock as it brings out the mush-

room flavour but you can also use vegetable stock)  
1 heaped tablespoon of dried mushroom powder  
2-3 tablespoons of mushroom ketchup  
75ml of double cream  
Salt and pepper to taste



### Preparation

- Soak the dried mushrooms in about ¼ pint of boiling water for 30 minutes;
- Melt the butter and oil. Sauté the fresh mushrooms, onions and garlic gently for 5 minutes;
- Add the dried mushrooms together with the liquid and the potato;

Add the stock, cover and bring to the boil. Then simmer gently for 20 minutes.

Let it cool a little then puree in a liquidiser.

Stir in the cream. Then add salt and pepper to taste.

Enjoy!



## *I get high with a little help from my friends*

A healthy love of walking turned into a more serious passion for rock-climbing for **Michael Teanby** thanks to the advice of a friend and a change of girlfriend

**P**erched on a long narrow ledge 40 metres above the sea and about 40m below the clifftop, the pressure was growing, the pressure that had replaced the normal 'urge' for a bowel motion 11 years ago.

The setting sun was still warming the rock and my girlfriend was about to set off on the second pitch<sup>1</sup> of the Atlantis/True Moments/Freebird route<sup>2</sup>; the long weaving route is a bit of a sought-after classic on the Castle Helen sea cliffs of Holyhead.

hollow under a thick section of moss, there I perched baring all on the narrow ledge, hoping to make do with the four sheets of tissue I found in my back pocket. Thankfully we had the cliff to ourselves and I have a very understanding partner.

There were however a couple of day fishers in boats who had been watching our steady progress up the cliff, and a kayaking party passing by; I just hope they weren't using binoculars!

is 4-5m above the last good piece of protection. A fall certainly wouldn't mean death, but you'd definitely be shaken as the ropes caught you after 10m of free fall.

Fortunately all went well; we gained the top without further issue just as the sun was setting over the Irish Sea, the summer's heat still radiating from the red quartzite rockface that had facilitated our passage up the cliff, and the coconut scent of the gorse flowers drifting



As I was shifting uneasily on the belay stance<sup>3</sup> regretting my earlier choice of downing that second cup of tar [my name for coffee], my pouch emitted an audible grumble. Looking at my girlfriend I uttered 'the time is nigh', crag code for 'I really need the toilet'.

Unfortunately there was the problem of our current position; the only way off the ledge was another two hours of climbing. So, making a

Burying my embarrassment and scratching a small apology onto a nearby loose rock before using it to weigh down the moss, we turned our attention back to the route's second pitch the 'True Moments' traverse<sup>4</sup>.

Eugenie set off steadily, calming her nerves for what was to come – before her lies a 15m traverse across slightly suspect rock. At the end of the traverse a bold vertical 8m section of climbing remains, the crux<sup>5</sup>

by on the breeze. My life had never been better.

Occasions like this are surprisingly rare for me. Compared to the usual three hours, when climbing I can often go six to eight hours without needing the toilet, and despite not changing my diet in preparation, there is usually ample time to bag<sup>6</sup> a route and remain in comfort. I don't know why; maybe it's just the adrenaline slowing my digestive system

as blood is diverted to more critical areas, though that too is strange as I find climbing relaxing. There's an addictive flow to it, that perfect level of clarity and stress that comes from having your entire being focused on a single task.

Mountains and cliffs haven't always been part of my life. The Lincolnshire Wolds and salt marshes of my youth are quite devoid of rock. In 2011, two years after I'd lost my left kidney to an adhesion, a friend invited me to North Wales. Nothing special, just a walk up Snowdon, but I was hooked.

Over the next three years my bond with this friend grew stronger, walks got continuously steeper and more technical, and we'd spend a week each summer roaming across the mountains of Scotland. Technically it's called scrambling, it blurs the line between walking and rock climbing.

In 2014 I picked up my first rope. As our scrambles were getting steeper still, learning how to protect ourselves correctly seemed prudent. We were soon moving across terrain that three years before would have seemed like an insane proposition, but here we were playing in the mountains to our hearts' content.

Climbing has added a great deal to my 'mental toolkit'. My stress response improved, and my social skills, situational awareness, general fitness and outlook on life all shifted thanks to this wonderful pursuit and the welcoming community that surrounds it. Though not all without cost. As my love (obsession?) for rock and adventure grew, so did a rift in my relationship at the time. We'd been together for nearly 10 years but 2016 saw an end to that. She'd been with me through all my surgeries and stuck with me. There was once love but it had faded; arguments would start and end with threats like "you'll not find anyone who'll accept your condition".

At times I was no kinder; looking back I realise that I was becoming ever more distant and continually more uninterested in the relationship. That's what decided it, I wouldn't stay in one relationship out of fear of rejection in another; it just wasn't healthy. I'd always been completely open about my condition

with friends and climbing partners and never once had someone not welcomed me or accepted my toilet habits.

Enter Eugenie, the wonderful woman who four years later would be sat at one end of a narrow ledge 40m above the sea, giggling at the ridiculousness of the situation whilst I wrestled with my harness trying to relieve myself a couple of metres away, all the while hoping another team of climbers didn't appear. She's sat there giggling a lot to be fair - the multiple times I've forgotten my toilet kit whilst heading to a crag, only to watch me gather various leaves to use as a paper substitute. For reference the best is sphagnum moss, naturally moist and quite durable, as good as a baby wipe and

compostable!

Hopefully 2021 will allow me to return to the mountains I love so much, and maybe I'll see a few of you among them? Just remember a toilet kit, not all areas offer substitutes as kind on the skin as sphagnum moss.

### **The climber's glossary**

- <sup>1</sup> A pitch is a rope length (50-80m)
- <sup>2</sup> The name of a tour
- <sup>3</sup> The belay stance is a climber's position when anchored to a rock and paying the rope out to a lead climber
- <sup>4</sup> To traverse means to move horizontally across the rock instead of vertically
- <sup>5</sup> The crux is the hardest section of a route
- <sup>6</sup> To 'bag' a route means to finish it



## When I visited the home of the red lion

Holidays – remember them? RLG member **Susan Burrows** certainly does and writes vividly and entertainingly about her trips in *Roar!* magazine. Here's her account of a memorable visit to Kenya

**S**hortly before the first lockdown I had a once-in-a-lifetime trip to the beautiful African country of Kenya.

We (I and my group of 16 intrepid travellers) spent the first two days of our visit in Nairobi, the country's sprawling, bustling capital where we discovered that much of the city's land is owned by the famous Maasai, a semi-nomadic tribe based in Kenya and Tanzania.

Once known as fearsome hunters and fighters, the Maasai's main

we also saw  
the tail end of  
the wildebeest  
migration –  
a fantastic  
spectacle as  
the animals ran  
down towards  
the river to rest  
before moving  
on to the  
Serengeti

activities today are herding and raising cattle, goats and sheep. It meant that at busy road junctions we often found ourselves jostling with herds of cattle which were being driven by young boys from the tribe.

Another feature of Nairobi is that there are no traffic lights and getting across junctions and around roundabouts was, to say the least, haphazard. I think that at times we all had our eyes shut – much to the amusement of our driver.

We also visited the Daphne Shel-drick Animal Orphanage – named after the pioneering conservationist and author who rescued, reared and reintegrated orphaned elephants

into the wild for more than 30 years. Here the young elephants feed in mini-herds, coming back three times a day for milk feeding and, in the hot weather, mud baths.

### Out of Africa

Another highlight was a visit to the Karen Blixen Museum – founded by the Danish author of the same name – where both the house and

– a favourite spot for hippopotami – and until then I didn't realise how noisy they can be particularly at daybreak.

The reserve is 1,500 square kilometres of broad, biscuit-coloured savannah (tropical grassland) and plays host to the most spectacular array of birds and animals. At times the vast landscape is dotted with shadows from small clouds which



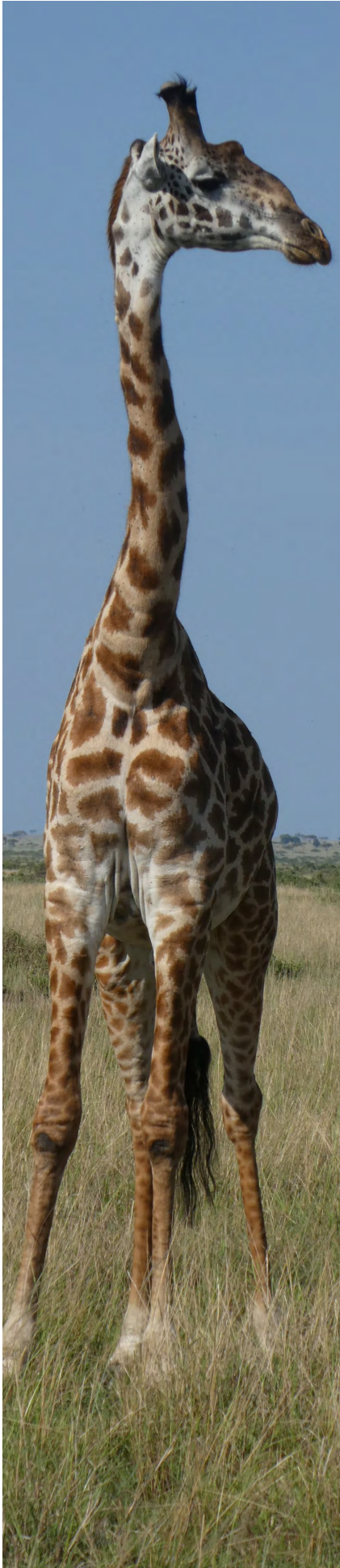
*It takes two to tango: A pair of secretary birds*

garden were made famous by the film "Out of Africa" which was based on the book she wrote.

On the third day we flew in a small private plane to the Maasai Mara [the word 'Mara' comes from the local dialect 'Maa' and means spotted], a huge game reserve in the Kenyan town of Narok. We stayed in a lodge on the edge of the Mara River

scud across the vast sky. It is adjacent to the Serengeti, another famous national park, and for five days we enjoyed the sights and sounds of the Maasai Mara on early morning, late afternoon and full-day game-viewing excursions.

And we saw so much – elephants, hippopotami, several prides of lions, a cheetah fast asleep under



*The world's tallest mammal*



*A group of Maasai women*



*A brave cheetah and her cub cross the road*



*Roar of approval: A hungry red lion*

a tree, a leopard and her cub who were notoriously shy but made their way around our vehicle to get to the other side of the track (see photo). There were zebras, giraffes (see photo), warthogs, cape buffaloes and, after many hours of searching, one of the 18 rhinoceri that still wander the Maasai Mara.

The list is seemingly endless but I must mention that we also saw the tail end of the wildebeest migration – a fantastic spectacle as the animals ran down towards the river to rest before moving on to the Serengeti.

Accompanied by an experienced Maasai guide we visited a typical local village. It was built along traditional lines complete with a cattle enclosure, outer palisade and mud and cow dung huts which are all built by the women.

We also discovered that cattle are a very important commodity, particularly if buying another wife!

Our five days on the Mara ended with a visit to a school. The school was supported by the lodge where we stayed and provides the portable water filtration systems to cleanse the local drinking water of the bacteria which causes many diseases. The children were on holiday but a number returned to tell us about their school life. They walk many miles a day to and from school but their enthusiasm for school life was uplifting.

### Health and safety

During the visit we took malaria tablets. It was not the first time that I had taken them and I had no adverse reactions to them. We drank bottled water as well as using it to clean our teeth. The water is clean but different chemicals are used to cleanse it and this can cause upset stomachs. I think that this applies in numerous countries. The toilets in the lodge were excellent and there was constant running water.

When we were on the game drives there were no toilets but the half-day drives were only about three hours long and the full-day drive probably around five hours. During the latter we stopped for a breakfast picnic and two of the vehicles were parked a short distance away and used to shield people who needed to use the facilities!

## My lockdown adventures with Ratty

When book-lover and former RLG committee member **Chris Lawton** decided to do a timely revamp of her growing collection of art books she met an unexpected foe



**H**ow have you been coping with Covid-19? Well, badly, indifferently or are you treating it as a type of challenge and finding some interesting things to do?

My brother and I certainly did! I have many art books, which were stored in various different places and whenever I wanted one, could never find it! Therefore I took advantage of the lockdown and catalogued and sorted them, putting them in a sideboard in the conservatory, which I use as an art room.

I also sorted out the sideboard in our conservatory, feeling very pleased that I now knew where everything was and could enjoy my books with renewed interest. I then cleaned and tidied the conservatory which helped make it even more inviting.

However my pleasure was short-lived because what I didn't know was that a certain creature would have other ideas!

One evening there was a rustling noise in my office. I thought it was just papers toppling over. The next day the noise came back. So I called my brother Christopher and togeth-

er we investigated but found nothing. When we looked on the other side of my office's wall which is in fact the back of the fridge we found that whatever it was had left it's calling card. And it wasn't a mouse!

After copiously sanitising and cleaning and, finally, replacing the fridge with a new one, we were reassured that the problem had been dealt with.

However, we failed to credit this creature with its incredible intelligence and military training. I once visited a Royal Marines sniper training centre in the Devonshire village of Lymptone. In order to pass the sniper training, the candidate has to hide in the middle of a gorse bush on Dartmoor and an officer has to pass only feet away and not detect the person. It is a remarkable achievement, which one would think impossible. Well, I think this creature had attended that course!

One evening, we heard a scratching and scraping noise of several decibels, coming again from the cabinet in the corner of my office. After shining a torch behind it, we could see the evidence but no sign of the

perpetrator, so we decided to ease the cabinet out a little. This proved to be too much for our 'sniper' and it shot out of its hiding place, between Christopher's legs. Christopher has never been interested in sport but I think he could have qualified for the Olympic high jump final that night!

In its panic, we think the creature – a rat – was making for a vent in the floor but when it found it blocked, shot back again towards the cabinet. We then spent the next hour securing the cabinet with netting, wood and board, till it was completely enclosed. Not even a lion could have escaped from our man-made lair. We went to bed pledging to deal with it in the morning.

Ha ha – how naïve can one get! The next morning we discovered Ratty had left a trail of calling cards and destruction, chewed the rubber tiling all over the floor and, obviously, exhausted from all that, had taken a well-earned rest on our conservatory furniture. We then had to take up all the rubber floor tiles, which were easily removable, and bin them. However, when we moved the sideboard near the back door which happened to be open, Ratty shot out and quickly scampered up the garden, through the hedge and out of sight! He must have spent the night there and not beneath the cupboard which we had spent a good hour securing.

The next three weeks were spent moving all the furniture from the



conservatory and the downstairs rooms, together with their contents (including my art books), cleaning the carpet, sanitising everything. We had to put some things upstairs. Finally we could just about navigate through it all to find the two vacant seats!

After sanding and varnishing the conservatory floor, courtesy of Christopher, a qualified cabinet maker, we were able to put things back, rear-

range and clean up Ratty's aftermath in my office, where my books are now on shelves for easy access.

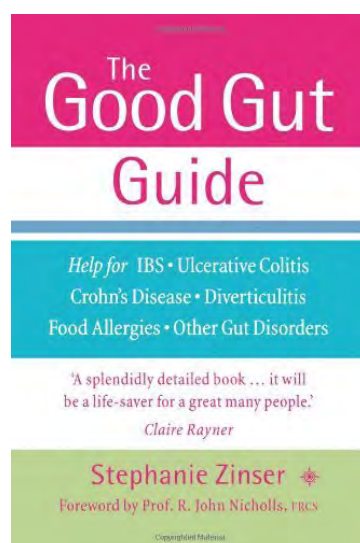
After our four-week experience we have decided that we won't go into the removal business or the lifestyle design business after all, even though we think we now have the qualifications.



## The Good Gut Guide

Did you know that apart from Zah Perry-Woodford's excellent *Ileo-anal pouch surgery for ulcerative colitis*, there's another guide to our remarkable insides written by a former member of the Red Lion Group?

Written by Stephanie Zinser, a former RLG committee member and press officer, the book, which is aptly titled *The Good Gut Guide*, covers everything from diet and stress to diverticulitis and alternative therapies such as aromatherapy and acupuncture. It also has a foreword by our patron, Professor John Nicholls. You can order a copy from Amazon for £2.99.



## Mind over matter – Roar!’s December mental health feature

**They say buying a property, getting married and having an operation are the three most important events in our lives. But how many of us actually prepare mentally for these experiences? Roar! editor Christopher Browne looks at how a group of poussees dealt with their illnesses before, during and after surgery**



**J**ust how fit are you? Or is fitness rather low on your list of priorities?

When faced with this question, I have no doubt most of you, like me, instantly think of physical fitness ie activities such as a morning or evening run, a swim or a bike ride, some regular indoor exercises perhaps or a game of tennis or golf.

Few-if any of us - think of mental fitness.

Yet our mental approach is as important to our well-being as our physical one. Some would say more so. For how can you perform an everyday task without putting your mind to it? The answer is: "You can't".

The same applies to illness. How can you cope with a debilitating condition like ulcerative colitis or FAP without trying to control or combat it? Once again the answer is: "You can't".

Apart from pain and emotional distress, there's another less predictable element that can help or hinder us when we are unwell and that is our psychological make-up or to use a more commonly used phrase "mind over matter".

But then how many of us can truly say they consciously thought about their mental health and how to apply it when they became ill and faced surgery?

Once again, I think the answer is very few of us (with one honourable exception as you'll see in the case

studies below). There is no doubt that - like a football, rugby or hockey manager or any other team sport for that matter - forging a plan or a strategy can certainly help us to cope and finally recover from operations and serious illness.

**I hope this Roar! report will help you find out just how mentally fit or unfit you are. It may even encourage you to write to Roar! and give us your own personal experiences of mental health before, during and after operations.**

We'll start with an initiative by a UK-based hospital which set up a series of mental health workshops for patients with Crohn's disease and ulcerative colitis.

The courses, which were run by Beaumont Hospital in Dublin, put the patient at the centre of their own care and thus encourage them to think about their lifestyles, thoughts, moods and also the behaviours that make up who they are.

### Self-management

Referred to as self-management, this approach to mental health includes making choices to improve your health such as being more active, eating more healthily and using self-care rituals.

It also helps you cope with important tasks like making sure you take the correct medication for your condition, monitoring the symptoms of your own illness, coping with

the emotional aspects of your condition and finally communicating with healthcare professionals.

RLG member Linda Tutty who joined one of the courses says: "There were 10 of us and each of us made weekly action plans, shared our experiences, and helped each other solve problems we faced in creating and carrying out our individual programmes."



Linda Tutty

As Linda points out: "I met wonderful people with a variety of different health conditions, and this made me feel I was not alone which helped me emotionally. It made me aware of my habits and gave me the tools to make positive changes."

The key message of the courses says Linda was "to learn to speak more openly about my condition - it was wonderfully comfortable be-

ing with other people with similar conditions.

"The other thing I focused on was to set achievable targets or goals for the week ahead and once you have reached your target there is a great sense of accomplishment, no matter how small your targets may be," says Linda.

She also learnt the value of relaxation techniques. "We were taught and practised breathing exercises and visualisation techniques. I absolutely recommend that all patients who have any chronic condition avail of a self-management programme if possible." [See RLG committee member and former chartered physiotherapist Theresa Parr's breathing and relaxation exercises at the end of this article.]

You can also order a copy of the course's handbook *Self-management of Long-term Health Conditions* by Kate Lorig from [www.amazon.co.uk](http://www.amazon.co.uk) (£2.98).

#### Ruth Cox's story

One person who has certainly had more than her fair share of illness, surgery and operations in the past four years is Red Lion Group member Ruth Cox.

In 2016 Ruth had emergency surgery after a chronic spell of uc and says that when doctors told her about her surgery "I was completely shell-shocked. I can remember feeling numb and as if I was in a dream and this wasn't real."

Then after her initial stoma operation Ruth says she was "quite determined to get back to my old self as soon as possible and came out of hospital a week after surgery."

But when she went back to hospital to have her J-pouch fitted a few months later, she discovered she had breast cancer. After the initial shock she was told that the cancer was at an early stage and after an operation to remove the tumour and four weeks' radiotherapy once again she started to make plans to have her J-pouch op.

Until setback number two. Soon afterwards Ruth was diagnosed with enteropathic arthritis which is linked to UC. Painful and debilitating particularly in her feet and ankles, it meant Ruth had to use a wheelchair and crutches to get around and rely



Ruth Cox

on her family for everyday tasks for six months. Eventually she saw a consultant who prescribed two drugs, Methotrexate and Humira, "and suddenly I was pain-free and walking around like normal again".

It meant Ruth was soon fit enough to have her closure which went ahead in April 2019. "My personal journey to a J-pouch has had a huge impact on me and has changed my perspective on life a lot. It's taken me much longer to heal mentally than physically and it can be a slow process," Ruth says now.

"I've tried mindfulness, spoken to counsellors and had lots of support from family and friends and in the end, time helped a lot. Luckily, I'm quite a resilient person and have always tried to stay positive and not let life events get me down.

"The way I look at it is that bad things will happen in life and you make the choice in how you deal with it. You can spend the rest of your life feeling sorry for yourself or you can make the best of what you've got now and look for the good things in life.

"I'm pretty sure that my experiences over the last few years have changed me as a person and I know that I appreciate the little things in life more now. I live for today and try to regularly tell people that I love them and appreciate them. Until you experience some adversity in life, you never know how strong you can be," says Ruth.

RLG committee member Michelle Martin devised her own personal recovery plan before, during and after her pouch surgery at Broomfield Hospital, Chelmsford, Essex, nearly two years ago.

"Within just a few weeks, I had gone from having an upset stomach to having my colon removed and living with a stoma, which I found

mentally and physically challenging. My family and friends didn't think I would cope and, initially, I wasn't too sure myself. I couldn't stand to look at my stoma or change the bag. I just wanted to be left alone," says the 42-year-old.

"However, as the days and weeks went by, I started to feel better," says Michelle. "I had spent most of my life feeling tired, having headaches, so feeling well was a novelty. I knew I was going to need more operations, and I also knew this would have a mental and physical impact on me."

She decided exercise was the key to her recovery and would help her prepare for her next operation. "I knew being fit and healthy would help me recover but it was also essential for my mental well-being," she says.



#### Michelle Martin's story

Eight weeks after being discharged from hospital she started going to the gym. "I took it easy to start with, focusing mainly on hydrotherapy. It did mean putting on a swimming costume, but as luck would have it, I had lost so much weight, my swimming costume could easily accommodate my bag!"

Michelle also took up yoga to help her relax. "Getting fit gave me something to focus on and helped me feel in control. I was fighting back and I was going to be fitter and healthier than I had been in a long time. I had a firm belief that I was the key to my rehabilitation, the surgeons saved my life, my consultant was putting me back together, but I had a responsibility to take this opportunity and do my part in improving the outcomes.

Michelle says keeping fit "was one of the ways I looked after my mental health and I feel for me per-

sonally was the most beneficial to my recovery.”

The other factor, she says, was making sure she continued to do what she loved, especially going on holiday. “So after each operation I planned a trip away, something positive to look forward to.”

However post-surgery she faced a 10-week wait for travel insurance cover. “I made my mind up that after that 10 weeks I would be on a flight, be it a city break or chilling out on a beach. Obviously the beach holiday won through and that helped me relax, feel normal, and recover!”

Michelle’s positivity is palpable. “I have been exceptionally lucky so far, I am really happy with my pouch, and my quality of life has improved.

### Brilliant Surgeon

I think my positive outcomes are due to having the right people around me. Knowing I had a brilliant surgeon, stoma nurses that looked after me both physically and emotionally, a supportive partner and family, great friends and a good employer who allowed me time to recover.

“That combined with keeping fit and having a clear goal, enabled me to get through a very difficult period in my life,” she says.

Another important event Michelle says helped her recovery was a conversation with a counsellor she knew. “We were talking about how people react to traumas and what influences our reactions. Interest-

ingly he said the actual trauma is just one aspect of how we are feeling when we go through a life-changing experience.

“We are also heavily influenced by our past life, our relationships, how we feel about ourselves both emotionally and physically and the circumstances which led us to this point in our lives,” she says.

As Michelle points out: “What I took from this conversation was that we focus so much on the surgery and our illness that we forget to take a holistic view of our life.

“There is a need to look beyond our health issues and focus on what else shapes us and how we can manage these to improve both our physical and mental well-being.”

## Relax, breathe and just let go

RLG committee member and former chartered physiotherapist **Theresa Parr** highlights some key ways to relax

“It is hardly surprising that many of us are reporting increased stress levels with the state of the world at the moment,” says Theresa.

“Stress triggers a primitive, reflex protective response designed to protect us from harm - and the sympathetic nervous system regulates the flight, fight or freeze response while its opposite number, the parasympathetic system, regulates the rest and digest response.

“This should be a short-term response and, once the threat is removed, body and mind should return to its normal, balanced state,” she says.

However prolonged stress makes it more difficult to switch off, adds Theresa. “This can lead to a state of constant hyper-arousal and various long-term health problems. On a physical level, the body can forget how to relax and so you end up with permanent muscular tension, associated aches and pains and digestive issues,” she says.

“When we are nervous or anxious, we tend to take a deep breath and then exhale as a natural way of trying to relax; we even talk about ‘taking a breather’.

“So, one quick way to relax is to

focus on your breathing. Deep relaxed breathing is the basis for most relaxation techniques and, if you don’t have time for anything else, it can be a good first-aid measure,” says Theresa.

Here’s Theresa’s guide to relaxation...

- First, find somewhere comfortable to sit or lie down;
- Rest your hands lightly on the bottom of your rib-cage with your fingertips just resting on your stomach in the gap between your lower ribs;
- Take a slow deep breath through your nose (this helps to warm and humidify the air). Feel your rib cage expand and your stomach gently lift. You should then feel your lungs fully expand;
- Hold for a moment, register how it feels to fully inflate your lungs and then gently and slowly breath out, feeling as though you have pushed out all the air from your lungs though this should not be forced [It may help to do this through pursed lips];
- Your lungs will naturally want to reinflate so repeat this process for another two cycles. Then return to your normal breathing

rate. If you take more than three or four deep breaths you will tend to feel light-headed. This is normal and will disappear as you return to your natural rhythm;

- Just find the rhythm and timing that suits you best. The most important aspects are that it is a slow and relaxed tempo and that you fully inflate and then deflate your lungs; it should be controlled but not forced.

Theresa comments: “While this is useful as a quick fix. If you are still struggling to relax you will need to use a deeper method of relaxing over a sustained period of time.”

You’ll find a fuller guide to Theresa Parr’s anti-stress and relaxation techniques on the RLG website [www.pouchsupport.org](http://www.pouchsupport.org). “If you experience difficulties with these techniques, then ask to be referred to a chartered physiotherapist,” says Theresa.

“Or if you are struggling with mental health issues, your local mental health team can also give you valuable advice and support. The Every Mind Matters website ([www.nhs.uk/oneyou/every-mind-matters/](http://www.nhs.uk/oneyou/every-mind-matters/)) has some excellent advice too,” she adds.

### Art as therapy

One way to help your recovery from an illness or a difficult episode is to take up an interest.

The textbook term is “occupational therapy”. Just ask RLG member Christine Lawton who turned to painting to help her after her pouch surgery. “Although I am not a psychologist, I know it has been proven that painting and drawing

are extremely good mental therapy. I am not surprised because when you are drawing or painting, you are looking at a subject with different eyes and you become completely engrossed away from the everyday hassles of life.

“It is invigorating to express mood and let out our pent-up feelings. Colours can also have a beneficial effect on your moods and morale

and brighten up your day. It doesn't matter what the result is: it is the journey that counts,” she says.

“I've found painting and art a wonderful way to relax during a difficult period and it has been a real boon and has also helped me to pass the time quicker during the lockdown.”



Two of Christine Lawton's recent animal portraits: a cockapoo and her local vicar's cat

If you haven't already done so, why not take a sharp, incisive survey on mental health by Zeina Bushnaq, a psychology Phd student at the University of Roehampton. The survey's aim is to help to improve the emotional and mental health of pouches, potential pouches and ileostomists.



The survey results will be published next year. Zeina told *Roar!*: “Through the help of charities such as The Red Lion Group and various social media platforms I have been able to recruit 79 participants with pouches. My aim is to continue recruiting as many participants as possible until 31 March, 2021. Any help would be greatly appreciated.”

To take the survey click the link below:  
[pouchsupport.org/zeina-bushnaq/](https://pouchsupport.org/zeina-bushnaq/)

## The importance of mental health in pouch surgery



**W**hen surgery is needed for ulcerative colitis I have noticed that different people have different reactions. Much of the decision to proceed to surgery depends on the quality of life of the individual and how the disease affects the quality of life. For an individual where there is a risk of cancer and surgery is proposed but the disease is well controlled, trading off good function for potentially worse bowel function can be a difficult decision. On some occasions, where the disease becomes acutely severe, the decision to surgery or not maybe taken away from the individual when emergency surgery is needed. In most situations the surgery is planned for when there are no further medical options.

The most important point to consider when making the decision to have surgery in ulcerative colitis is that removal of the colon or rectum removes the disease as well but whether an individual chooses a J-pouch or permanent ileostomy

depends on the perceived quality of life gain. In this regard, the mental health of an individual is vitally important. Often when surgery is considered, an individual can be tired, in pain and feeling generally 'unwell'. Post operatively when the individual feels better as the disease is not causing sickness, decision-making can be a lot clearer. It is at this time the decisions regarding stoma and J-pouch should be made.

At this stage one can decide if the stoma is something they can live with or if they wish to proceed to J-pouch surgery.

Making a decision when one is relatively well means that a more objective assessment can be made. When the stress of the disease and its effects on mental health have been removed more relevant decisions can be made.

Post-operatively, the success or otherwise of the J-pouch varies according to the mindset of an individual. This is why pre-operative

counselling is so important as it helps to understand the nature and consequences of surgery.

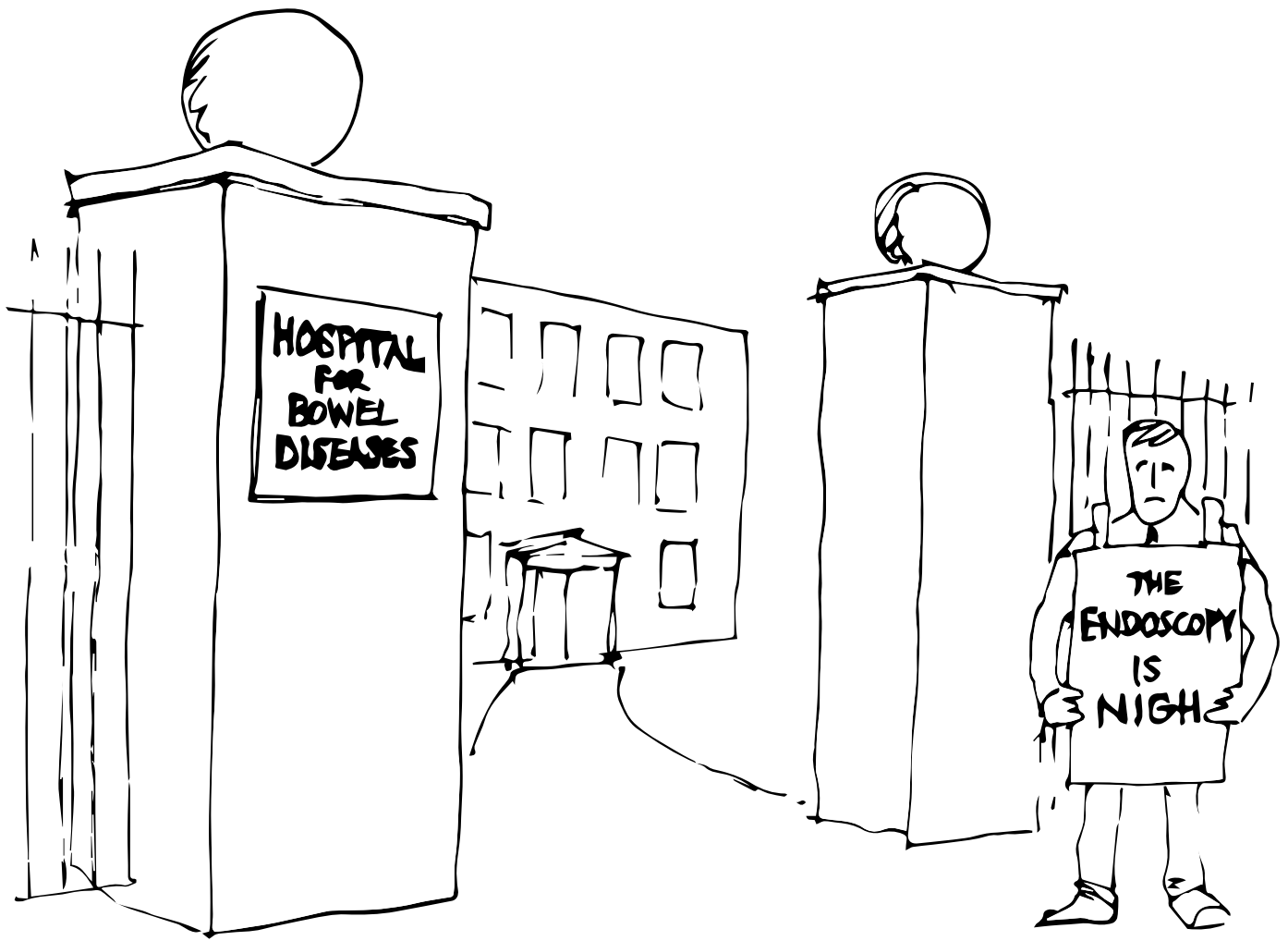
When this aspect is well understood an individual having a J-pouch is better able to understand the inner working of the pouch and this can help with overall quality of life and well-being. When a pouch does not function appropriately, there can be many reasons for this and having the appropriate team with the appropriate support is essential.

When the hope of a quality of life improvement is resting on surgery then any change in this expectation has to be managed appropriately.

It is under these circumstances that managing the mental health of an individual is just as important as dealing with the clinical issues.

This requires understanding on the part of the clinical team and reassurance to the individual. The J-pouch is for quality of life and mental well-being is vital for quality of life.

JANINDRA WARUSAVITARNE



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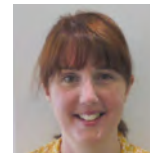
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## Join the Red Lion Group

- Newsletter twice a year with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to the Membership Secretary (see above) for a membership form

## Write for Roar!

### *Ideas, Ideas and More Ideas*

Yes, *Roar!* thrives on them for it's ideas that make the magazine the readable package that we all like it to be.

Whether it's something that happened to you on the way to work,

an interesting holiday or personal experience, an insight into your life with a pouch or a lively letter, please don't hesitate to send it in.

But then if writing articles isn't exactly your favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

*Please email info@pouchsupport.org if your email address or contact details change*

That way we can keep your newsletter bursting with life and information and make reading about pouch issues fun and stimulating. Please send your articles, letters and ideas to:  
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