

Summer 2005  
NEWSLETTER

**INSIDE**

**OUT**

VOLUME 2  
ISSUE 12

**STOMA SUPPORT GROUP WORKING WITH ST. MARKS AND NORTHWICK PARK HOSPITAL**  
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1088119



## Bob's Hello



Hi Everyone,

I hope you are having a great summer! Me, well if you get this before the end of August, then I am still lying in the sun recharging my batteries for the next round of operations.

It got me thinking what happens if? Have I written my will and put things in order? I spoke to a man that knows and he asked me what I wanted. When he asked me "do you want to leave a legacy or donation to a charity?" It got me contemplating. He told me many of us have had to watch our spending carefully throughout life but when it comes to making a will it is an ideal opportunity to support those causes that are dear to our hearts. Donations or Legacy income is vital for charities, knowing that funds may become available gives them security and allows them to plan for the future.

A Legacy gift is an excellent way to support the charity/ies. It can be very tax efficient as a gift to a registered charity is free from inheritance tax. A legacy to any charity would effectively reduce any tax your family or any other beneficiaries would have to pay. Your solicitor will be able to advise you on the exact wording.

These things are always difficult and we try to put them off for as long as we can, knowing full well that if we don't do it then it's left to those who are left behind to sort out and it can get very messy, believe me.

Inside Out Stoma Support Group would welcome any form of donation or legacy. This would help to supplement our income, as we are a small group who depend on our membership subscription or on the fundraising we do throughout the year to continue providing support to those who need.

I look forward to seeing you all at our Open/Information Day & AGM on the 10th September, Level 6 of St Marks. We have 3 very interesting speakers and all our stoma suppliers will be there for you to see and check out their new products.

**Best Wishes**  
**Bob**  
**Chairman, Inside Out**

## Inside Out Coffee Mornings

In the Out Patients Department of St. Mark's, Level 3  
10.00am to 12 noon

We are there to enable you to seek advice about your stomas, or if you just want a good old chin-wag and a cup of tea or coffee, then you are more than welcome.

**September** Thursday 2<sup>nd</sup>, Monday 13<sup>th</sup>, Tuesday 28<sup>th</sup>  
**October** Wednesday 13<sup>th</sup> Thursday 28<sup>th</sup>  
**November** Monday 8<sup>th</sup>, Tuesday 23<sup>rd</sup>  
**December** Wednesday 8<sup>th</sup>, Thursday 16<sup>th</sup>



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- 3 Carry a bottle of water with you in your car.
- 4 Keep a sport bottle with you at work or when you are relaxing.
- 5 Start a meal with a bowl of soup.
- 6 Drink a beverage with each meal.
- 7 Drink more when exercising, especially if it is hot and humid. Drink one or two glasses of water or diluted fruit juice (one part juice to one or two parts water) about 30 minutes to an hour before you begin exercising. Drink another glass or more when you finish the exercise regime. For more intense or longer workouts increase your fluid intake to a glass every 20-30 minutes. Skip the high calorie sports drinks, unless you are working out continuously for at least 90 minutes.
- 8 Consider food as sources of water too. Lettuce, watermelon, broccoli, carrots, and apples are all more than 80% water by weight. Low fat cottage cheese, yoghurt, potatoes, and canned drained tuna all contain 70% water by weight.



Finally, do not include beverages containing caffeine (coffee and cola) or alcohol when tallying your daily fluid intake. These are diuretics and cause water loss.

### **Scheduled Water Breaks**



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Try this simple schedule then make changes to it to best suit your specific daily schedule.

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- 6 With dinner
- 7 During the evening
- 8 Bedtime



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If you have an E111 form from before December 2004 this is now out of date and you should obtain a new one from the post office.

# Adjusting to life as a doctor with a colostomy - David Parkins

*shares his experiences of having a colostomy and gives some advice*



I knew that it was very likely that I would need to have a colostomy, but when the consultant colorectal surgeon confirmed my suspicion it still came as a bit of a shock. I thought, "stomas are for old people, they smell, they're not cool or sexy and they're certainly not for doctors." All of these prejudices and more were tested in the next few months; some proved to be partly true while others were just blown out of the water.

My worst fear before returning to work was breaking some bad news to a relative when my stoma would decide to "work".

## My Story

In the mid 1990s I'd developed an abscess in the ischio-rectal fossa, which led to fistula formation. This was laid open a few times, and I'd also had a Seton drain in for a short while. My symptoms settled, and I continued a fairly uneventful life as a consultant in Accident and Emergency medicine until September 2001 when pain, sepsis, and rigors started again. A magnetic resonance imaging scan confirmed spreading sepsis, and the previous treatment was repeated. I managed a brief return to work in February 2002, but the symptoms persisted and I needed radical surgery to "lay it open." The postoperative period was rocky, and I was soon on intimate professional terms with many of the medical and nursing staff in the small district general hospital where I work, having been a surgical patient for five weeks, as well as seeing radiologists, gastroenterologists,

dermatologists, and anaesthetists.

By April 2003 my symptoms were worse, with pain, rigors, and anaemia topping the list; I was also depressed. At this stage I was seen again by a colorectal surgeon, who confirmed my fears that without a colostomy and another laying open my symptoms would persist and I might become incontinent. With a big shadow I agreed to have the stoma.

The ultimate irony of the preoperative preparation for colostomy is that you are dosed with Picolax 24 hours before surgery, so for the last few hours of its functional life your rectum works overtime. My postoperative recovery was fairly uneventful and now that my perineum was healed I was exactly what my surgeon said I would be: an Accident and Emergency doctor who happened to have a colostomy.

## Tips for dealing with chronic illness

- ❖ Make early contact with an occupational health consultant
- ❖ Take out a loss of earnings insurance policy today
- ❖ Don't accept early retirement unless you're really ready for this, intellectually and financially
- ❖ Get regular sick notes from your general practitioner. Keep photocopies of each note
- ❖ Make early contact with involved professionals - for example, a stoma therapist
- ❖ Whilst on sick leave keep up to date professionally as much as possible
- ❖ On return to work don't be scared to ask colleagues for clinical advice and support. Consider observing a few sessions first (obviously revalidation will make this mandatory)
- ❖ Don't despair. Life after illness is possible and even enjoyable

## Highs and Lows

Living with the stoma has had its highs and lows. It has been a fairly steep learning curve, helped primarily by my local stoma therapist. At first there was no logic to the colostomys activity. I read all of the available advice sheets about what to avoid. Most of this is common sense; food and drinks that cause alteration of bowel habit in "normal" people cause the same effects in people with colostomies, albeit with occasionally more noticeable signs. A year after surgery I have now developed a "pattern."

## Adjustments

It has been necessary to make some adjustments to the way I work. Without being too graphic, the gastrocolic reflex after breakfast can be a hindrance to having a shower, getting dressed, and going off to work in record quick time. I now get up at 5.30am and have a solo breakfast, then sit and listen to Radio 4 while nature takes its course. By 7am I'm ready to wake the rest of the household with breakfast on the table.

The interruption to this routine is when I'm on call; an urgent summons in the small hours means five minutes delay while I change bags and dress, although the simple act of waking can itself promote colonic activity. Since I live within 10 minutes of work I can still be in fairly quickly.

## Openness

I made an early decision to be quite open about surgery. I don't exactly go up to strangers and tell them that I have a

### Tips for dealing with a colostomy

- ❖ Plan your day around how your stoma functions
- ❖ Be honest; if it "goes off" just tell the truth. "I've got a colostomy"
- ❖ Always have spare bags (precut to size) plus your other 'kit' available in a bag or pocket. I always carry some spare eau de cologne as well
- ❖ Avoid large meals in the middle of the day; as if any of us have the time anyway. Also avoid food and drinks that cause excess gas, unless it's not going to be a problem. Curry is best confined to weekends when not on call
- ❖ Discuss your unique problems with your clinical or medical director; don't forget you are covered by the Disability Discrimination Act. You may need to introduce some flexibility or alternative working practices into your schedule
- ❖ Using disabled toilets makes it easier to cope with the unique problems of having a stoma
- ❖ When travelling have plenty of stoma bags (for at least 3 days) in your hand luggage in case the airline loses your supply. Don't carry scissors (to cut stoma flange to size) on to an aircraft. Don't forget that gases expand in an aircraft at altitude
- ❖ Wardrobe adjustments may be necessary, especially if you develop a parastomal hernia. Buy a waist size too large, use braces rather than belts, and consider waistcoats or bulky sweaters
- ❖ Medical care for doctors with illness can be a bit haphazard. Try to arrange routine follow up, rather than the ad hoc system that most of us use; as in, "Oh, give me a call if you've got any problems. You know where to find me"

colostomy, but certainly all of the staff in my department know. Since I've developed a parastomal hernia it's more difficult to hide anyway. The only activity that I'm banned from at work is manual handling; usually lifting a patient on a spinal board from the ambulance stretcher on to our trolley. At first I used to feel that everyone was thinking, "Arrogant \*\*\*\*, why can't he lift with the rest of us," but after telling our senior clinical nurse my dilemma the word spread, and I now get admonished for even laying a hand on the stretcher.

A colostomy is just one manifestation of illness

## Inappropriate Moments

My worst fear before returning to work was breaking some bad news to a relative when my stoma would decide to "work." This hasn't happened so far, and my experience is that the "adrenaline" of the moment stops that from happening. With a year's experience I now have a few seconds warning and can muffle all but the loudest eruptions. A strategically placed folded handkerchief also acts as a silencer; another tip from my stoma therapist.

## At Home

At home, my main concern would be how my two children, then aged 10 and 5 years, would react to the stoma. My son, the older one of the two, was fairly sanguine, but my daughter was very curious and still dissolves into peels of laughter whenever "George" makes his presence known.

It was actually the children who came up with the idea of naming the stoma, and I was very impressed with this unique thought. However, my stoma therapist informs me that it is her experience that most patients nickname their stoma. I'm sure this is an ideal mechanism to deal with what may be perceived as a scary enfant terrible.

## Other Practical Points

Trousers can be problematic, especially as my stoma is on the waistline. Belts are now useless, and my mother has performed a sterling service in sewing buttons on to all of my trousers for braces. A waistcoat helps to

hide the bulge as well as providing additional soundproofing. At work, scrub suits tend to be fairly voluminous anyway, so that's what I usually wear on the shop floor.

Adjusting to work was harder than I thought. Acute medicine had moved on even in the relatively short time I was on sick leave (two years), and reading the journals at home was not enough to keep up with developments, especially local ones within my own hospital and department.

### Support from Occupational Health

One of the most important professional contacts in returning to work was with a consultant in occupational health. He dictated to my Trust my pattern of return to work, which worked well; the pressure to return to full time with on-call as soon as possible was intense from managers, as was the suggestion that I took early retirement through ill health. Fortunately, seeing an occupational health specialist helped me to resist this. He will also be there for me as I contemplate a possible reversal in the future after my peritoneum has been repaired - more major surgery.

### Final Word

I am now more used to my colostomy and, despite the occasional bag detachment, feel that I have adjusted well. A colostomy is just one manifestation of illness; it may be a sternal scar from a cardiac bypass, a limb amputation, or an entirely hidden sign. As doctors we are not exempt from being ill, although we may think that we are. It is possible to live life and practise medicine, at least in some form, despite coincident medical problems. I think it makes us better doctors by doing so.

**David Parkins** *Consultant in Emergency Medicine Wansbeck General Hospital, Ashington, Northumberland NE63 9JJ*  
david.parkins@northumbria-healthcare.nhs.uk  
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We are very grateful to Mr Parkins for allowing us to approach the BMJ Group for permission to reprint his article and to the BMJ Group for allowing us to do so.

### Further Information

- ❖ British Colostomy Association, 15 Station Road, Berks, RG1 1LB Telephone: 01189 391 537 Website: [www.bcass.org.uk](http://www.bcass.org.uk) Provides information and support, including chat forums and links to companies specialising in specialist clothing
- ❖ The Ileostomy and Internal Pouch Support Group. A UK registered charity whose primary aim is to help people who have to undergo surgery which involves the removal of their colon (colectomy) and the creation of either an ileostomy or an ileo-anal pouch. Their site has lots of information: [www.the-ia.org.uk](http://www.the-ia.org.uk)
- ❖ International Ostomists Association. An association of ostomy associations, is committed to the improvement of the quality of life of ostomates and those with related surgeries, worldwide. It provides its member associations with information and management guidelines, helps to form new ostomy associations, and advocates on all related matters and policies:  
[www.ostomyinternational.org](http://www.ostomyinternational.org)
- ❖ Fittleworth, is one of the leading suppliers of stoma and continence goods in the UK. Telephone 0800 378 846 or [www.fittleworth.com](http://www.fittleworth.com)



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**By Wendy Hetherington**  
**CliniMed Representative**

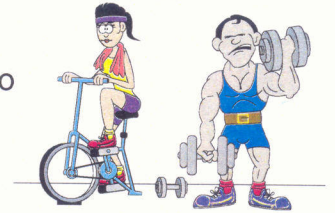
# How do I know if I'm dehydrated!

## *Are you at risk?*

Your GP will tell you that the best way to determine if you are getting enough water each day is to listen to your body.

## *Activity*

People who exercise strenuously need to drink more water. It is also wise to avoid exercising outdoors during the hottest period of summer.



## *Weather*

People living in hot, humid climates need more water than usual. Holiday makers take note: don't forget to factor in the weather conditions of your destination.

A person who lives in a cool or cold climate may jog 3km a day at home but the same amount of exercise on the beaches of a balmy tropical island could lead to trouble.

## *Age*

According to the American College of sports medicine, the body's ability to conserve water is reduced by aging. The body excretes more water through urination and perspiration than is taken in.

Those aged 65 or over may not feel thirsty even when their bodies need water. So be sure to drink your eight glasses (2 litres) of water a day before you feel thirsty.

## *Health*

Anyone who is sick with fever, diarrhoea, nausea and /or vomiting, should increase their intake. Children and the elderly are at additional risk.



## *Medications*

People who take diuretics (water pills) such as Frusemide must monitor themselves closely for signs of dehydration.

## *Signs of dehydration*

Most of the time dehydration does not reach the danger level. The danger level may result in dizziness, loss of consciousness, rapid heart rate, kidney failure and finally death.

## *How to get more water*

To prevent dehydration you need to take plenty of fluids throughout the day, at least 8 glasses (2 litres) of water daily even if you don't feel thirsty.

Follow these eight tips (one for each glass you should drink) from the American Dietetic Association to achieve the fluid intake your body needs.





- 1 Take a water break frequently throughout the day.
- 2 Always take a sip when you pass a water fountain.
- 3 Carry a bottle of water with you in your car.
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# Useful Contacts

**Chairman ~ Bob Azevedo-Gilbert**

256 Merlins Court, Alexandra Avenue  
South Harrow, HA2 9BZ  
020 8426 5203  
insiedout.bag256@btinternet.com

**Vice Chairman ~ Barry Kindred**

020 8423 7845

**Secretary / Treasurer ~ Diane Owen**

170 Malvern Avenue, Harrow  
Middlesex, HA2 9HD  
020 8248 6684  
insideoutbag170@aol.com

**Editors ~ Henry & Joan Greenwood**

020 8248 4740  
hjgreenwood@lineone.net



**Ileostomy & Internal Pouch Support Group**

0800 018 4724

**NACC**

01727 830 038

**Urostomy Association**

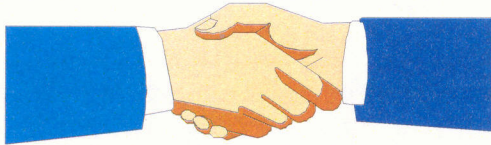
0845 2412 159

**British Colostomy Association**

0800 328 4257

**CUI Wear**

Underwear + Swimwear for ostomists  
0800 279 2050 Quote Ref IOU256



**Want to join  
the support group?**

If you have a colostomy, ileostomy or a urostomy and you would like more information, please complete the form below and send it to:

Clare Bossom & Sarah Varma c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_ Telephone \_\_\_\_\_



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