ROAR!

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***Roar!* is the 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 Red Lion Group rep, please contact Morag Gaherty (phone number on back page).

AVON		
David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
Wendy Gunn	Luton	01582 423714
BERKSHIRE		
Liz Davies	Langley	01753 586593
CAMBRIDGESHIRE		
Joyce Shotton	Peterborough	01733 706071
CLEVELAND & NORTH YORKSHIRE		
Christine Jackson	Saltburn	01947 840836
		chrisjacks@supanet.com
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DEVON		
Gill Tomlin	Kingsbridge	01548 810028
DORSET		
Clive Brown	Bridport	01308 458666
DYFED		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
ESSEX		
Peter Zammit	Benfleet	01702 551501
Clare Shanahan	Ilford	01708 444359
HAMPSHIRE		
Phil Smith	Portsmouth	023 9236 5851
Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Carol George	Stevenage	01438 365707
Susan Burrows	St. Albans	01727 869709
KENT		
Phil Elliment	Barnehurst	01322 558467
KENT (WEST)		
Rosalyn Hiscock	Pembury	01892 823171
LANCASHIRE		
Joan Whiteley	Clitheroe	01200 422093
MERSEYSIDE		
Blanche Farley	Liverpool	0151 924 4282
NORFOLK		
Sandy Hyams	King's Lynn	01485 542380
NORTHAMPTONSHIRE		
Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	01604 450305
NORTHERN IRELAND		
Sharon Hendron	Lisburn	02892 661559
SOUTH LONDON		
Andy Jones	SE6	020 8690 1360
Jonathan English	SW12	020 8673 3092
SUFFOLK		
Anna Morling	Leiston	01728 830574
WEST LONDON		
Dee O'Dell-Athill	W10	020 8960 6726
		colin@odell-athill.demon.co.uk
WEST MIDLANDS		
Linda Bowman	Birmingham	
		0121 766 6611 ext 4332 or pager 0027
WILTSHIRE & DORSET		
Bernadette Monks	Salisbury	01722 327388
YORKSHIRE		
Neil Anderton	Leeds	0113 258 2740
Sue Appleyard	Huddersfield	01484 641227

Front cover: Red Sea, Egypt

Back cover: Jersey Harbour

Room With a Loo

Not all houses are created equal in the lavatorial stakes. Morag Gaherty examines what to consider when moving house and how to make the smallest room in the house more acoustically pouch friendly.

At some time or other, every one of us—pouch owner or not—will probably either move house or decorate the one they are living in. As I consider whether to paint the kitchen yellow this summer, my mind returns to a brief conversation I had last year with Margaret Dean.

"Ah, yes," she said "I have a tapestry on the wall of my toilet. It helps to deaden the sound and looks nice at the same time".

Until that moment, I had never even thought about attempts to improve (or, should I say, reduce?) the acoustics for a pouch owner. But it all made perfect sense, and since then I've picked up offhand tips from people all over the place.

So these are my top tips for a house-hunting pouchee:

Don't even look at a house if it only has one toilet. It doesn't matter how much you love it, it will never work with inadequate plumbing. Your needs are greater than most, and should be considered. You need at least two toilets, so that other members of the family can "go" at leisure, without worrying that at any moment they may be required to remove their bottom for a more deserving cause.

Do flush the toilets when you are being shown round a house, and ask if there are any problems with the plumbing. That's the only way to find out about a toilet's "idiosyncrasies". When we moved here 6 years ago, we did not realise until the day we moved in that the downstairs toilet flush was extremely temperamental. In fact, we now warn visitors against using it, and have had to perfect a special technique for getting it to work ourselves. No visitor wants to find out about that kind of issue when they have already made use of the facilities. It's embarrassing enough to have to explain as a preventative, let alone after the event.

Having a toilet which is separate from the bathroom is also advantageous, as it ensures the toilet-user is not taking another room out of operation at the same time.

If you're looking at a semi detached house, think about where the toilet is placed, especially in modern homes. Sound carries not only within your home, but also to your attached neighbour, so look for a house with a toilet on the outside wall rather than the conjoined wall. At least they will then be able to look you in the eye when you meet.

One of the other little niceties is a bidet, for keeping your nether regions clean. But there is a strict rule here: toilet *and* bidet in the bathroom, or together in a separate room. Toilets and bidets are like twins, and should not be separated from each other under any circumstances, or disaster will ensue. For my part, I have never understood the French system – why do they always keep the toilet and bathroom separate (sensible), but then have the bidet in the bathroom rather than in the toilet? I have visions of Frenchmen wandering around the house with their trousers round their ankles as they deal with the necessaries…. it's not a pleasant thought.

Don't forget to consider the general age of the property, referring back to the question of sound transference. Generally speaking, anything built between about 1960 and 1990 is going to let a lot of noise float around, because partition walls of this era are little more than plasterboard. Before 1960, internal walls tended to be solidly-built. Since about 1990, insulation has improved vastly, although the inner walls are still thin partitions.

If you can, an Edwardian house (roughly 1900-1930) is the age to aim for. Mind you, of course, a modern house with a second toilet added downstairs to the outside wall will have just as good sound protection from the rest of the house, because the separating wall is an outside one rather than a partition one.

The exact location of the toilet in relation to the main living areas is

crucial, too. There is nothing worse than going to a friend's house for dinner, your pouch owner partner discreetly leaving part way through the meal to perform, only for all the sounds to be completely audible to everyone around the table. It kind of puts a dampener on things when they get back. And who on earth would be able to explain the resultant strain (forgive the pun) away?

So that's the wish list out of the way. We're not all house-hunting though (and even those that are may not be able to find the ideal toilet situation). Most of us already live in our homes, and may now have realised a few things which could be done to make life more pleasant for the whole family.

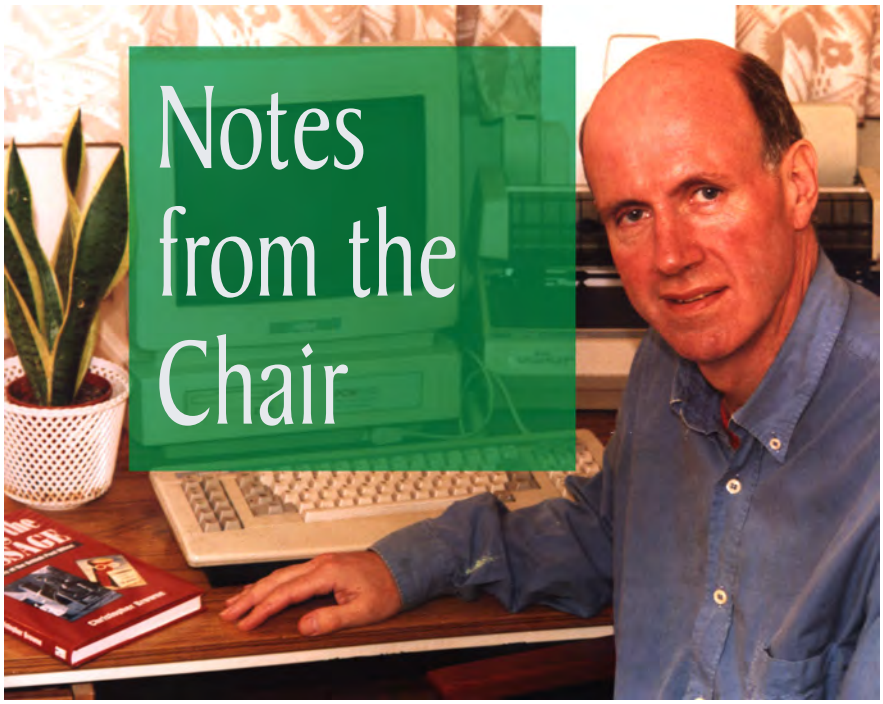
As Margaret Dean said, they don't have to be expensive changes. You could think about a nice solid picture or tapestry on the wall, or maybe something on the door. A big cork board onto which postcards and photos can be pinned is an ideal and non-obvious sound absorber. If the cork offends you, you could cover it in a fabric which complements your room décor.

If the room location is already a bit dodgy, regardless of poor quality partition walls, you could consider effectively adding an additional partition wall with thin batten strips, insulation and a top layer of plasterboard. A competent DIYer could do it, although I've got to say I personally would pay someone else to. But, then, I'm married to Brian, and I know his limitations, even if he doesn't! You could lose as little as 1.5 inches off the width of your room, but gain so much more in terms of privacy.

People tend to have strong views about whether carpeting in the toilet is a good idea or not. Obviously, though, carpeting or carpet tiles are going to offer far better insulation than floor tiles or a laminated/wood floor, which will increase echoes. Perhaps a compromise, such as a washable rug over a large proportion of the floor, might help?

Last, but not least, there are different dimensions of toilet bowl. Just remember, the larger the bowl, the bigger the echo. Equally, the longer the drop to the water, the bigger the splash. Need I say more?

Morag Gaherty



Notes from the Chair

I'm off to buy some tablets for my eavesdropping habit. But before I do, there's something I want to tell you. I was visiting my doctor at London's Chelsea and Westminster Hospital the other day when I overhead two consultants talking. There was none of this "And I said to Mary and Mary said to me" stuff. No, this was a shade more serious, and what I heard stopped me in my tracks.

The taller one with the small goatee said: "Have you heard the news? It won't be long before there's a cure for UC - I'd say five years in fact." If I'd been carrying a cup of coffee I would have dropped it.

In fact I was several minutes late for my appointment - and my consultant Professor Brian Gazzard said it was all true. The professor, who used to treat Freddie Mercury lead singer of Queen (remember them?) for Aids, said: "The laboratories have made several breakthroughs and it won't be long before there's an announcement."

Perhaps I won't buy those anti-eavesdropping tablets after all. Earplugs might be far more effective - but then I think I'll pass on those too.

Just as people like to ask if you had an enjoyable Easter break or, if you are an American, a lively Independence Day, when the word gets round it'll be: "Did you have a good Information Day?"

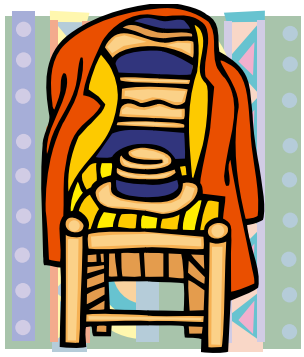
The answer to this year's event is a resounding yes. It may not have been the best-attended—we have not yet topped the 130 who came to our third or fourth in the late-1990s but for sheer quality it was unbeatable. And much of the credit for it is down to three people the retiring chairman Mike Dean, the new Red Lion secretary Margaret Dean and St Mark's clinical nurse specialist Jo Wagland.

The trio performed a unique "Up All Hours" act—as the rest of the committee found when they turned up and found they had very little to do. So it's Mike for Prime Minister, Margaret as new Home Secretary and Jo a highly pro-active Health Secretary.

In my two-year span as chairman, I'll be writing these "Notes from the Chair" to you in each edition of *Roar!*. Next time I'll tell you what our president Professor John Nicholls says about the remarkable laboratory research into ulcerative colitis.

So have a good summer...and watch this space.

Christopher Browne



Control Freak

The following article is taken from the information sheet accompanying Trish Evan's talk entitled *The St Mark's Biofeedback Programme: Developing Bowel Control* given at the recent Red Lion Group Information Day.

Your bowels are part of your body, and you need to take control of them. This may seem difficult at times, especially when you feel under stress. The following routine will help you to regain control. *Every day*, set aside approximately 10 minutes for this (preferably, take half an hour after breakfast). It is important that you are not interrupted.

Identify the Different Muscles You Will Use

a.) First, your waist muscles. These are the muscles you push/propel with. Place your hands on either side of your waist. Now cough. Can you feel the muscles work? Try to brace (i.e. use these muscles to expand and widen your waist).

b.) Now your anal sphincter or back passage muscle. When you go to the toilet you **must** relax and open this muscle. Insert your index finger just inside your back passage. Squeeze and contract your back passage as if you are trying to stop yourself from going to the toilet. It should feel tight around your finger (learn to recognise this and if you feel you are tightening your back passage when you are going to the toilet, STOP). Now, relax your back passage so that it feels loose and slightly open.

Check your Sitting Position on the Toilet

Lean forward with your forearms resting on your thighs and your feet raised on a small block (like a toddler step).

Relax

Relax and lower your shoulders.

Breathe slowly and gently. In through your nose and out through your mouth.

Try to let go with all of your muscles.

Now Try to Open your Bowels

Remember NOT to hold your breath (i.e. do not take a big breath in first).

Slowly brace outwards (i.e. widen your waist)

There are two explanations for how to do the exercise – pick the one which makes more sense to you:

Version 1

a.) Imagine your back passage is a lift resting on the first floor
b.) Slowly push your lift down to ground floor …. down to basement … down to cellar
c.) You can use your brace to help you push
d.) Relax for a second. Do not allow your lift to rise
e.) Push your lift down again

Version 2

a.) When fully braced, push/propel from your waist back and downwards into your back passage at an angle, as if you are skiing on the toilet. DO NOT STRAIN (i.e. keep breathing!)
b.) Stop pushing for a second. Keep your tummy out fat – you must maintain a level of pressure with your brace, whilst not pushing with it
c.) Push downwards again. This should be repeated

You should be using your brace as a pump.

Remember, this takes time and practice.

The Aim of Complementary Therapy Should Be…to Complement

There are many things I do not envy about the American healthcare system, particularly the way it disadvantages those who cannot afford the cost of health cover. However, it's nice to see that there are high-tech, entirely mainstream medical centres (or centers, as those pesky Americans insist on spelling it) who do not brush off complementary therapies as some kind of mumbo-jumbo. Instead, they use those therapies, where appropriate, to complement the surgery.

Columbia-Presbyterian Medical Center, New York is one such place. Before undergoing heart surgery, patients are given every possible relaxant:

First of all, *music therapy* is offered, to minimise stress. The technique requires that patients set aside at least 15 minutes a day to listen to their favourite music through headphones. Columbia can also provide specially mastered recordings designed to stimulate brain waves and promote relaxation (the Monroe Institute's Binaural "Hemi-Sync" Tapes, 62 Roberts Mountain Road, Faber, VA 22938-2317; (804) 361-1252; www.monroe-inst.com/programs/hemi-sync.html).

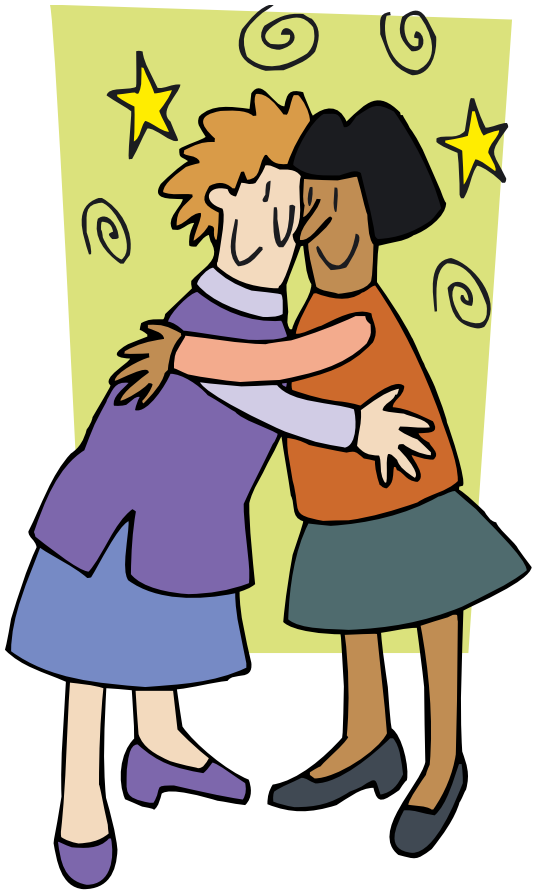
Hypnosis and meditation training a few days before surgery can reduce anxiety and increase the patient's sense of control before, during, and after the operation. A staff hypnotherapist leads the patient through progressively deeper stages of relaxation and makes such suggestions as "You will feel very little pain after the operation" or "You will have a fast recovery." A good book on the subject is *Discovering the Power of Self-Hypnosis* by Stanley Fisher, Ph.D. (HarperCollins, 1991).

Massage. Most patients find that its stress-relieving benefits last beyond the half-hour or hour-long session. Reflexology, or massage of specific points on the feet or hands, is a good alternative for those who can't get body massages for medical reasons. The hands and feet are rich in nerve endings, and rubbing them fosters drainage of lymphatic fluids. According to Eastern beliefs, reflexology promotes energy flow and stimulates healing of internal organs.

During the operation

Studies are beginning to confirm that patients are subconsciously aware of what's going on around them when under general anaesthesia. Listening to *music* through headphones is highly recommended during the operation and in the recovery room. It not only promotes relaxation but helps filter out the disturbing noises of the operating room and ICU.

Patients may also request *therapeutic touch*, or laying on of hands, during or after the operation. Nurses at the hospital pass their hands over the body without actually touching it. This action is thought to help unblock and balance the chakras (energy channels), thereby boosting the body's natural healing capacities. A survey of 10 patients who were initially "extremely sceptical" of the technique found it to be "remarkably helpful." The complementary care team at Columbia is following up with studies in Kirlian photography, in which special photographic film is used to record the ability of energy healers to control the body's electromagnetic fields.



Recovery

A personal favourite of Dr. Oz is *yoga*, because it combines physical activity with meditation to reduce stress. The most important yoga exercise is deep breathing, with the back straight. Staff therapists teach this along with gentle leg stretches, carefully modified to avoid potential harm around incisions and ease strain on the rib cage after heart surgery.

Dr. Oz also advises patients to begin a rigorous *new diet*. A low-fat, mostly vegetarian regimen rich in grains, beans, fruits, and vegetables, with few dairy products and little sugar, can promote wound healing and over the long term boost heart health.

In addition, a number of *nutrients* are recommended to speed recovery. Supplements might include vitamin A with mixed carotenes (25,000 IU a day); vitamin C (1,000 mg a day); and vitamin E (400 IU a day). Other nutrients recommended by Dr. Oz include the antioxidant co-enzyme Q_{10} (30 mg 3 times a day); the amino acid L-carnitine (500 mg twice a day); calcium citrate (1,000 mg a day); magnesium citrate (500 mg a day); folic acid (400 mcg daily); and EPA/DHA essential fatty acids (1 g daily). [Ed: Bear in mind that these nutrient supplements have been designed for heart patients and may not be suitable for pouch patients. Your hospital nutritionist can advise].

Finally, once the patient is home from the hospital, *aromatherapy* may be a useful adjunct for reducing stress and improving sleep. Flowery scents, such as lavender and neroli oils, have long been thought to have a soothing effect and to dull pain.

Source:
www.wholehealthmd.com

Music Therapy

Music therapy is the use of music to induce relaxation, promote healing, enhance mental functioning, and create an overall sense of wellbeing. Individuals doing music therapy typically listen to or perform music under the guidance of a specially trained and certified music therapist. Considered one of the "creative arts therapies" or "expressive therapies" (which include art therapy, dance therapy, writing therapy, and drama therapy), music therapy can be used alone or in conjunction with other therapies or healing treatments.

Music therapists work with all age groups, from infants to the elderly, and can be found in a variety of settings, including private practice, schools, senior centres and nursing homes, outpatient clinics, psychiatric and medical hospitals, and hospices.

Music as therapy is almost as old as civilization itself. The ancient Greek philosophers believed that music could facilitate healing, as did early Native Americans, who used chanting and other musical practices as part of their healing rituals. In the Unites States, music therapy as a formal discipline was first employed during World War I to help disabled soldiers in Veterans Administration hospitals. The first music therapy degrees were granted in the 1940s, and the American Music Therapy Association (AMTA) was founded in 1998.

How Does It Work?

Most people tend to experience a visceral reaction to music: a burst of energy upon hearing an upbeat song or a sense of calm during a soothing classical piece. Music therapy harnesses this connection between music and mood. Moreover, scientific studies show that music can affect physiological functions, such as respiration, heart rate, and blood pressure, as well. Music has also been shown to lower amounts of the hormone cortisol, which becomes elevated under stress, and to increase the release of endorphins, the body's natural "feel-good" hormones.

Music therapists often use music to communicate. With its beat, melody, and lyrics, music is a kind of language in and of itself. Because of this, music therapy can be used to help the mentally and physically disabled express themselves. It can also encourage introverted patients to become more outgoing and can be used to draw schizophrenic and autistic patients out of their isolated worlds.

Music therapy can also be beneficial for stroke victims and other patients with neurological problems through a process called "entrainment". When patients listen to rhythmic music, their muscle movements become synchronized with the beat. As their motions become more regular and efficient, their motor skills improve in turn. Entrainment can also induce a sedative, relaxing response if the music has a slow, steady rhythm.

Music therapy can also distract patients from negative thoughts, feelings, and experiences. For example, the therapy has been effective at helping keep people's minds from dwelling on the pain of dental work, surgery, and labour.

What You Can Expect

Because music therapists work in many different settings and with many different kinds of patients, treatment programs and durations vary.

If you consult a music therapist for a particular condition, the therapist will first talk to you about your symptoms and needs. In addition, the therapist will assess your emotional wellbeing, physical health, social functioning, communication abilities, and cognitive skills through your musical responses. Using this information, an appropriate treatment program will then be designed, which will probably include playing music, listening to music, analysing lyrics, composing songs, improvising, and/or using rhythmic movement. During your regular sessions, the therapist may participate in these activities with you or simply guide you. You may also be encouraged to talk about the images or feelings that are evoked by the music.

You and your therapist will select the music used for your therapy according to your needs and tastes. You can choose any kind of music, from classical or New Age to jazz or rock. You do not need to have previous musical experience or even musical ability to undergo music therapy.

Some music therapy is conducted in a group setting. You might perform music with others who have the same ailment or condition as you, or interact and relax with others as music plays in the background. If you are in the hospital for surgery or to give birth, your music therapy might simply entail listening to your favourite songs to help you relax and reduce pain.

Health Benefits

Studies have found that music therapy is effective at promoting relaxation, relieving anxiety and stress, and treating depression. Music therapy allows people with emotional problems to explore feelings, make posi-

tive changes in mood, practice problem solving, and resolve conflicts. It can strengthen communication and physical coordination skills, and improve the physical and mental functioning of those with neurological or developmental disorders.

As far as pain management goes, music therapy is increasingly used in hospitals to reduce the need for medication during childbirth and to complement the use of anaesthesia during surgery. It is also used to help ease the pain of chronic ailments such as headache.

Music therapy can also improve the quality of life of terminally ill patients and enhance the wellbeing of the elderly, including those suffering from Alzheimer's disease and other forms of dementia. It has also been used to complement the treatment of AIDS, stroke, Parkinson's, and cancer. Those with learning disabilities and speech and hearing problems may also find music therapy helpful.

How To Choose a Practitioner

Music therapists work in private practice, in institutional settings, and as part of treatment teams that can also include psychiatrists, psychologists, rehabilitation counsellors, and primary-care practitioners. There are an estimated 5,000 music therapists currently practising in the United States.

Make sure your music therapist has completed an approved college music therapy curriculum including an internship. The therapist should also have earned an appropriate professional qualification.

To find a qualified music therapist in your area, ask your primary care consultant for a referral or contact the British Society for Music Therapy (www.bsmt.org) on 020 8441 6226. Try to interview several therapists before making your selection; you should feel very comfortable with the therapist you choose.

Cautions

- Music therapy is not for everyone. Some people become agitated by the therapy and some do not respond to it at all.
- If you have a specific symptom that you'd like treated with music therapy, consult your GP first to rule out any serious underlying medical problems.

Conserving Energy During Recovery

The following article by Dana Davis (Physical Therapist) and Susan Spinasanta was originally written for patients recovering from spinal surgery, hence its stress on protecting the back. However, the suggestions it offers in respect of coping with the post-operative recuperation period are relevant to anyone who has had major surgery. (source: www.spineuniverse.com).

Due to changes in our health care system, patients are spending less time convalescing in the hospital and more time recovering at home. Although most patients are delighted to continue physical therapy or other treatment on an outpatient basis, home recovery can be a challenge.

For some, fatigue interferes with their desire to "get things done". However, fatigue should be expected following spinal surgery or injury. During the recovery process, the body uses a great deal of energy to heal. This combined with possible side effects from medication taken for pain and inflammation can account for that "drained" feeling.

The following are suggested ways to conserve energy while protecting the spine. It is a good idea to review this list with your physician and/or therapist, as this list is inconclusive. They will be able to offer additional suggestions specific to your situation.

By simplifying movement and eliminating unnecessary steps you may be able to conserve energy vital for healing and recovery.

> You might start out by asking yourself, "what are today's priorities?"

Setting Priorities

You might start out by asking yourself, "what are today's priorities?" and "what can I realistically accomplish?" This may necessitate making a list of work to be done today and other tasks for later in the week.

Remember, if you schedule too much for yourself you will only feel anxious (to get it done!), overwhelmed (my list is too long!), and discouraged (I'll never get this all done today!).

Many patients have found if they avoid the following four things - they are able to reward themselves with a bit more energy and a better mental outlook for tomorrow.

- Avoid...Perfectionism - stick to your list of priorities
- Avoid...Rushing - don't try to 'beat the clock'
- Avoid...Unnecessary movement
- Avoid...Worrying about what you cannot change

Smart Planning

You may need more rest than a normal night's sleep affords. This means scheduling periods of rest between activities, perhaps lying down for 15 minutes.

Don't underestimate a child's

ability—they can be quite capable of handling a variety of tasks: running errands, household chores, and gardening.

Spread out light and heavy tasks throughout the day and week. The entire house probably does not need to be cleaned top to bottom in one day!

Organize work to avoid unnecessary movement such as bending, leaning, reaching, walking, and prolonged

sitting and standing.

Do not start an activity that cannot be stopped.

Sit in a structured chair that offers support at a height that is appropriate for the activity. Consider sitting down to iron or prepare food.

Use both hands to work if appropriate to the task.

Stop an activity before you become tired - it will probably be there later!

Smart Kitchen Choices

As a general rule, organize cupboards and drawers so frequently used items are within easy reach and below shoulder level (e.g. eliminate reaching). Many patients have applied this principle to other areas in their homes and found it most helpful.

Eliminate needless motion by organizing utensils where they will be used.

Work in one direction instead of going back and forth.

Use pots and pans that are lighter in weight (e.g. aluminium, stainless steel). Consider using plastic bowls in lieu of ceramic or glass. Slide pans or bowls across the counter instead of lifting and carrying. Less weight moved = less energy used.

Consider one-dish, easy to prepare meals. The choices of prepared mixes and healthy foods is incredible - even fresh salad is available in easy to open bags.

Dish food from the stove instead of lifting the pan(s). A stable cart on wheels can be a valuable assistant to move food to the table or clearing the table after a meal.

Soak dirty dishes and pans instead of standing and scrubbing. Save more time and energy by allowing these items to drip-dry rather than towel drying.

Energy Saving Tips—Cleaning

Gather what will be needed and transport it to the area to be cleaned on a stable cart with wheels - or ask someone to carry the items for you in a plastic bucket.

Many vacuum cleaners come with wonderful attachments designed to eliminate unnecessary bending and reaching. Use long smooth movements.

Use long handled mops and dusters to eliminate the need to bend and reach. Many sponge mops come equipped with automatic squeezing devices. These can be used to clean the bathtub and shower too!

Use long handled tongs to pick items up from the floor. Many home centres carry these items and others designed to help around the house.

Complete one area before moving to the next. This principle applies to making the bed too - complete one side before moving to the other.

Heavy cleaning - this is not the time! If absolutely necessary, coordinate these tasks with family members or friends.

Laundry and Ironing

Once again organization is key - keep laundry products nearby. Provide a table near the washer and dryer so clothes can be sorted and folded at a proper height eliminating bending over, stooping, and twisting. Front loading washers and dryers can be elevated to eliminate the need to bend over to load and unload clothes.

Sit down on a structured comfortable chair at an appropriate height to iron. The ironing board should be positioned just above the lap. Make sure the clothes to be ironed and a hanging rack are convenient. Work in one direction and slide the iron instead of lifting. Again, to conserve energy, don't iron anything that doesn't require ironing (e.g. sheets, pillow slips).

In General

Instead of diving into your day, plan how you will "get things done" by setting realistic priorities and organizing an efficient means for task completion. You can reward yourself with more energy and feel better for it!

Don't underestimate a child's ability—they can be quite capable of handling a variety of tasks

...that common side effects from taking prebiotics are flatulence and bloating?

Another Day to Remember

Probiotics, biofeedback and life-enhancing experiences may be trendy but they're also key to the future of the pouch and its faithful pouchees - as a hundred or so Red Lion members, partners, families, friends and health experts heard at this year's Information Day and AGM at St Mark's on 24 April.

Sun, sparkling speakers and spectacle. The day itself was a life-enhancing experience. Mauritian beaches, snowy mountains, the Gardens of Babylon. You can keep 'em. This was almost as good as it gets in the annals of pouchdom and much of its success was down to two people – the outgoing chairman Michael Dean and the incoming secretary Margaret Dean.

Sun, sparkling speakers and spectacle. The day itself was a life-enhancing experience.

Margaret may not forgive me for saying so, but as she packed, unpacked, sold, told and extolled like the cheerful cove that she is, she was harbouring a dark secret - reconstructive surgery two days later. Some people can carry on regardless. Some can't. Margaret can, and with aplomb. And so can Michael. Chairman Mike's been good, very good. And he too has a secret. It's called Planning. Everything from laminated posters (yes the Deans have their own laminating machine) to sleekly-produced programmes (they've got two printers at home, too) had been carefully preened and prepared for P-Day (Ahem!).

And just to add some elusive je ne sais quoi, "Mr Pouch" Professor John Nicholls, Red Lion's president, was there to hear two of his former students discuss the work they have been so intimately involved with at St Mark's. As many of you already know, Prof Nicholls was Sir Alan Parks' senior registrar when the first ileo pouch was created in 1978. Then John decided to make his own - the redoubtable J-pouch - nine years later.

Biofeedback - don't you just love it? Or appreciate it, anyway. I certainly do. I was there when they first tried this unique system of mucus and movement (urrgh!) on a few St Mark's patients 10 years ago. And yes it certainly works. I have the proof - and on Saturday St Mark's physio Trish Evans took us through the motions, so to speak.

There we were sitting comfortably ready for some quiet audience appreciation, when Trish had us holding our sides (often with laughter), clutching our tummies and bending with the best of them as we joined in the unique biofeedback experience.

You can just see the headlines: "Diaphragm Man meets Pelvic Penelope"

We also played with some hollow plastic tubes that emitted funny gurgling noises and all in the interests of medical research, I'll have you know. You can just see the headlines: "Diaphragm Man meets Pelvic Penelope".

And if, after a few weeks of biofeedback, you want to know how to run your life, ask Paris Tekkis. A St Mark's senior registrar, Paris gave pouchees and partners useful tips on improving their Quality of Life. As many a large company and corporation knows, damage limitation works – and particularly so on pouches said Paris. So does knowledge - and St Mark's is piloting an online registry where pouchees can give annual updates of their operations, experiences and treatment.

The registry is due to start this month (June). So watch this space for details. Meantime, log on to www.riskprediction.org.uk for some interesting ideas about your favourite part of the anatomy.

Then it was probiotics time. These are friendly bacteria that help fight the millions of unfriendly ones we have in our bodies—and pouches. Dr Matt Johnson, a research fellow at St Mark's, said you could take it in several supermarket products and high doses can combat mild pouchitis. One of the best sources was breast milk, said Dr Johnson, adding that it was difficult to get hold of - though he didn't offer any tips!

It all started however with a talk

on pouch function by Professor Christine Norton, who helps run St Mark's continence unit. After an information-packed half-hour about the causes and effects as well as the pauses and after-effects (notably wind and f..ting), she left to give a similar talk to the annual meeting of NACC (National Association for Colitis and Crohn's Disease) at London's Barbican.

Meanwhile at the St Mark's AGM, Mike Dean retired after two highly productive years as chairman, handing over to myself, while Margaret Dean was elected secretary, with Christine Lawton continuing in her role of notes secretary - and a very high-speed one she is too. And Stephanie Zinser, who wrote The Good Gut Guide (Thorsons, £10.99 and available at all good bookshops) was elected to take over from me as press officer. The other committee members who were re-elected are Morag Gaherty, Roar co-editor, Tim Rogers, Roar co-editor, Marion Silvey, liaison officer, Brian Gaherty, retiring vice chairman, and Joanna Wagland, St Mark's clinical nurse specialist, co-opted member.

Joanna and Lisa Young, another St Mark's clinical nurse specialist, led workshops on IBD (inflammatory bowel disease) and Pregnancy and Fertility, and Kay Neale, the hospital's polyposis registrar, ran one on Manifestations of FAP (familial adenomatous polyposis).

Finally, Yours Truly talked about travelling overseas with a pouch, handing out a checklist of the "ayes" - such as drinking bottled instead of tap water and packing ample quantities of Dioralyte - and the "no's" such as keeping off hot spices and food from street vendors. I think the ayes had it.

As new chairman, I thanked the committee and the outgoing chairman for a promising and progressive year and the lively and enthusiastic band of members, partners and professionals who helped to make information day really happen.

Yes, it certainly had been a Day to Remember.

Christopher Browne

> Then it was probiotics time. These are friendly bacteria that help fight the millions of unfriendly ones we have in our bodies—and pouches.

So What Does the New Committee Look Like?

In the interests of bringing a 'personal touch' to *Roar!*, committee members were each asked to provide a photograph of themself for this issue. An artist's impression has been used where no photograph was forthcoming...

Christopher Browne
Chair

John White
Treasurer

Mike Dean
Vice-Chair

Marion Silvey
Liaison Officer

Margaret Dean
Secretary

Joanna Wagland
Clinical Nurse Specialist

Stephanie Zinser
Press Officer

Morag Gaherty
Newsletter Co-Editor (Content)

Christine Lawton
Notes Secretary

Tim Rogers
Newsletter Co-Editor (Layout)

> ...that inulin is a natural prebiotic, and that boiled root of chicory is 90% inulin?

Letters

Dear Newsletter Editor

I pray that you are able to print my letter in hope that someone somewhere may help me.

Following my surgery in the year 2000 I was absolutely fine until October 2002. During August 2002, I underwent a Caesarean section and gave birth to a baby boy. During the month of October, I developed an infection to the wound and was prescribed some antibiotics which made me very ill the day I took them and during the night. I suffered vomiting and pain on the left side of my abdomen.

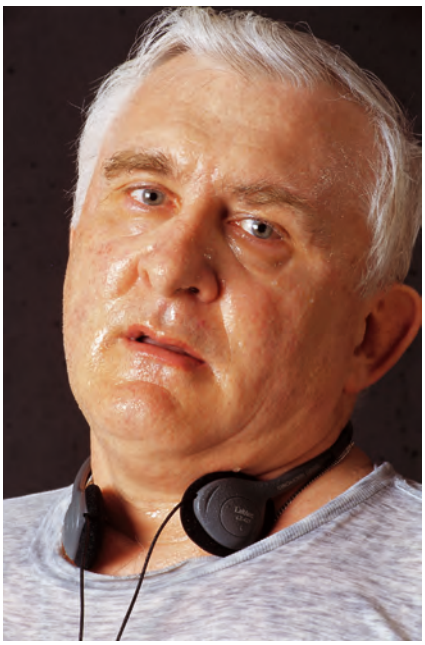
It has now been 16 months and I am still in constant pain on the left side of my abdomen. I have undergone several scans which have revealed a cyst on the right ovary, but nothing on the left. My surgeon is very reluctant to carry out a laparoscopy or surgery. He advises me that this could take me backwards as I have already have had extensive surgery. I have tried herbal and homeopathic alternatives but have not been successful. It would be a miracle for me if someone out there could put an end to my suffering.

Thank you

Anonymous

Dear Editor

I wanted to ask about a long-standing problem since I had my pouch made, six years ago. Luckily, surgery to remove my colon has left me in overall good health, but one of the legacies I have been left with is 'end-of-day' exhaustion.



I know most people get tired after a busy day, but with me it comes on really suddenly, often at about 5 or 6pm, and leaves me so exhausted I could literally cry. Often I find myself in bed at this time, and can sleep all night through (except for bathroom visits!). I've seen my doctor and he says I neither have ME nor apparently any other physical problems (like thyroid) which might cause extreme tiredness.

I've heard two different theories to explain my problem: one says that our colon actually contributes to the body's energy reserves and that without it we don't have the stamina to rival the Duracell Bunny. The other theory says that dehydration causes extreme tiredness, and pouch owners are very susceptible to dehydration. Although it is true that drinking more liquids can sometimes lessen my tiredness, it doesn't by any means stop the crippling exhaustion from washing over me on a regular basis.

I would love to know if anyone else suffers from this, or if there are other solutions to be had? I'm in my mid-40s and both my husband and I would love it if I felt more energetic during the evenings!

Sally Thomson

NW8

Dear Editor

What a great information day. Excellent speakers, good turnout, and the brightest of spring days. I was forgetting how good it is to meet up with other people who have pouches. This was my second meeting. The first was in 1999. Although that was also good meeting too, this time we had the advantage of a sunny day and some very sunny people and I particularly enjoyed the workshop session on Pregnancy and Fertility.

I've been in and out of hospital for several years with my problems. I had a fistula one year, an abscess the next, and then pouchitis which kept coming back. Although I seem to be in remission now, thank goodness. Meeting up with everybody the other day really cheered me up.

So thanks fellow Red Lions and roll on next year's AGM and Information Day.

Name and address supplied

...that there are ten times as many bacteria in the body as there are cells?

The Twinning Game

Our town has three twins, in Normandy, Bavaria and Portugal. I have been going on visits for at least twenty years and now have a number of friends in each of the three.

My pouch came to live with me six years ago. It is generally very well behaved and quite equal to meals in any language. Living in someone else's house as a family is a bit different to going on holiday to a hotel, not least because the loo is almost always situated right opposite the kitchen. We have been to farmhouses in Normandy, town apartments in Portugal and luxury bungalows in Bavaria, but we have never found an ensuite bathroom.

For those who have never twinned, let me explain the system. You join your local twinning association. If you live in a large village, your twin will be an equivalent village; a town will twin with a town, and so on. Visits are made annually. A group comes to your locality, followed by a return visit later.

The visitors will be allocated to families, who will do their best to provide them with evening meals, comfortable bed and breakfast, conversation in a fascinating mixture of languages (with frequent recourse to the dictionary to resolve disputes), outings to the pub, fish and chip suppers, and packed lunches to take out for day trips with their group. They will have an interesting programme arranged, including the ceremonial ("meet and greet" by the local mayor and some kind of party on the last evening), municipal (visit to local recycling plant), cultural (visits to church/castle/stately home) and – of course – plenty of time for *le shopping*. At the weekend, there is usually a day or two days to be spent with the host family, who may take their visitors to a local beauty spot, followed by a cream tea or whatever seems appropriate. The visitors will arrive laden with gifts, local wine or other alcoholic brew, decorative plates or mugs, honey, cookies etc.

Last year, we went to Portugal, and were all set for a week of hectic sightseeing: monasteries, old fortifications, port cellars etc., when trouble struck. Our hostess had her little grandson to care for on the Friday, as his crèche had refused him entry – he'd been vomiting overnight. And, yes, you've guessed it: he had gastro-enteritis, which rapidly spread around the family and us.

I spent the Sunday in bed (visit to Sintra, you're joking!) sipping orange juice and water with a pinch of salt added and swallowing antibiotics prescribed by the family doctor. Elder daughter had translated my problems very competently and he seemed quite impressed. I also had Loperamide capsules with me. Later we got some Dioralyte, and then I progressed to the hostess's cream of pumpkin soup and stewed apples.

The bug only lasted 36 hours, but it made me lose more than 3 pounds in weight and, even a week later, my stamina was not back to where it was. By Wednesday evening, we were just about ready to go to the farewell dinner and sample local sausage, bean soup, salt cod with salad and mashed potatoes, and fruit salad.

I just thank heaven that it happened in the middle of our visit rather than the day we were due to fly home!

Carole Moore

...that 55% of stool is made of bacteria?

My Story…by Stephanie Dawson

I came across *Roar!* at the NAPG Conference in Oxford last year and took it home to read. I decided to pick up my pen and respond to the request for "good" pouch stories, as mine is – so far – quite a big success. Before I had my pouch surgery, I needed to hear about the good pouches because then I knew that it was a possible reality for me also, and it gave me something to really aspire to. I remember my Stoma nurse telling me about a fellow pouchie at our hospital who only went to the loo twice a day. It was a true story of hope amid all the dreadful ones, and one that I clung onto.

So, here goes with mine…

I was diagnosed with Proctitis in May 1997. I wasn't terribly ill, but it was a nuisance. I was treated with foam enemas and it went away very quickly. Wonderful! I had a mild re-occurrence in 1998, but then I enjoyed excellent health until I became pregnant in April 2000. Unhappily, this was the start of major health problems, which even threatened the life of my unborn child.

The colitis spread along the colon and I became very ill indeed. By week 26, I was admitted to hospital and treated with IV steroids. I recovered reasonably quickly, but the damage had been done.

The placenta slowly began to fail, and my son was born by emergency Caesarian section at 32 weeks, weighing just 2lbs 10ozs. It was touch and go, but – after 7 weeks and 3 days in the Special Baby Care Unit – he came home on the day he had been due to be born.

I suffered another full-blown flare up just 8 months later. This time I didn't respond to steroids and I had an emergency ileostomy 10 months to the day after my emergency Caesarian. I was desperately weak, but the thought of my baby at home without his mummy was all I needed to get me up and running …. well, not literally!

I got on far better with my bag than I ever would have imagined, but then came the massive decision: to be a pouchie or not to be a pouchie! After much discussion with my husband, stoma nurse and surgeon, I decided to take the plunge. I had my reservations, but the bottom line was I wanted to have more of my life without a bag.

My pouch was created in January 2002. The aftermath was very difficult. I was readmitted to hospital twice and could barely eat a thing. But when I had my closure, it was as though someone had waved a magic wand. I didn't go to the loo 20 or even 10 times a day. I started with a modest 7 visits (5 during the day, 2 at night), I felt well, and I ate like a horse!

During this time I kept a diary and each day I aimed to hold on for a bit longer. I ate my main meal of the day at lunchtime (and still do), I never used Imodium, and over time managed to "drop" visits. I kept thinking of the "twice a day" girl!

After 3 months I settled at 3 visits a day and none at night. Nineteen months on, this is still the case. Occasionally – every month or so – I do reach the "twice a day" plateau. I know it is a combination of good fortune and determination that has helped me get to where I am, and I am truly delighted with my lot. Yes, I've had my problems (an anal fissure, anaemia and an ovarian cyst), but I am learning to accept that these blips can and do happen following such major surgery.

In my experience, you can still come out smiling. So, if you're reading this and considering pouch surgery, don't be put off. It's different for everyone. And it could be great for you, too!

Stephanie Dawson

Special thanks go to my husband Tim, my surgeon Ling Wong, my Stoma nurse Jan Ballard, my gastroenterologist Chuka Nwokola and my obstetrician Chris Griffin. What a team!

Please support the Red Lion Group

Registered Charity number 1068124

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

Contact the Red Lion Group

CHAIR
Christopher Browne
89 Fulwell Park Avenue
Twickenham
TW2 5HG
Tel: 020 8894 1598
chair@redliongroup.org

VICE-CHAIR
Michael Dean
9 Mornington Crescent
Benfleet
Essex
SS7 2HW
Tel: 01702 552500
vice-chair@redliongroup.org

SECRETARY
Margaret Dean
Address, and home telephone number as for Vice-Chair.
secretary@redliongroup.org

NOTES SECRETARY
Christine Lawton
19 Nathans Road
North Wembley
Middlesex
HA0 3RY
Tel: 020 8904 7851
notessecretary@redliongroup.org

TREASURER
John White
44 France Hill Drive
Camberley
GU15 3QE
Tel: 01276 24886
treasurer@redliongroup.org

LIAISON OFFICER
Marion Silvey
76 Innsworth Lane
Gloucester
GL2 0DE
Tel: 01452 417124
liaison@redliongroup.org

PRESS OFFICER
Stephanie Zinser
Tel: 01932 867474
Fax: 01932 867444
pr@redliongroup.org

PRESIDENT
Professor John Nicholls

PATRON
Claire Rayner

CLINICAL NURSE SPECIALIST
Joanna Wagland
St Mark's Hospital
Northwick Park
Watford Road
Harrow
HA1 3UJ
Tel (work): 020 8235 4126
pouchnurse@redliongroup.org

NEWSLETTER CO-EDITORS

Content*
Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW
Tel: 01622 739034
Fax: 020 7691 9527
newsletter@redliongroup.org

Layout*
Tim Rogers
30 Amberley Gardens
Epsom KT19 0NH
Tel: 020 8393 6968
layout@redliongroup.org

* contributions to the newsletter should be sent to Morag Gaherty

Join the Red Lion Group

- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

Visit Our Website

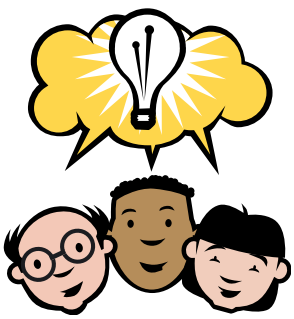
www.redliongroup.org

Write for *Roar!*

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

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

Perhaps you've taken up a new hobby since having your pouch operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share?



We'd even be willing to publish an article about why having a pouch was a bad idea.

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

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

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

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