Summer 2017 | Issue 46

colostomy association

Tidings

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Thaila uses ***Brava® Skin Cleanser*** wipes to help soothe her dry and irritated skin.

What’s right for you?

There can be many reasons for skin irritation. In Thaila’s case, she suffers from dry skin and occasional leakage. Part of her solution is the ***Brava® Skin Cleanser*** which she uses to manage and soothe any red, sore skin around the stoma.

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*Data on file

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Cover picture
Sarah Squire, Ian Jackson, Jackie Dudley, Shell Lawes and Abi Brown promoting Colostomy Day – Find out more on pages 28 and 29

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dear READERS

Our cover this time promotes Colostomy Day. It was in 1992 that the three UK stoma support Associations got together to organise World Ostomy Day held every three years to promote awareness of people living with a stoma. Then on the first Saturday in October 2014 the Colostomy Association launched an annual event to complement this internationally–recognised awareness day. Now known as Colostomy Day, the aim is to change the general public's perception of stomas to make people aware that having a colostomy can be a positive change.

A stoma not only saves lives but it can also improve the quality of life. Rob Fearn is an example of this. His colostomy was formed during emergency surgery, but he welcomed it; his life was no longer restricted by the bowel problems he had experienced for more than fifteen years. He was free to pursue his hobby of wildlife photography and three years after his surgery he has won the Daily Mail Weekend magazine wildlife photography competition.

An acute attack of diverticulitis was the reason that Rob had emergency surgery to form a stoma. Following on from his story we have an article explaining this condition. It is written by Alison Horner who has not only spent a large part of her nursing career working on colorectal wards and operating theatres but has also had diverticulitis which led to emergency surgery to form a colostomy.

On the Dear Nurse page, we have two questions about rectal discomfort following stoma surgery. We asked Andrew Bird, who has worked as a specialist nurse in both stoma care and pain management to write about why this can happen and how this discomfort can be treated.

Joanne was 38, Abi was 40 and George was 62 when they were diagnosed with cancer. In their real life stories they all say that having a colostomy was a positive change as it saved their life. However, they all admit that it took time to come to terms with life with a stoma. Janet, on the other hand, has never known life without a colostomy. She was diagnosed with Hirschsprung's disease and had surgery to form a colostomy when she was a tiny baby. Now 79 years later she writes about *A life worth Living*. When she was a child there were no patient support organisations for people with stomas. It would be in 1967, almost 30 years after she was born, that the Colostomy Welfare Group (CWG) became a registered charity.

To coincide with the 50th Anniversary this year we trace the charity's history, first as the CWG then the British Colostomy Association (BCA) and now the **Colostomy Association** (CA). On 16 September this year we celebrate half a century of supporting people with stomas at an Open Day, a Fashion Show and Dinner at Wokefield Park in Berkshire.

During the last few years I have really enjoyed editing *Tidings*. It has been a privilege to meet and correspond with committed health professionals and many other people who, like myself, cope every day with a stoma. At the end of the year, however, I plan to step down from my voluntary position as editor of *Tidings*. This is for two reasons: Firstly, to hand over to someone with fresh ideas and who is familiar with modern technology and more involved in social media. Secondly, to return to writing the book – on a subject far removed from stomas – which I 'put on the back–burner' when I was asked to head up the editorial team in 2014. I will, however, remain as editor for the autumn issue and look forward to receiving your letters and reading about your real–life experiences.

I hope that many of you are able to join us on 16 September to celebrate the Association's 50th Anniversary and will be out there on 7 October raising awareness on Colostomy Day.

With Best Wishes

Rosemary

Rosemary Brierley
Editor
editor@colostomyassociation.org.uk

How to get in touch with the Colostomy Association

The Association represents the interests of colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

How to become a supporter of the Colostomy Association

Simply contact us by post:
Colostomy Association
Enterprise House, 95 London Street
Reading RG1 4QA

By telephone:
General Enquiries: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

By E–mail:
cass@colostomyassociation.org.uk

Find us on FACEBOOK:

Find us on Facebook

Join our 'closed' group today simply put Colostomy Association into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!

Visit us and register at:
www.colostomyassociation.org.uk

Don't delay Donate Online today!

There are **NOW two ways to donate online**

1

Visit the **Colostomy Association website** and **simply click** on the **donate panel** on **the home page.**

JustGiving

2

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy Association.**

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Support

colostomy association The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471).

Bulletin Board

NEWS AND UPDATES

Stoma Friendly Society

As the UK's largest stoma charity, we strive to be a voice for the ostomy community and will champion the rights and raise awareness of people living with a stoma

Toilet Campaign

Following the news that Stoke City FC now have stoma friendly toilets and signage we are pleased to say that West Bromwich Albion FC and Leicester City FC have also joined our campaign.

Colostomy Association Volunteer Irene Constable (pictured right) has been working hard in her home town of Oswestry to make toilets stoma friendly. At the end of March she was joined by the Mayor to officially make the town centre public toilet stoma friendly.

Toilet Consortium

In April we joined the following charities: Around the Toilet, British Toilet Association, Crohn's and Colitis UK, Public Toilets UK, and The IBS Network for the first meeting of the newly formed Toilet Consortium UK. The group's aims are to make public toilets more accessible and to be a united front campaigning on toilet related issues. We will keep you updated.

Holby City got it wrong

In April the BBC aired an episode of Holby City that portrayed having to have stoma surgery in a negative light. As part of our campaign to reduce the stigma around having a stoma we released a statement to the press and the BBC making known our disappointment.

Social Care

In January we joined 75 organisations in signing an open letter to the Prime Minister calling for her to urgently begin cross–party talks to find a long–term solution to the crisis in health and social care funding. In the spring budget the chancellor announced an additional £2 billion to councils in England to spend on adult social care services.

This is considered a stop–gap measure to enable councils to take immediate action to fund care packages and relieve pressure on the NHS. The government has advised that it will be publishing a social care green paper sometime in the future. At the **Colostomy Association** we are taking a keen interest in developments and, in partnership with the Care and Support Alliance, are working to ensure that the issue doesn't drop off the agenda. So watch this space for updates!

Appointments

As you may know Sue Hale, left the **Colostomy Association** in February for 'pastures new'. Sue joined us over five years ago and whilst she has been with us the Association has grown from strength to strength. During her time as General Manager, Sue oversaw the Association's move to larger offices and recruited staff to develop fundraising and marketing. She was responsible for the very successful 2015 **Colostomy Association** Open Day and fashion show, for the launch of Colostomy Day in 2014 and for creating links with other bowel–related charities. Sue leaves with our best wishes for her future and grateful thanks from us all for the inestimable contribution she has made.

We would like to welcome Libby Herbert as our new General Manager. Libby's background is in Engagement, Internal Communications, Recruitment & Human Resources, Event Management and Office Management within various sectors.

She was born in Kenya and lives with her husband Steve in Reading. The trustees and staff look forward to Libby becoming part of the team, getting 'up to speed' on the great work the **Colostomy Association** is involved with and bringing a new perspective on what we do and how we do it.

Active ostomates

Our Active Ostomates project launched in January 2016 with our free booklet 'sport and fitness after stoma surgery' and the start of a chair yoga pilot with the East Berkshire Ostomy Club.

The booklet has been extremely popular with over 1,000 distributed already. As well as examples of core exercises that can be safely tried at home, it advises ostomates how and where they can get back in to or take up sport for the first time after surgery.

The chair yoga pilot proved a success and we have extended the project to support groups in Ealing, High Wycombe, Stevenage, Milton Keynes, and Chester, with plans to extend further later in the year.

Caring for Ostomates

Our 'Caring for ostomates' project is a National Lottery funded programme that provides both professional carers and family members with practical advice and guidance on how to care for someone with a stoma.

The project has allowed individuals, support groups, care home and agency staff and reablement teams in Berkshire and the Home Counties to benefit from an intensive three–hour workshop that covers everything from stoma management, to a guide to different appliances, common concerns, support from Stoma Care Nurses, and psychological issues connected with having a stoma.

By educating care staff on the practical and emotional side of stoma care the **Colostomy Association** can directly improve the quality of life of those ostomates who need regular care and support.

While the National lottery funding ended at the end of 2016, the project is continuing and also branching out geographically and in terms of the type of guidance it gives.

If you're interested in finding out more about our projects please email **Giovanni.cinque@colostomyassociation.org.uk**

How your donations help

2016 was a very busy year for the **Colostomy Association**. Your donations helped us to:

- Respond to 7,000 calls for help and advice from ostomates.
- Attend 118 open days.
- Send out over 19,000 information leaflets and booklets to stoma care nurses, across 339 hospitals and 69 other locations (GP surgeries, care homes etc.).
- Publish *Tidings* and distribute 25,000 copies each quarter.
- Help our Stoma Aid project collate and send 182,080 stoma bags to developing countries.
- Encourage ostomates to be fit and healthy through our Active Ostomates campaign.
- Train family members and healthcare professionals to better look after a person with a stoma through our Caring for Ostomates project.
- Raise awareness of the day–to–day issues faced by ostomates through our Stoma Friendly campaign.

Thank you

2013 Holding my greatgranddaughter

A Life worth living

It was bank holiday Monday 1 August 1938 when I arrived in the world. My eight–year old brother was not very pleased as Mum and Dad had promised to take him to the seaside for the day. We lived on the south coast and as it turned out that was the last opportunity they would have to take him as the following year, with the threat of war with Germany looming, barricades of barbed wire were erected on the beaches.

After a while it became apparent that all was not well with me. Doctors at the local hospital were unable to find out what was wrong and, as my health deteriorated, I was hastily christened in our nearby church then taken to Great Ormond Street Hospital in London. It was here that the eminent surgeon, Thomas Twistington Higgins, soon diagnosed the problem. I had been born with Hirschsprung's disease; he operated and my journey through life with a colostomy began.

Until the age of seven I was to spend long periods of my life in Great Ormond Street undergoing several more operations. It was during this time that sadly my mother was to die from TB which was then rife in England, so I never got the chance to know her. Things were so different in hospital in those days. Visiting was not encouraged because of the fear of infection and in case the children became upset and of course when World War II broke out travelling to London became dangerous. To compensate for this the hospital took photographs of the children which were then posted to the parents to reassure them that their child was in safe hands.

1939 In Peter Pan Ward at Great Ormond Street Hospital

My only bad memory of Great Ormond Street was going to theatre. Back then there was no injection to send you to sleep beforehand, just a black rubber mask forced on your face, before an anaesthetic was administered. Christmas was magical, the nurses wore their capes with the red side showing and walked through the wards carrying lanterns and singing carols. Then they distributed wonderful presents given by the many benefactors of the hospital. Another memory is of being evacuated to another hospital in Surrey in 1940 when the bombing of London was at its height.

Last year I had the privilege of having a guided tour of Great Ormond Street Hospital along with other ex–patients and former staff and to visit Peter Pan Ward where I spent so much time as a child. It was soon to be demolished but the nursery–rhyme wall tiles that I remembered had been saved and now take pride of place in a reception area.

Going back to my childhood, when I was finally allowed home I found life was going to be so different. After my mother died, my father's sister moved in to look after the family. She was very Victorian in her ways and very strict. She told me that I was going to be brought up in a very tough way, in her words: "to help you cope with the knocks life will throw at you" and yes, I have taken quite a few knocks, but thanks to her have always managed to bounce back.

Growing up pre NHS with a colostomy was not easy, things that medical staff encourage today were taboo back then. I was forbidden to do any PE at school, not that I minded getting out of having to play hockey on a freezing cold day. Diet was also restricted to foods like steamed fish and egg custard which were easy to digest and which I still dislike eating today as much as I did then. Few appliances were available in those days. In my case, it was a pad of cotton wool, on top of that a sort of plastic disc and this was all held in place with a surgical belt which was neither effective nor comfortable. As you can imagine, 'accidents' were a frequent occurrence. We really are spoilt for choice now, well in this country at least. My heart aches when I read about the conditions that people with a colostomy have to endure in developing countries.

By the age of 12 I began to feel more confident about life, but then I had more health problems and operations to overcome. So many stays in hospital meant that my education was disrupted and I left school with no qualifications. In all, I have had surgery from top to toe, but I am still here to tell the tale.

After leaving school I found work in a local factory as this was the only employment opportunity open to me. From here on life progressed as near normal as I could have wished. I did everything that all other teenagers were doing: dances on Saturday nights, visits to the cinema several times a week and get–togethers in pubs if anyone had a birthday to celebrate. It was at one of these birthday celebrations that I met my future husband. He was home on leave from the Royal Navy. We got talking and it turned out that his aunt worked at the same factory as I did, and, to cut a long story short, he asked if I would write to him while he was away. We corresponded for 18 months, and when he left the Navy we got engaged.

It was then I told him about my colostomy. Although I was not ashamed of my condition, in those days, people did not talk about personal things like that, so it was not until that point in our relationship that I felt I wanted to say anything. I was lucky in the fact that in the Navy he had served alongside someone who had a colostomy which made it easier to explain. We went to see my GP together but, rather than try to help, he put obstacles in the way. He told us that I would never be able to have children and said to think carefully about getting married at all.

We were married a year later, something that I had thought would never be possible for me. I remember I bought some suspender belts, cut off the suspenders and wore them instead of the horrible surgical belt. It made me feel more feminine. Despite what the doctor had said, I became pregnant in 1960. I had to buy an old–fashioned corset that laced up at the sides so that I could adjust it to fit my bump. I was able to have a natural birth and was blessed with a son and then later a daughter.

I cannot remember when stoma bags became available, but I think it must have been the late 1960s. They were everything that the present–day stoma bags are not: flat, noisy, the adhesive almost non–existent and they did not fit the uneven surface surrounding the stoma. The first time I saw a stoma care nurse was in 1989.

Unfortunately, after 32 years our marriage ended in divorce. Although I had worked part time whilst bringing up the children, I knew I would have to find full time work to support myself. As luck would have it, I heard they were advertising for nursing auxiliaries on the psychiatric ward at the local hospital. I went for an interview and was lucky enough to be offered the post and spent 13 years doing a job that I really loved.

2009 At the Colosseum in Rome

After some years of living alone and working hard, a new man entered my life. He had been a family friend for a long time and already knew that I had a stoma. When he underwent the same surgery, I was able to reassure him. We eventually married and were very happy, but this wasn't to last as, after just three years of marriage, my husband died.

Although I am alone again, I am not lonely as both my son and daughter had three children so I now have six grandchildren and three great grandchildren. My life is so full with family and a wide circle of friends; we go to the theatre, concerts and on day trips together. I am involved with my church and WI, belong to a scrabble group, go walking and love hosting dinner parties. Being a football fanatic there is nothing I enjoy more than the chance to go to the Emirates Stadium to watch my beloved Arsenal play.

In recent years, I have caught the travel bug and have managed to travel around most of Europe, the USA, taking in eight different states from Dallas to Washington DC including New Orleans, which because of my love of jazz was a dream come true. Going to China was a wonderful experience, but a word of warning, the public toilets can prove a bit of a problem if you have a colostomy. It is better to use toilets in hotels or better–class restaurants. You are also warned not to use water from taps, not even to clean your teeth. So something else to consider, but despite everything, China is still an amazing country to visit.

I hope my story has given you inspiration and encouragement to live life to the full.

My grateful thanks to all the people who have made my life worth living.

Janet

Medical Terms Explained

Hirschsprung's disease is a condition, present from birth, in which nerve cells that control the movement of faeces are absent in part of the bowel. This results in pain, constipation and blockage.

Looking back and moving forward

As you may know we have been researching the Colostomy Association's history in readiness for our 50th anniversary. With so much material in the archives it hasn't been easy! In the last half century, we have changed names three times and occupied five different premises. From humble beginnings in a London hospital, we now have over 23,000 registered supporters nationwide. More recently, through our Stoma–Aid campaign we have started to reach ostomates across the globe. To make sense of our history we have divided it into a series of periods, which you can read about below. First though, it's worth saying something about the context in which today's charity was formed.

Our origins can be traced to the 1960s. This was a torrid time as it had become clear that scientific advances were creating a cost dynamic in the fledgling NHS: with each advance, more people could be treated. In an attempt to reconcile the problem, government put its faith in technology and modernisation. They envisaged that building state–of–the–art District General Hospitals was the way to offer high quality healthcare while at the same time containing costs through economies of scale. With government convinced that 'modern' was good, some feared patients might just become 'medical problems' to be solved through the application of technology. Luckily, at the coalface, healthcare professionals were not prepared to allow this dystopian vision to become a reality. At one London hospital the therapeutic value of human contact was appreciated by one of the surgical registrars. In 1963 he approached Gertrude Swithenbank (herself a colostomate) and asked if she would visit his colostomy patients on the wards. It quickly became clear that her visits encouraged recovery. She provided the reassurance that patients needed and proof that it was possible to lead an active life after stoma surgery.

In the same year as Gertrude started her hospital visits she told Frances Goodhall about what she was doing. By 1963 Frances had been retired for some years, which suggests that the women may have known each other. One possibility is that they had worked together as nurses. Either way, it was an important connection. In 1966, as a result of Frances' involvement, the King Edward's Hospital Fund provided the money to conduct a pilot study into the need for a national service for colostomates. 29 hospitals in London took part. The findings of the study led to the founding of the Colostomy Welfare Group, which advertised for its first member of staff in November 1966.

Frances Goodhall (1893–1976) CBE, MBE

Frances Goodhall came from a medical family. Three of her uncles worked at Guy's and in 1916 she began training as a nurse at the same hospital. This marked the start of a stellar career in which ophthalmic nursing became her great love. According to her biographer, Monica Baly, Frances' delicate hands and skill in the field became legendary. At the age of 35 Frances was appointed assistant general secretary of the College of Nursing. In 1935 she took over as general secretary. In this capacity she contributed to post–war discussions about the NHS, coming into contact with figures such as Nye Bevin. By the time she retired, Frances was well respected in medical and political circles.

The Colostomy Welfare Group (CWG) 1967–1989

The recruitment advertisement (reproduced in the last edition of *Tidings*) resulted in the appointment of Emily Brain as welfare officer. Emily went on to become our general secretary from 1968–79. The CWG began life operating out of two rooms at St Luke's Hospital, Chelsea.

Emily Brain MBE, pictured in later life

As you can see, much was achieved in the years that followed.

1967: With demands for the services of the group spreading to other hospitals, the CWG became a registered charity.

1970: As demand continued to grow, the charity struggled to raise sufficient funds. In order to continue its activities, CWG applied for, and was granted, £5,000 from the National Society for Cancer Relief (now Macmillan Cancer Support). This covered the bulk of operating costs.

1972: CWG moved to new premises in Ecclestone Square, London. It also became one of four 'associated charities' financed by the National Society for Cancer Relief. This arrangement continued for the next 33 years.

1980s: Consultant surgeon Mr Brendan Delvin CBE, FRCS, assisted in the preparation of support literature. Foreign language versions were also produced. As you can see from the photos, our literature has since undergone substantial change!

Late 1980s: CWG had developed a greater presence being mentioned in the publications of other charities, manufacturers and suppliers, as well as in leaflets written by healthcare professionals. By now, the CWG had also established a network of area organisers and visiting volunteers (all colostomates).

An early booklet, date unknown

British Colostomy Association, 2000

Colostomy Association, 2009

Colostomy Association, 2017

The British Colostomy Association (BCA) 1989–2005

As the CWG became well known, issues emerged with its name. The word 'welfare' was the problem. It was felt that this was misleading and gave the impression that financial support was on offer. Consequently, the name 'British Colostomy Association' was adopted in 1989, with the purple iris as its emblem. Rent increases led to the BCA relocating to Reading. It was from here that the first issue of *Tidings* was published, the 24–hour helpline was launched and the charity continued to build its impressive portfolio of literature. By 2005 BCA was taking in excess of 6,000 phone calls per year, sending out 25,000 leaflets to ostomates and healthcare professionals and had volunteers across the country visiting patients, talking to them on the telephone and attending open days. The BCA years had many other highs:

1992: Following a meeting with the IA and the Urostomy Association the three charities set up a co–ordination committee to organise the first World Ostomy Day. This event, which aimed to raise awareness of the needs and aspirations of ostomates, has continued ever since.

1998: The first issue of *Tidings* was published and announced that consultant surgeon, Mr Brendan Delvin (involved since the early days of CWG) had agreed to succeed Sir Ian Todd as the BCA's next president. Sadly, Mr Delvin died six months later.

2000: *Tidings* started to include advertisements as a way to cover production costs. Initially adverts were enclosed as loose inserts. The iris emblem underwent change with a new bolder look. This coincided with the release of a revised set of literature. Colorectal surgeon Professor Robin Phillips became the BCA's new president.

2002: Helpline hours were extended to include weekends and bank holidays.

The first issue of Tidings, July 1998

Tidings, Spring 2017

Iris Emblem, 2005

Iris Emblem, 2016

The Colostomy Association, 2005–to date

In 2004, what was now the Cancer Relief MacMillan Fund, announced its intention to discontinue the financial support of 'associated' charities. The BCA thus faced the daunting prospect of trying to go alone, becoming a self–funding charity. Luckily both the appetite, energy and courage to continue was there. The idea that ostomates might be left without support and that four decades of hard work could be lost was inconceivable. Eight people came forward to act as trustees and on 15 November 2005 the **Colostomy Association** was formed. To accord with the change, the new charity launched a website to further reinforce its message that help was there for people in need. The last twelve years have been exciting times, including the challenge of raising our profile on the internet and reaching out to ostomates in the new digital age:

2008 & 2013: Saw moves in premises, with the **Colostomy Association** ending up at Enterprise House in Reading, where we are today.

2010: Further improvements were made to the website making it easier for ostomates to access news and information. By 2015 the site was receiving over 513,000 visits per annum.

2012: The **Colostomy Association's** Facebook group was made 'closed'. Within a year it had 1,000 members. Today, this ever–growing and vibrant community numbers well over 4,500 and provides a vital, safe environment in which ostomates talk and support one another.

2014: Mr Ian Daniels took over as our president from his colleague Professor Bill Heald who had held the position since 2008 and was an internationally known colorectal surgeon. The **Colostomy Association** launched its Junior Ostomate Support Helpline aimed at providing support to the families and carers of children with stomas and other bowel and bladder dysfunctions.

2015: The first monthly e–newsletter was sent and in excess of 84,000 copies of *Tidings* were distributed.

2016: Saw the start of two new campaigns: Stoma Aid and Stoma Friendly Society. By the end of October more than 182,000 stoma bags had been distributed to developing countries, while our stoma friendly toilet stickers started to appear at sites across the country, following a letter and social media campaign.

Looking Forward…

We hope that you've enjoyed this trip down memory lane and seeing how the **Colostomy Association** has developed over the past half century. We are confident that the next 50 years will be just as exciting. As well as continuing to provide all our current services we have plans to expand the support that we give. We're looking forward to sharing these plans with you in the months and years ahead. In the meantime, don't forget our Open Day on 16 September. It would be great if you could drop by and say 'hello'! ■

50th Anniversary
Open Day 2017 and Fashion Show
Saturday 16 September 2017

1967-2017

Booking Form

I would like to attend the following **Colostomy Association** events at

Wokefield Park
Goodboys Lane
Mortimer
Reading
RG7 3AE

(please insert the number of places required):

		Quantity
Open Day only	*Free of charge*	☐
Open Day, Fashion Show and Evening Meal	*£25 per person*	☐
Fashion Show and Evening Meal only	*£25 per person*	☐

I enclose a cheque made payable to 'CA Ltd' totalling .... **£ .**

Details: Title: First Name: Surname:

Address:

Postcode:

Telephone (home): Mobile:

Email:

Dietary requirements:

NOTE: Please remember to book your own overnight accommodation if needed.

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** no later than **31 August 2017**, but bear in mind places are strictly limited so it will be best to book early to avoid disappointment.

Official tickets for the Fashion Show and Dinner will be sent to you nearer the time.

Colostomy Association Facebook Group

Group Meet in Scotland

Tai Chi practice at the Group Meet in Glasgow

Sarah Squire, Trustee and Facebook Admin writes:

The CA Facebook Group is an active online support group of over 4,500 members. New members arrive, sometimes with many worries about life with their stoma and the Group pull together to help out. Friendships form while problems are shared and solved, often with a few laughs on the way. Group Admins: Ian, Michael, Sally, Steve and myself try to arrange a couple of Group Meets a year in different parts of the country where members can meet in person, where virtual hugs can be turned into real life ones.

In March 2017 we were kindly invited to Glasgow by Coloplast. Ian and I attended a conference in Edinburgh last year and spent the two days manning the **Colostomy Association** stand opposite Coloplast. Here we met Damian Crombie, NHS Liaison Manager, and we happened to mention we were keen to hold a Facebook Group Meet in Scotland. He said Coloplast/Charter would be happy to get involved – I didn't need asking twice and was on it as soon as I got home!

Claire Jackson, Territory Manager for Scotland, did an amazing job of organising the event and despite my constant emails asking this, that and the other about venue, food, accessibility and much more, she came up with the perfect day. This was our first official Meet Up in Scotland and it was lovely to see so many local people attend, along with a few die hard members who travel anywhere for the Meets, this time travelling hundreds of miles to join in.

Coloplast held the event at House for an Art Lover in the grounds of Glasgow's Bellahouston Park. We had the top floor of the house and it was a beautiful setting with amazing views. We were met by Coloplast and Charter representatives: Adrian Summerson, Senior Market Manager, Wendy Osborne, Ostomy Clinical Lead, Rebecca Preston, Territory Manager Scotland, along with Claire and Damian.

After tea, coffee and those all–important hugs, the day began with interesting talks on the history of Coloplast and Charter by Claire and Rebecca, followed by a talk on hernias by Wendy. With hernias being so common in ostomates it was great to have chance to interact with Wendy and ask questions. I, for one, learnt a few things.

We broke for lunch (lovely spread Coloplast!) then carried on the afternoon with a talk about sore skin – another hot topic for us ostomates and again most interesting. By that point we had been sitting down for a fair amount of the day so to encourage us to be active ostomates, Coloplast had arranged for us to have an introduction to Tai Chi. This was great fun and, although many of us collapsed into fits of giggles at various points, it was great to see everyone joining in and enjoying the gentle exercise. Those who weren't able to take part seemed to have almost as much fun watching and taking some very 'interesting' photos!

After a quick pit stop for a cuppa and a tasty cake we returned for the final session with Adrian who was so relaxed after the Tai Chi that he led the session with no shoes on! We discussed life with a stoma and completed questionnaires on stoma issues. Interestingly our group seemed to have a lower incidence of problems compared to the average.

By now I was hearing murmurs about some rugby game that was taking place between England and Scotland. This is the second Meet Up where I have managed to clash with a Six Nations match so we headed to the Premier Inn where many of us were staying so those who wanted to could catch up with the game. After a very good result for England (apologies to our Scottish hosts!) we met for drinks and dinner, kindly covered by Coloplast. We held a raffle with a number of prizes including umbrellas donated by Vanilla Blush, Stoma Aid tote bags, goodies donated by Group Admins plus of course a Tomas Bear personalised for the Meet. Many people donated the deposit they'd paid to secure their place on the Meet and that along with raffle ticket sales resulted in a brilliant **£200** raised for the **Colostomy Association**.

We had a lovely day and I would like to thank Coloplast for hosting the event and for being great company. To any Facebook Group members who would like to attend one of these Meets we hope to see you at the **Colostomy Association** Open Day in September, and keep your eyes peeled on the Group for the next event.

If you would like to join the closed CA Facebook Group, search "**Colostomy Association**" in your Facebook search box. Choose the Group and when you get the Group page, click on the join tab. One of the admins will add you as soon as they can. We look forward to seeing you there.

Fundraising Focus

2017 Raffle

The last issue of *Tidings* contained two books of tickets for the 2017 Colostomy Association annual raffle, and this year there's an even greater chance to win! We've still got our fantastic first prize of £2,500, second prize of £500, and four chances of winning £250, but there are now five chances to win £100 as well. What better way to start the new year than spending your winnings in the sales or on a last–minute holiday!

Tickets are £1 and all money raised from the raffle will go towards supporting vital **Colostomy Association** services such as our 24–hour helpline, free literature and *Tidings* magazine.

We've had a brilliant response so far, and if you haven't returned your tickets yet there's still plenty of time to do so.

All completed stubs need to be in by **Friday 15 December** and the winners will be notified by email, phone or post and announced in the spring 2018 edition of *Tidings*.

Please note there is a printing error on the stub of the tickets. The date of the draw is stated as taking place in 2016 rather than 2017. The draw date is correct on the ticket portion that the purchaser keeps. The fundraising regulator and the Gambling Commission have both confirmed that these tickets are valid for sale.

Darren's Dazzels Parachute Jump

Darren Pote is jumping out of an airplane for the **Colostomy Association**!

In his own words Darren has chosen to raise funds in this way because "On the 13 July 2016 (my 43rd birthday) I was rushed back into A&E with severe stomach pain and PR bleeding, I was losing so much blood.

I had a sigmod diverticulitis perforation and required immediate surgery. After the op which took 14 hours, was a living nightmare as I got sepsis and pneumonia. I was cut from the chest to the private area (43 stitches) I've had so many complications, my wound had to be opened in three places to drain the infection, several months under tissue viability. It's only now eight months later it's healing.

I want to the parachute jump to raise as much money as I can for the **Colostomy Association** who receive no government funding. I found their website, blogs etc a God send when I hit some very very dark times."

You can support Darren by donating through his just giving page at **https://www.justgiving.com/fundraising/Darren-Pote**

Winnie's 5th Birthday

On Saturday April 8 Christine Burgin held a '5th Birthday' for her Stoma 'Winnie'.

The party took place in her local scout hut (Christine has been a scout for 38 years) and through a raffle, tombola, sales of cakes and coffee, Christine and her friends managed to raise an amazing **£1,324**!

Thank you

Yet again our supporters, their friends, and family members have been busy raising funds for the **Colostomy Association**. As always we are hugely grateful and humbled by the efforts of so many people who help financially support our various services.

The Gateshead Stoma Support group raised **£373.81** for Stoma Aid through raffles and refreshment donations.

Mooray Ostomates donated **£300** as a result of their fundraising activities.

The Church of Scotland Guild Irvine and Kilmarnock Presbyterial Council donated **£50** to the **Colostomy Association**.

Salts healthcare raised **£86** after they donated £1 for every response they received from a recent survey they conducted with healthcare professionals.

Judi and Brian O'Connor collected **£160** on their Golden wedding anniversary through asking friends and family for donations to the **Colostomy Association** rather than giving presents.

Hilary Tristram donated **£325** which was received for donations from friends and family at her 'un–birthday' lunch.

The Stoma Care department at **Colchester University Hospital** collected **£40** from their Christmas Support group meeting.

The Kay Park Parish Church Guild donated **£50**.

Are you an Active Ostomate?

The **Colostomy Association** is looking for ostomates and non ostomates who are interested in representing the charity in various sporting events in the near future. It could be as individuals or as a team. Whatever activity you enjoy be it running, cycling, bowls, walking, swimming, tennis or football, we'd love to hear from you!

For further information or to register your interest please contact our development officer Giovanni Cinque at **Giovanni.cinque@colostomyassociation.org.uk**

Unity Lottery

It's now been over a year since the **Unity Lottery** replaced our 500 Club and we are glad to say that not only is its popularity growing with supporters on a weekly basis, they are also winning regularly as well!

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to the **Colostomy Association**), as well as smaller prizes of £5, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 49 or online by visiting **www.unitylottery.co.uk** but remember to link to our Charity.

Grants and Trusts

The **Colostomy Association** is grateful to the following trusts and foundations who have recently agreed to support our work through contributions to our core costs and various projects:

The Lynn Foundation, The Constance Travis Charitable Trust, The Cardy Beaver Foundation, and the Sir James Roll Charitable Trust.

Textgiving

You can now make a donation to the **Colostomy Association** with a text message!

Whatever mobile network you're on, simply text our unique code CASS01 and an amount of £4, £5 or £10 to 70070.

Donating via text is free. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more 100% of your text donation (including Gift Aid) will be sent to the **Colostomy Association**.

The amount you donate will be added to your mobile phone bill or deducted from your pay as you go credit. JustTextGiving will send you a link in a text message confirming your donation

Leave a Legacy

Giving in your will is a truly special way to make a lasting difference. It will help ostomates of tomorrow, their family members and carers, receive life–changing support from the **Colostomy Association**.

What your gift means

Legacies large and small can have an extraordinary impact for all the people we help and support. They can:

- Ensure there is always a voice at the other end of the phone.
- Train volunteers to provide support at open days and in hospitals.
- Fund our campaign for a stoma friendly society.
- Make sure the ostomates of tomorrow receive the same support from us that you have.

How to leave a legacy

A solicitor can help you to write a will or, if you already have a will, a codicil. Your legacy could be used wherever it is most needed or you can choose to support a specific area.

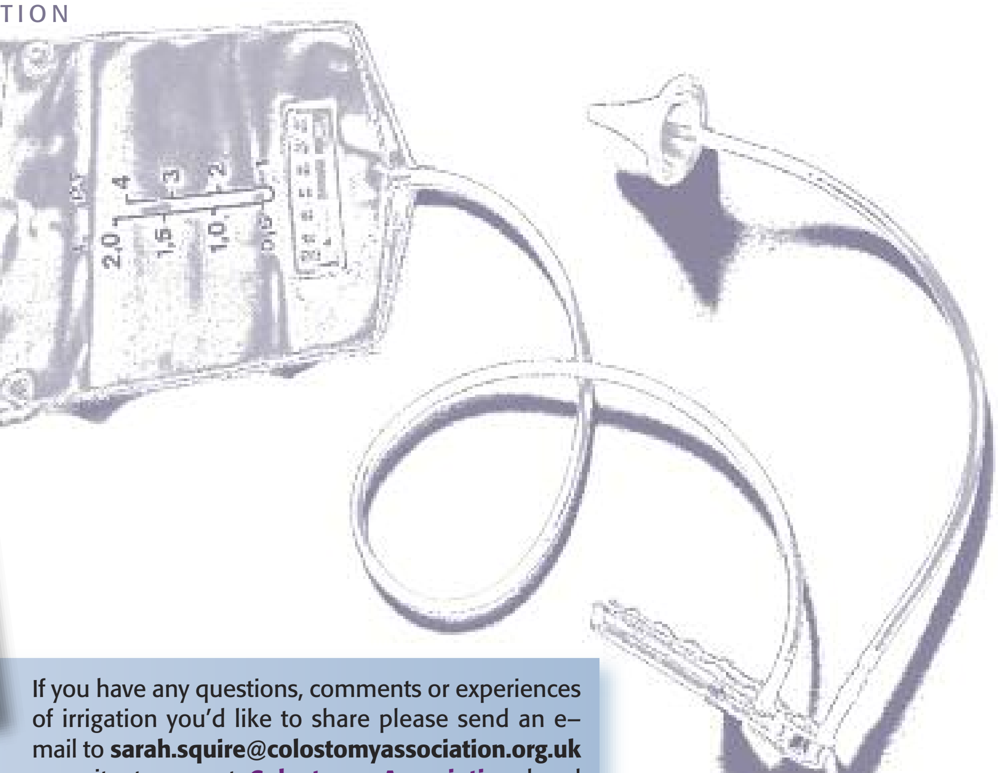
Your solicitor will need the following information on our charity:

Name: **Colostomy Association**

Registered address: Enterprise House, 95 London Street, Reading RG1 4QA

Charity Commission registration number: 1113471

After you have provided for your loved ones we hope you will consider a gift to our Charity.



If you have any questions, comments or experiences of irrigation you'd like to share please send an e–mail to **sarah.squire@colostomyassociation.org.uk** or write to me at **Colostomy Association** head office.

Sarah Squire

Irrigation: Past and Present

In this 50th Anniversary year of the Colostomy Association, I started to look into how long colostomy irrigation had been practiced and I have to say I'm surprised how far back it took me. I thought it was a fairly modern approach to colostomy management but in 1934, in the British Journal of Surgery, Tilson Dinnick gave an account of a child born in 1793 with an imperforste anus. A surgeon named Duret formed a stoma and four days post op ordered a 'washing out' with water and syrup of rhubarb! Other authors give credit to Pillore and Fine who suggested the use of irrigation as a way of managing a stoma sometime in the 18th century.

In 1927 J P Lockhart–Mummery revisited irrigation in his publications and its popularity did increase for a while, although some negative results influenced success. In the 1940s an American music teacher, Sophia M Secor, became an important spokesperson for the irrigation method. She wrote about the difficulties she encountered while learning to deal with her colostomy, and how she became a colostomy counsellor at Beth David Hospital in New York. It wasn't until the 1950s when specialist equipment was introduced, including early versions of the cone we use today, that irrigation became more widely used.

I am always delighted to receive emails and letters from our readers about their irrigation experiences and would love to hear from people who have been long term irrigators. What were the early kits like? How much training did you receive? I feel very fortunate to be an ostomate in modern times as the variety of products and choices we have to allow us to manage our stoma comfortably and confidently mean we can get on with enjoying life.

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents.

Many Ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the **Colostomy Association** website or purchase the *Irrigation and you* DVD using the form on the right.

Colostomy Association has always been very committed to promoting irrigation and credit for this must go to **Sue Hatton**. When MacMillan withdrew funding from the British Colostomy Association, Sue was among the eight volunteers who stepped forward to ensure that support for ostomates would continue. When the new **Colostomy Association** became a self–funding charity she was elected Chair of Trustees.

Sue Hatton

Sue began irrigating just six weeks after her colostomy operation in 1998 after being encouraged and taught by ward sister, Ann Leppington Clarke. Irrigation became Sue's 'soapbox' subject as she was determined to spread the word about this liberating way of managing a colostomy. Sue would promote irrigation whenever it was appropriate. She was among the first **Colostomy Association** volunteers to man the 24–hour helpline so would often ask callers if they had considered irrigation if she felt it would fit their lifestyle. In 2006 Sue suggested an eight–page supplement on irrigation be featured in *Tidings*. This appeared in the Winter 2007 edition and was later reproduced as an information leaflet. In 2009 Sue began writing the regular irrigation page in *Tidings* and continued until 2014 when she passed the baton on to me as she needed surgery to form an ileostomy.

I feel very privileged to have taken over the *Tidings* Irrigation page from Sue, and was delighted to be involved in the production of the **Colostomy Association** 'Irrigation and You' DVD, also the brainchild of this special lady. Sue had long wondered why irrigation wasn't more widely offered to patients and wondered if part of the reason was time constraints and lack of confidence in teaching the procedure among stoma nurses. At conferences and meetings with health professionals Sue asked questions and it became clear there was some truth in her assumptions. She had the idea of producing a DVD to highlight the benefits of irrigation for patients but to also include a toolkit to support best practice of how to teach the technique to patients.

Two DVDs were produced, one an educational tool for health professionals and patients, raising awareness of irrigation and another which is more clinically based to increase confidence in the teaching of irrigation. Both DVDs feature **Colostomy Association** Trustee, Judy Colston, irrigating plus other patients and nurses discussing the advantages of this method of colostomy management. We tried very hard to include hints and tips which would help irrigators, new and old, master the technique in order to make it work best for them.

Sue, you did us proud. The DVDs are brilliant and will continue to help make irrigation more widely promoted, to provide suitable colostomates with this choice of stoma management. ■

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced by the **Colostomy Association** to raise awareness about ***colostomy Irrigation* as a method of bowel management. Note:** Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £4.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **CA Ltd,** to:
Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

Title:

Name:

Address:

Postcode:

Tel:

Email:

Please allow 30 days for delivery.

Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA Charity No. 1113471 VAT No. 917079312

Please cut along the dotted line and return to the address on this form - thank you


EMPLOYEE NUMBER:
1,984,657

Get your Colostomy Association 2018 Calendar

The calendar competition results are in… so prepare for your virtual holiday!

Ever sat there on a cold miserable day and wished you were somewhere else? If so, then our 2018 Calendar is just the ticket. Spiral bound and measuring 210mm x 420mm, each month opens to reveal a stunning photograph which, with a little imagination, will see you jetting off to faraway places. We have everything covered, from cityscapes to sunsets in tobacco coloured skies. There is also plenty of space to record appointments and even, perhaps, the date of your 'real' holiday.

Our calendar competition received a total of 96 entries and, just like last year, the standard was so high that it caused our judging panel a few headaches. Every single photograph was taken by one of our supporters. Mr Kevin Young was the eventual winner with his photograph of a sunset near Stromness, Orkney, Scotland. Second and third place went to Mr Trevor Andrews and Mrs Phyllis Oliver respectively, with photographs of Castillo de Casares, Málaga, Spain and Yardenit Baptismal Site along River Jordon, Galilee, Israel. They say that a picture is worth a thousand words. We couldn't agree more. Those that make up our new calendar are more than just visually stunning. They are also tangible evidence of ostomates living full and active lives.

The calendar costs **£9.50** including postage and packing. All proceeds will help support the various services we offer including our 24/7 Helpline, our extensive range of free booklets and, of course, *Tidings*. So don't delay ordering. What's more, every calendar comes in its own white presentation envelope, making it an ideal gift for Christmas!

Calendars can be ordered using the form below or via our online shop.

Please send me [Quantity: ☐] **Colostomy Association 2018 calendar/s** at the cost of **£9.50 each** (price inclusive of VAT & p+p). Please allow 28 days for delivery.

I enclose a cheque for £ ☐ made payable to: **CA Commercial Ltd**.

Title:

Name:

Address:

Postcode:

Tel:

Email:

Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA

'Focusing' on a better life

This photograph was the overall winner of the Daily Mail Weekend magazine's annual wildlife photography competition. The head judge, David Suchet said: "I like everything about this – the colours, the texture, the way it all blends together. For me it's not only the beauty of the two young stoats but of their natural environment."

The photograph was taken by Rob Fearn whose story featured on page 11 in the Spring 2014 issue of *Tidings*. Rob had suffered from bowel problems for 15 years. His life revolved around knowing where to find the next toilet. This posed quite a problem as he worked as a sales representative and spent his working life on the road. It also made it difficult for him to pursue his hobby of wildlife photography. Tests for ulcerative colitis and Crohn's disease proved negative and Rob was told he had IBS. Then in October 2013, when he was 43, his colon perforated due to diverticulitis. When he woke up from emergency surgery to find he had a stoma, instead of being devastated, he realised immediately that it would change his life for the better.

Rob takes up the story

I didn't have a clue what a stoma was. I had heard of a colostomy but I assumed that was just something that old people had. As soon as it all sank in, however, I was over the moon. Not only had I survived the operation but I could also see an end to my 15 years of suffering.

I am really lucky to have found a good combination of products right from the start so I have never had a single leak. I get an allergic reaction to certain adhesives – even regular sticking plasters can cause problems – so during the first couple of months I ordered samples from all the main manufacturers. I cut a 1" square from each of the flanges and labelled them up. I stuck them to the opposite side of my abdomen (so as not too aggravate my stoma site) then left them overnight. This was a safe way to test how well my skin reacted to the adhesive.

My road to recovery had begun along with a new freedom to enjoy my life. I was able to go out for meals, to concerts and to play golf fairly regularly without any worries. I have changed my pouch many times while out and about in supermarket toilets and even in the car when really necessary.

Healthwise, I still suffer from an upset stomach from time to time but due to my stoma it's not a big problem anymore. I sleep soundly every night whereas before my op I would spend many hours sat on the loo doubled up in agony. The only slight problem I have now is trying to maintain a healthy weight as I am eating better than ever.

When I saw my consultant about eight months after my surgery I was prepared for an argument. I thought he would insist on a reversal as I realise how much my supplies cost the NHS. Considering that I am relatively young I assumed that they wouldn't want me to keep my stoma due to the ongoing cost.

I couldn't have been more wrong. The consultant initially explained that the reversal operation is another major operation with no guarantee of success. I told him that I wasn't interested anyway as my quality of life had improved immeasurably. He was delighted to hear that and said: "OK, I will write to your GP and tell her that 'we' have decided that your stoma will be permanent." He reassured me that as I'd had a Hartmann's procedure my remaining 'plumbing' is still mainly intact and, should I have a change of heart in the coming years, a reversal would still be possible. I asked if there was a time limit on this, to which he replied no.

Having a stoma means I am not tied to the nearest loo and I can get out and walk for miles and enjoy the countryside. My wife, Helen, and I both have fairly stressful customer–facing careers so it's great to be able to get away from it all at the weekends and on holidays. This freedom has helped me to develop my hobby.

Rob's photograph of the sun setting behind the war memorial at Tyne Cot cemetery in Belgium selected for the month of November in the Colostomy Association 2017 Calendar.

I have always enjoyed photography but due to my illness before I had my stoma I was very restricted to where I could go; there's only so much wildlife that you can photograph in the back garden! I can now visit nature reserves and walk out in the countryside without any fears, or having to starve myself beforehand.

Last year we spent a week in Suffolk and really enjoyed visiting all the nature reserves. On one particular day we visited Lackford Lakes Reserve, well known locally for its kingfishers. We sat for over five hours in the kingfisher hide and I got some fantastic shots. On the way back to the car we came across two juvenile stoats playing on a wood pile. They were pre–occupied, fighting over the remains of a dead bird, so didn't appear to notice that we were there watching them for about 10 minutes. I managed to get a good selection of photos.

In October 2016, the Daily Mail Weekend magazine held their national wildlife photography competition and a friend suggested that I should enter. I sent in one of my stoat shots then forgot all about it. In February this year I was surprised to receive a call to say that, out of more than 10,000 entries, my stoat photograph had been selected as the winner in the mammal category. The prize was camera equipment worth £1,000. All five category winners then went through to be judged for the overall prize which, to my amazement, I also won.

The main prize is a four–day trip with a professional wildlife photographer to Slovakia to photograph wild bears and wolves. I was absolutely delighted as I know I am now able to go and enjoy myself. If I had won this prize prior to my operation I would have had to refuse it. Getting there involves a three–hour flight and a five–hour transfer from the airport. Once there I will spend up to eight hours a day in a photography hide in the middle of the woods on the Slovakian mountains.

I couldn't have even considered doing any part of this prior to the operation, but now I cannot wait.

My photograph, two stoats on a woodpile, was on the cover of the Daily Mail Weekend magazine on 1 April. All the winning photographs were displayed at a free exhibition in the Strand Gallery in London for the week beginning 8 May. We were invited to the launch party. The head judge, David Suchet, gave a very complimentary speech about my winning photograph. He is very passionate about photography as his grandad, Jimmy Jarché, was one of the original Fleet Street photographers.

We enjoyed the evening chatting with a couple of the other judges, several journalists and editors from the Daily Mail as well as many of the other photographers who had entered the competition.

It was great to be able to go and enjoy the party without having to starve myself first or overdose on Imodium!

The positive moral behind this story is that prior to my stoma none of this would have been possible. I'm now free to take up photography seriously after being released from my fifteen–year battle with IBS and diverticular disease and a life that revolved around locating the nearest loo.

Rob and Helen with David Suchet at the Strand Gallery exhibition

Diverticular disease and Diverticulitis

Alison Horner

RGN, BSc(Hons) Nursing, Independent Nurse Prescriber

Alison began her nursing career at St Mark's Hospital in London and later moved on to work in colo–rectal operating theatres. In 2013 she was diagnosed with diverticular disease and the following year developed complicated diverticulitis and required emergency surgery to form a stoma. We published her story in the spring 2016 issue of Tidings. Since then Alison has had her stoma reversed and is now back at work as an Advanced Nurse Practitioner in a GP surgery.

When people ask me why I needed emergency bowel surgery, I tell them it was due to diverticulitis and they usually look puzzled and ask, "What's that?" This article will describe diverticular disease, explain when it becomes diverticulitis and consider the management and possible outcomes.

A diverticulum occurs when the inner lining of the bowel is squeezed out through the muscle wall which surrounds the outside of the bowel. Diverticula can be present in small or great numbers. Although they can be present throughout the small and large bowel, they mainly affect the descending and sigmoid colon. Often their discovery can be an incidental finding when being investigated for something else i.e. colon cancer or irritable bowel syndrome (IBS); this is often by sigmoidoscopy or colonoscopy, but can be by other investigative tests.

There is debate about what causes these small pouches or sacs. Leading opinion is that the cause is constipation and a low fibre diet, which is thought to increase the pressure inside the colon. The truth is that we don't really know for sure, and the evidence is limited. It is likely that in practice doctors have seen this scenario in many patients, but it is by no means the case for everyone. Personally, I never had a day of constipation in my life, my life was ruled by diarrhoea from my IBS, but mostly due to the high fibre diet I ate to avoid diverticular disease!

Who gets diverticulosis?

- Approximately 50% of all people have diverticula by the time they are 50 years of age, and nearly 70% of all people have diverticula by the time they are 80 years of age.
- Approximately 75% of people with diverticula have asymptomatic diverticulosis; of the 25% of people with diverticula who develop symptomatic diverticular disease, approximately 75% will have at least one episode of diverticulitis. (NICE 2013)
- Diverticular disease is rare in people younger than 40 years. Disease is more virulent in young patients, with a high risk of recurrences or complications.
- The prevalence is similar in men and women.

Overall, those of us who end up having surgery are still in the minority. One of my surgeon colleagues said to me: "You were just very unlucky."

Symptoms

It is not uncommon for people with diverticula to have no symptoms at all.

The symptoms of diverticular disease are intermittent, often cramp–like, left lower abdominal pain, sometimes bloating, and the pain can be eased by having the bowels opened. Some people develop diarrhoea or constipation, and occasionally mucus is passed with the stool.

Diverticulitis causes constant pain in the abdomen, often felt in the lower left side, nausea and vomiting, fever, constipation or diarrhoea, possibly blood in the stool.

Careful examination by a doctor will detect if complications may be present and hospital admission is required.

It is not clear why one person develops diverticulitis and another does not. Indeed, why diverticulitis occurs is not fully known; there is talk of a bacterial infection occurring due to obstruction or food becoming trapped in a diverticulum, but it is not fully understood. My personal opinion is that there is a coming together of events and environment, as yet unknown, that causes the climate within the gut to change and infection to develop.

Symptoms may be chronic i.e. they occur on repeated occasions over time, or acute i.e. they develop into something more serious much sooner.

Diagnosis

Diagnosis of diverticular disease and acute diverticulitis is made on the basis of a detailed symptom history and physical examination, including a family history (both my parents had surgery for diverticulitis). What is found will direct the next stage of the investigation. Blood tests can be done to check for signs of infection and inflammation, as well as anaemia.

Ruling out other causes of abdominal pain is as important as trying to identify the cause. A urine culture should be done, especially where a fistula may be suspected. A pregnancy test will be carried out in women of childbearing age. In an acute event, CT scan is used and also abdominal X–ray.

Management

The management of diverticular disease is decided by the symptom history and results of investigative tests. For those patients experiencing episodes of abdominal pain with no fever or signs of infection, it is important to maintain a good fluid intake and an appropriate diet.

What is an appropriate diet? One that includes enough fibre so that stools are soft and formed. There is much debate about seeds, nuts and popcorn causing problems, but there is no robust evidence to support this and lots of anecdotal evidence to the contrary! Fibre from a variety of sources should be taken, but any foods that cause problems avoided. Fibre supplements i.e. ispaghula husk can be taken.

It may take a while for you to find what works best for you; the goal is to avoid constipation and straining, but also diarrhoea and urgency! A good fluid intake can be gauged by the colour of your urine: pale yellow indicates you are drinking enough, dark, orange and concentrated means you need to drink more.

During an episode of acute diverticulitis, where abdominal pain and fever are present, antibiotics, which will cover a variety of bacteria, are usually prescribed. Resting the bowel by taking only clear fluids is recommended and providing symptoms do not worsen most people can be managed at home. Introduction of soft foods and then a low residue diet can be made once recovery is apparent, which is usually within 48–72 hours. Regular pain relief with paracetamol would be indicated.

If management at home is not working then admission to hospital would be appropriate. Whilst there, intravenous antibiotics and pain killers can be given, plus scans and X–rays can be undertaken. Patient's blood pressure, pulse, temperature, pain levels and bowel movements are all monitored and blood tests carried out. If this conservative approach to treatment is successful and the patient improves then they will be discharged home with advice on diet and oral antibiotics (tablets).

Definitions

- Diverticulosis – diverticula are present without symptoms.
- Diverticular disease – diverticula cause intermittent lower abdominal pain without inflammation and infection.
- Diverticulitis – diverticula become inflamed and infected causing marked lower abdominal pain usually accompanied by fever and general malaise. Occasionally it may be accompanied by large rectal bleeds.
- Complicated diverticulitis – diverticulitis accompanied by formation of an abscess, perforation or fistula. (NICE 2013)

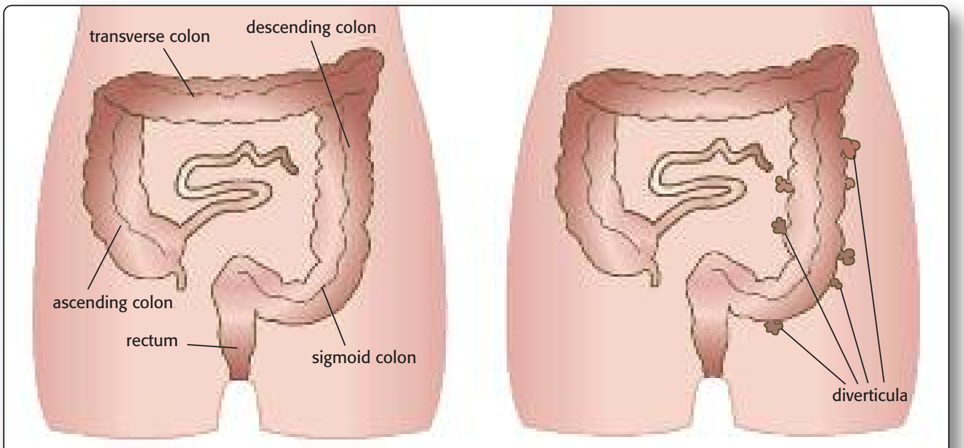
Reference

National Institute for Health and Care Excellence (2013)
Clinical Knowledge Summaries: Diverticular disease
https://cks.nice.org.uk/diverticular-disease

Surgery

The need for surgery is decided upon on an individual basis, with discussion between the surgeon and patient. An evaluation of the number and severity of episodes, the presence of any complications, any pre–existing health problems, the patient's age and the impact of the disease all need to be evaluated, along with the risk of major abdominal surgery.

Ideally, all surgery should be carried out electively, and generally no sooner than four to six weeks after an acute episode.



Normal colon

Colon with several diverticula

Discussion with the surgeon about whether an open (laparotomy) approach or whether a laparoscopic approach (keyhole) can be used, will take place. Where possible, the keyhole approach is favoured due to reduced wound pain, infection and a speedier recovery post–operatively. The goal would be to perform a resection and re–join the bowel with no need for a stoma. Not everyone having surgery for diverticulitis ends up with a stoma, it is usually only those patients who have developed complications.

Patients with complications such as a perforated abscess, bowel obstruction, peritonitis, overwhelming sepsis and failure to improve with conservative management would require emergency surgery. This is done via a laparotomy and a Hartmann's procedure is performed whereby the diseased colon is removed, the lower end (rectum) is closed, and the other end brought up through the abdominal wall to form a stoma (colostomy).

Having a Hartmann's procedure for diverticulitis is considered a cure, even if diverticula are still present in other parts of the bowel. This is because problems with these remaining diverticula is very rare and the most vulnerable area has been removed.

Reversal of Hartmann's is an option for some patients, and my own surgeon told me that approximately 30% of those who had a Hartmann's procedure would be reversed. Reversal is no mean undertaking– it is technically challenging for the surgeon and more major surgery for the patient, with a chance of a temporary ileostomy until the join in the bowel is well healed. An in–depth talk with the surgeon is vital, as well as a full assessment of the bowel, prior to any decisions being made.

In summary, diverticular disease is very common, but on balance it is a relatively small number of patients who end up with complications and a colostomy. ■

Pathway to a Colostomy: Diverticulitis

For ten years, I was told that I had Irritable Bowel Syndrome (IBS) and prescribed peppermint capsules. The bloating, wind and irregular bowel movements continued and I developed painful spasms in my lower tummy. At A&E an X–ray showed massive constipation and I was advised to continue with the laxatives. Then I saw a GP, new to the practice, who arranged blood tests and an ultrasound scan. When they provided no answers, she referred me to the colorectal department at the hospital. The first colonoscopy had to be abandoned because it was too painful so I was given a CT scan. It showed a severe narrowing of the sigmoid colon caused by diverticular disease.

In January 2016 I was admitted to hospital for a laparoscopic sigmoid colectomy as the bowel had narrowed to a severe degree and wasn't functioning very well. By now, as well bloating and severe spasms of pain, I was also experiencing frequent bouts of diarrhoea so spent increasing amounts of time tied to the bathroom and was feeling very low.

Prior to the operation, the stoma nurse visited me to mark my tummy. At this stage, it didn't really impact on me that I would have a stoma. I was focusing more on getting prepared for the operation. It was enough to concentrate on as the bowel prep was not a pleasant experience!

When I came round in the recovery room, even though I was still drowsy, the first thing I asked was: "Is it a stoma?" The nurse said it was, but I was so relieved it was all over I didn't think too much about it. It was several hours before I peeped beneath the blanket to have my first curious look at my stoma. Not having been shown any pictures beforehand, I didn't know what to expect. First impressions were that it seemed large and very pink.

It took two or three days to start working but I had no problems or pain. The stoma nurse came to examine me and change the bag.

Lorraine and her stoma nurse at the awareness day

I soon learnt to care for my stoma myself so I could go home. I can honestly say I accepted my stoma immediately which amazed me as I really hadn't wanted one to be necessary. For the first four weeks, the stoma nurse came to see me and after that I could visit her in clinic. As you probably know, the size of a stoma changes in the weeks following the procedure so she checks in case it is necessary to alter the aperture in the pouch. Mine was 35mm after the operation but shrank to 30mm and has remained that size.

At home I got myself a routine for cleaning my stoma, preparing my skin and applying the bag. You do get quicker but it isn't a race and even now I take my time to check I've done it properly as I dread leaks or accidents. I've had one or two near misses but thankfully nothing disastrous.

I've learned to cope with unexpected situations and 'keep calm and carry on'. After a few incidents, you learn to anticipate these and are prepared. For example, when I was a novice ostomate the doctor wanted to have a look at my stoma; I hadn't thought to take a spare bag with me to the appointment so he couldn't! Wherever you go always take spares not just bags but also any additional products you regularly use.

Early issues I had to deal with were skin sensitivity which caused a rash. I tried samples of different bags and then chose the best one for me. Because I swim, I needed a very reliable pouch which would stay stuck. My stoma nurse was very caring and helpful and suggested flange extenders for extra security while in the water. I built up my strength by taking regular short walks every day and I was back in the pool three weeks after my operation. Sometimes I find that the stoma carries on working whilst I'm exercising and I worry that someone will notice a bump beneath my swimming costume. My ever–helpful stoma nurse and husband suggested wearing a patterned swimsuit or one with a frill or wrap effect. As my pool is on the cool side I often wear a rash vest.

In April 2016, three months after my operation, we went on a two–day break to Chester to celebrate our wedding anniversary and I managed quite well. I made my husband stop part way there to check, yet again, that I had all my stoma products. We had to take all the cases out of the boot, check, then reload! I'd already

Lorraine and her husband celebrating their wedding anniversary on a mini break in Cheshire

Medical Terms Explained

Laparoscopic surgery: A procedure carried out using an instrument called a laparoscope, which allows the surgeon to access the inside of the abdomen without having to make a large incision. Also known as keyhole or minimally invasive surgery.

Sigmoid colectomy: The removal of the sigmoid colon, the terminal section of the large intestine that connects the descending colon to the rectum.

checked I had everything but this was my first time away from home and I needed to be sure. We then went on four other short breaks and I grew more confident about travelling.

Later that year, my stoma nurse invited me to a stoma awareness day. This was worthwhile as I talked to some interesting people and we shared our experiences. I spoke to company reps about problems and was able to order samples to try out at home. I would recommend these sort of events as they are informative and social.

I've learned by trial and error but my husband has been good at going on websites for information so that too is useful. I wish, however, that I'd had a copy of *Tidings* at the time of surgery as I would have learned a lot from the articles and reading about other people's experiences. In a recent edition of *Tidings* there was a feature on granulomas. It was about two months after surgery when I developed two tiny raised areas around my stoma; they bled each time I changed my bag. I had no idea what they were. I saw my stoma nurse and she told me they were granulomas and treated them with silver nitrate. This worked and they haven't recurred. I began wearing a seal soon after that as I had some leakage and this has helped with both issues.

Back swimming again

I feel content with having my stoma. I'm fortunate to be the age I am and not a younger person. I am so grateful to be free of the awful symptoms I used to suffer and appreciate all I can do now that I couldn't do before. Now I'm in a routine I can plan to do things rather than be tied to the bathroom for much of the day! I can't be complacent though as I have developed a parastomal hernia.

Now that I have a hernia, my original stoma bag does not fit as well as it did, so my stoma nurse helped me to find me one that suits me better. I've also begun wearing a support belt when I'm doing jobs and going for walks as recommended by my stoma nurse. I've found exercises to do daily to help strengthen my tummy muscles to prevent the condition worsening. I wish, however, I'd known about the exercises and stoma support wear earlier as I may have avoided getting a hernia.

It is wonderful to be able to eat normally again. Last Christmas was the first time in years that I could join in and eat a variety of foods. I felt a hundred times better than the year before; I got to see people and do stuff instead of occupying the bathroom for most of the day with only the radio for company.

Sometimes you hear about people who have done truly marvellous feats such as marathons, sky jumps, etc. But we have all achieved so much already just to have come through and accept our stoma.

Lorraine

COLOSTOMY DAY 2017 #SUPERSTOMA

Saturday 7 October 2017

Whether it be a colostomy, Ileostomy or urostomy, the fact is stoma surgery saves and improves lives. People with stomas work, play, have children, raise families and run marathons, but still there is a stigma attached to having one. We need to change this.

Colostomy Day is our opportunity to raise awareness, challenge perceptions and show the world what it actually means to live with a stoma. Whether it was because of cancer, Crohn's, ulcerative colitis, or trauma to the bowel, we need to tell people that stoma surgery made the difference.

Join us on Saturday 7 October for Colostomy Day – our national awareness day – where super stomas are the theme. It's time to celebrate and tell the world just how great they are!

Abi's #superstoma

After living a fit and healthy life, eating well and attending the gym regularly, it came as a huge shock to be diagnosed with advanced rectal cancer just two months before I was 40. During those first discussions about my tumour and the treatment recommended before surgery, wearing a bag was mentioned and I must admit I had absolutely no idea what they meant. I had simply never been aware of stomas prior to this.

It was not something I focused on during those first few months to be honest, I dealt with everything just one step at a time – four cycles of chemo, a brief break before the five week radiotherapy course started. Some of the side effects were awful, including the sense of urgency and having accidents whilst travelling. At the planning stage for radiotherapy it was made clear my colostomy would highly likely be a permanent one with no room for reversal. I felt emotional and worried, but again I didn't dwell on this or what it might mean until I had my visit with the stoma nurses prior to surgery. This was when it really hit home.

I've come to realise a lot of people end up with a stoma due to emergency or because of a chronic condition, whereas I had plenty of time to process what was to come; personally I'm glad I had this time to go through the emotions: sadness, anxiety and worry. The surgery was performed in August 2016, thankfully successful and I was very surprised how small and tidy my stoma was when I saw it for the first time (two days later). I had been so worried about dealing with it, but it was actually very straight forward and the nurses were so helpful.

The recovery period, particularly fatigue was tough going but the bag changes were the easiest part. Now approaching nine months from the operation, I've been trained to irrigate and really enjoy the confidence this gives me when I'm out. I'm back in the gym doing cardio and weight training, wearing support underwear and definitely feeling more like myself again. No one would know I have a bag unless I choose to tell them, and in comparison to the symptoms and difficulties I faced pre–op I am much happier now. I'll be wearing my bikini with pride this year that's for sure!

There are many ways you can get involved in Colostomy Day.

Social Media

We want to get **#superstoma** trending. So please share your **#superstoma** on Twitter, Facebook and Instagram. You could post a picture like the one here or, if you don't fancy showing your bag, then just do a 'thumbs up' where the bag would be. And don't forget to involve your family and friends. They can do a clothed 'thumbs up' too.

Share your story

Celebrate your stoma and how it saved your life. We will be featuring stories across our website and social media. Alternatively, why not let the local paper know or perhaps turn your story into a blog. Let's raise awareness of the different issues that lead to stoma surgery and let the world know that anybody, regardless of age or background can have a stoma.

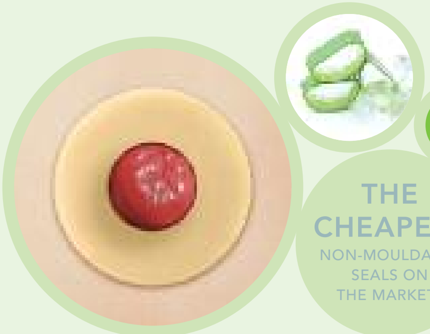
Become a Superhero

And do a run, swim or bike ride. Maybe instead, you could hold a superhero themed bake sale or just do good deeds for the day? If you are planning on holding an event or taking part in an activity, then let us know. We can spread the word and also send you one of our Colostomy Day t–shirts. Together we can raise awareness.

For more information, visit our website or email **cass@colostomyassociation.org.uk** for a Colostomy Day pack

Huge thanks to the wonderful people that took part in our photoshoot. Sarah Squire, Ian Jackson, Jackie Dudley, Shell Lawes and Abi Brown. You can find out more about their super stoma stories in the run up to Colostomy Day.

A KINDER way TO PROTECT skin



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- Skin-friendly, quick and easy to apply
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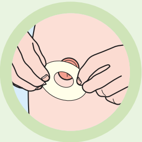

- Thin, flexible and can be stretched to accommodate moderately oval stomas
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"I've found the perfect Aloe Ring product for me. No leaks, no sore red skin. It gets on with the job of protecting me, leaving me to get on with my life."
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Mr L, West Midlands

"It has been 100% successful in protecting me from leakage."
Ms J, Warwickshire

"I have tried other companies' rings and at present, this is by far the best I have used in 20 years."
Mr J, Wolverhampton

"It gives me the back-up and confidence I need."
Mrs S, West Yorkshire

"This product has helped me in my day-to-day life immensely. It's given me confidence in wearing my stoma pouch in everyday life, and I cannot put into words how much this product has helped me."
Mr M, Selby

"Leaks are now a thing of the past! Before using SecuPlast® Aloe Rings, leaks were quite common and annoying. Now, none at all! Thank you."
Mr K, Devon

"No skin problems, no leaks – so it gives me total confidence which is so very, very important."
Mr J, Lancashire

"It is easy to use and comfortable to wear."
Mr J, Hampshire

"I have tried other products but nothing works as well as this one. It's nice and thin and adheres very well – also I can cut a small piece out of a ring and fill any creases around the stoma, giving me a flat surface."
Mrs B, Devon

"It's comfortable, secure and doesn't affect my skin. Retains shape and doesn't disintegrate."
Mrs S, Nottingham

*Data correct as of March 2017

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The diagnosis that changed our lives

Margaret writes about how she and her husband, George, have coped with cancer and a stoma.

George kayaking in North Wales

It started in the outpatient's clinic at our local hospital in 2009. I remember that sick feeling, shock and disbelief, when I heard the surgeon confirm the diagnosis that George, my husband, had rectal cancer and would need to have a permanent stoma.

George had never heard of a stoma. I wanted to reassure him that it would be alright, but everything seemed so uncertain at the time. The surgeon said George could not have surgery to get rid of the tumour straight away. First there had to be a course of radiotherapy along with a course of chemotherapy to shrink the tumour. Eventually George had surgery and after this came another course of chemotherapy to make sure all the cancer cells had gone.

Normal life and routine all changed, as the priority and focus was on treatment and hospital appointments. George had six weeks of radiotherapy, and on a Friday morning, we would go to a café at Clatterbridge and celebrate getting through another week, with a big plate of toast and tea; it was our toast party. Looking back, I do not know how we came through it all.

When it was all over we just wanted to get back to a normal life as soon as possible. Could we still go swimming? What would happen if the bag leaked or came off? Could we go on holiday? We now know the answers to these questions, but at that time it was all undiscovered territory. The stoma nurse at our hospital was helpful, and *Tidings* magazine is a mine of useful information.

For our first weekend away, we stayed in bed and breakfast accommodation. The bin in the carpeted bathroom was covered in floral fabric and trimmed with lace. There was no way we could have deposited a poo bag in there. We solved our problem by taking it with us when we went out and disposing of it in a dog–waste bin. Before going away, I purchased a waterproof cover for the bed just in case of any leaks. I do not know if the landlady discovered it and, if she did, what she made of it, but it made us feel better.

We celebrated our silver wedding anniversary; it was a very happy occasion, with all our family around us for a church service and a lovely meal at a hotel afterwards. We also attended our grandson's wedding, which was a lovely family celebration. At this time my husband was experiencing some urine retention problems and had to have a leg bag, but it did not stop him dancing.

George going snorkelling in Connemara

George loves the sea. Years ago, he used to go sub–aqua diving. Now that he has a stoma he thought he would try snorkelling. This was during a long weekend break in Connemara on the Wild Atlantic Way on the west coast of Ireland. We stayed at a lovely country hotel but did not take a waterproof bed cover this time.

As the Atlantic is very cold, George needed a wet suit. On each of the two days we were there he did an hour session of snorkelling, duck diving down to ten feet underwater. I must confess I was a bit concerned, as the waves were a bit choppy and he was on his own, except for me on the beach keeping an eye on him. He really enjoyed it and there were no problems with his stoma bag.

Well there was no stopping George now. Next it was kayaking. We hired two sit–on–top kayaks on the river Dee in Chester, to see how we got on. It was a bit outside my comfort zone, but we both enjoyed the experience. George went on to buy a sit–on kayak, and has taken it on rivers and Bala Lake. Last year while we were in North Wales he took it out to sea and got rolled over twice in the surf and still did not experience any problems with his stoma bag.

They say to have lovely memories, you have to create lovely experiences, I think we certainly did this together. Oh, did I forget to say George has also climbed Mount Snowdon even though he has arthritis in both knees and last year it was camping, with a new blow–up tent!

George, now six years in remission, says: "If it wasn't for the love, caring, understanding, and encouragement of my wife, Margaret, I would not have had the willpower to carry on and be where I am now." ■

Update on stoma care products and services

Tidings **is always interested to learn about new stoma care products and services from manufacturers and suppliers.** If you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let *Tidings* know. YOUR findings could make ALL the difference to others.**

Ami/Suportx are proud to launch the new Breathable Easy Peel and Tube belts. The unique Cotton rich fabric provides firm support and is fully breathable. The belts are designed so the back is shaped for maximum comfort. A wide self–grip elastic ensures the belt stays in position.

A wide range of sizes, depths and three colours are available.

For more information go to page 48

New!

Aura® Convex Colostomy

Designed to support colostomates with poorly sited, recessed or retracted stomas, Aura Convex conforms to the body shape to provide a secure seal and gentle pressure helps the stoma to protrude into the bag to prevent leakage. The inclusion of medical grade Manuka honey in the Hyperflex® hydrocolloid may help to promote healthy skin around the stoma.

For a free sample call **0800 036 0100**
or email **info@clinimed.co.uk**

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See our main advert on page 20

PID: 4478

Hyperseal washers with medical grade Manuka honey – new sizes now available!

Hyperseal with medical grade Manuka honey washers are ideal for problematic stomas with crevices, fistulas or scar tissue. The unique Hyperflex® hydrocolloid is completely mouldable against the body contours offering extra security and protection.

Now available in three new sizes – 30mm, 40mm and 50mm.

For a free sample please call **0800 036 0100**
or email **info@clinimed.co.uk**

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PID: 4483

New Brava® Skin Cleanser – developed for stoma care

Simple wipes that **sooth** and **clean** without affecting adhesion. They contain provitamin B5 which helps **manage redness, irritated skin,** and acts as a **moisturiser** to **improve skin** hydration. To learn more about how they can help your skin recover and to get a sample, visit **www.coloplast.co.uk/tidings**

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Used by ostomists with a parastomal hernia (a bulging around the stoma) to help prevent muscle damage and enlargement of the hernia.

Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region when wearing the belt.

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Stoma Shield *Ref. No. SS104*

The Shield will help protect the stoma from accidental chaffing or knocks.

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Security & Leakage Belt

This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the skin during all activities.

The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch.

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Web: www.sashstomabelts.com

Stoma and Sanity

I've never been one to reach out when I needed help. I have been living with poor mental health for the past 20 years (I'm now 40), rarely asking for help from my loved–ones.

And then along came a stoma.

I must admit I've always felt a sense of some impending doom, like I knew that one day something bad would happen to me. Was it just my mental health, the darkness of negativity translating into one of the worse scenarios I could imagine? Probably. So, it didn't really come as a shock when, at a follow–up appointment, the colorectal surgeon, Mr Krishna, explained that the growth in my rectum was cancer. Sitting next to me, my fiancé looked blank. My mum broke down immediately – even at 38 I was still her baby. I found myself comforting her, telling her things would be OK and we'd get through this.

As the treatment plan was explained I sat like a good pupil nodding at the right moments and answering the questions being asked of me. I wasn't that worried about the prospect of early menopause, chemo/radiotherapy or even the cancer itself. And then I heard a new word. Stoma. Apparently, I would need one of these, hopefully temporary but quite likely permanent. As the word colostomy was spoken, it started to dawn on me; I'd definitely heard that word before. I kept nodding, smiling and making jokes as I usually do. But inside I was screaming. I could feel the horror rising, a feeling of complete terror and hopelessness. I took the take–home pack containing the fake stoma, colostomy bag and gel crystals from my new colorectal specialist nurse, Lisa. Thank you. No problem. See you soon.

That day the tears didn't come. I had to explain to the rest of my close family and friends that I had this cancer I'd never really heard of. I felt guilty for putting them through this. But where were my emotions? The years I had spent crying and anxious for no apparent reason belied this new calm me. It was cancer. I daren't think about that horrible 'colostomy' word.

The next day I stuck on the little rubber stoma I had been given. I added the crystals to the bag and felt them turn into sludge, attached it to the stoma and cried.

Finally. Something I could really get upset about. I sat down and hated the feeling of the bag. I was heartbroken. I tried to stand up and it felt as though this alien thing on my stomach was going to explode as I bent double. Honestly, I wanted to die. I didn't want to poo out of my belly – I would rather take my chances with the cancer than have to deal with this thing of nightmares. One day I opened up to my sister–in–law: would I ever feel normal again? Ever positive? She told me she knew I was going to cope, in fact she said I would 'totally own it'. I just lightheartedly agreed and said she was probably right. Inside I wondered how she had the cheek to say that to me, it was my life being ruined and she had no idea how it felt. I continued on with my treatment plan, all the while slowly and secretly giving up on life.

I led a robotic life right up until after my surgery. Just before, I was told that there was no chance of a reversal, this was going to be for life. Any hope of going back to 'normal' was dashed on the rocks of my tumultuous brain. I was in intensive care for five days after surgery, dosed up on painkillers, not fully aware of my surroundings. It was when I got onto the ward I started to feel the impact of what was going on. It was a dark time. I had a smile plastered on when I had visitors but as soon as the curtain was drawn around my bed I sobbed myself silly. What had I done? Why on earth had I gone through with this stupid surgery? It was too late now, I should never have agreed to it.

At home things weren't much better. The first bag change I did on my own was a nightmare. I felt faint, cried and got poo all down me. The second time was a little better and thanks to my fiancé I made it through. The grief I felt for the part of my body I'd lost was overwhelming, but, as time went by, things slowly got better.

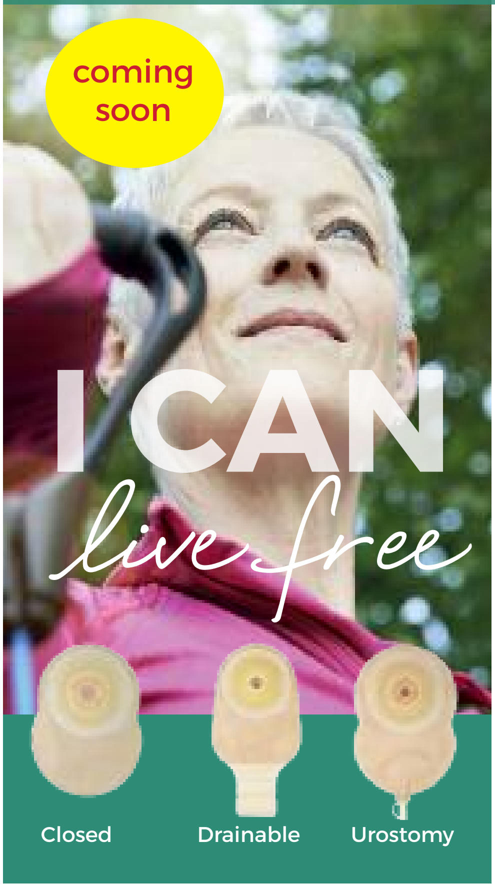
I wish I could have told myself what I know now: That life with a stoma is Great! I wouldn't have believed my future self, I would have laughed in her face. But I've grown to love my stoma, or Butt Face as I named him (I didn't want a sentimental name, so I opted for a humorous one). He's the reason I'm alive today and I can do everything I did before he was born. Nothing phases me anymore. I just take it in my stride, and get great laughs when I share funny poo stories with my friends and family. My mental health issues haven't gone away, but my stoma isn't one of the things that set me off. Somehow my brain decided I would cope with the big things in life, not that Butt Face is big; he's tiny and perfectly formed and I thank my lucky stars for him every day.

Sometimes it all seems like a lot of trouble to get out of bed on a bad day for a bag change. I just tell myself to power through it. I might get angry and irritated that I have to do it but never am I sad about having a stoma. I feel blessed and grateful to be part of this amazing, awe–inspiring community of ostomates, like I'm part of an elite group I would never have had access to otherwise. I started filming an on–line vlog series to offer a positive view–point to new colostomates, because I know not everyone is going to take to it as well as I have. Doing it has helped my mental health so much and made me even more joyful to be a part of the gang.

So thank you Butt Face, thank you to my surgeon, Mr Krishna, and to Lisa, my stoma nurse, for giving me a new lease of life. And thank you to the **Colostomy Association** for being there, allowing me be a part of something truly amazing. I'll never look back.

Joanna Phillips

Got Stoma? Vlogostomy on YouTube **https://www.youtube.com/channel/UCGG9J0wN9141mKalSHU4DMg**



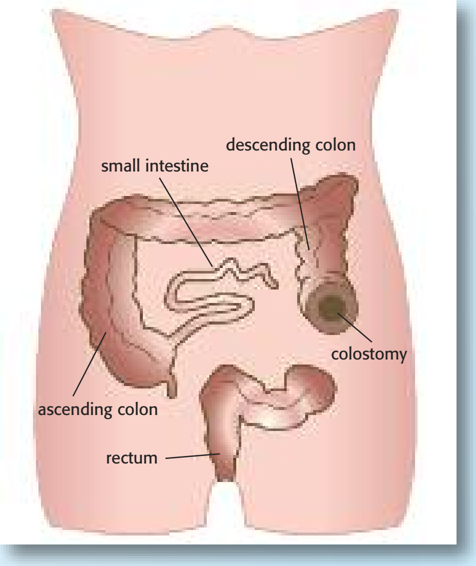
Rectal Discomfort Following Colostomy Surgery

Andrew Bird RN. BSc. PG Cert.

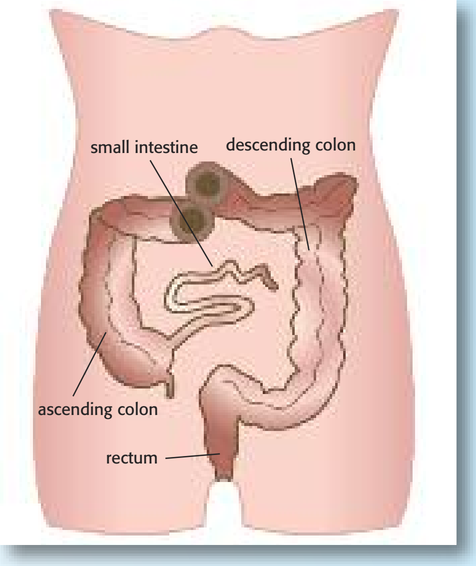
Andrew currently works at Queens Medical Centre in Nottingham as Lead Stoma Care Nurse Specialist in the Colorectal and Stoma Care Department. Earlier in his career he held a post as Nurse Specialist in Pain Management.

Discomfort in the rectum (back passage) can be a distressing symptom experienced by people who have had surgery to form a colostomy. After some operations, such as Hartmann's procedure and loop colostomy formation, the rectum will be left in place but during other surgery, such as abdominoperineal excision of rectum (APeR), the rectum and anus is removed and the wound in the bottom stitched up. In both cases, a feeling of discomfort in the rectum can be felt and this is discussed here along with ways that may help to relieve the discomfort.

Discomfort with the rectum intact



Hartmann's procedure



Transverse loop colostomy

Mucus build–up

For ostomates who have not had their rectum removed, the most likely cause of rectal discomfort is the build up of mucus. Mucus is a lubricant produced by the bowel to help the faeces pass through the system. The mucus continues to be produced in the rectum after surgery even though it is no longer needed. As the rectum fills with mucus, the pressure inside rises. Nerves near the rectum sense this raise in pressure and send a message to the brain alerting you to the fact that you need to empty the rectum. It is in this manner that you may experience the discomfort of feeling the need to open your bowels after your colostomy operation.

For most ostomates with an intact rectum, simply sitting on the toilet and bearing down as if trying to open your bowels will allow the mucus to pass and will relieve the symptom of discomfort. It may be worth doing this daily to avoid the build up of mucus, particularly if you find you are producing a lot of mucus.

Some ostomates find that they are unable to pass the mucus without assistance. This may be because the rectum has absorbed the water from the mucus making the mucus very sticky and difficult to pass. In these instances, the use of glycerine suppositories, which can effectively clear the rectum within 10–15 minutes by irritating the lining of the bowel, may be necessary. They can be obtained over the counter or via your General Practitioner (GP) and are safe to use on a regular basis.

Alternatively, small enemas, such as Microlax, may be needed to help with evacuation if other methods have been unsuccessful. These will need to be prescribed by your GP and are safe to use regularly after review by a health professional. They work by lubricating the bowel and softening the mucus, which is particularly helpful if the mucus has dried up into a plug that is difficult to pass.

If these methods fail to clear the mucus you may benefit from using a rectal washout device. You must discuss this with a health professional before using to ensure that it is safe for you to do so.

If you have tried all of these or the amount of mucus that is produced is excessive your surgeon may discuss with you an operation to remove the rectum. This is another big operation and there is no guarantee that it will get rid of the discomfort, as you will read below, so careful consideration is needed.

Proctalgia fugax

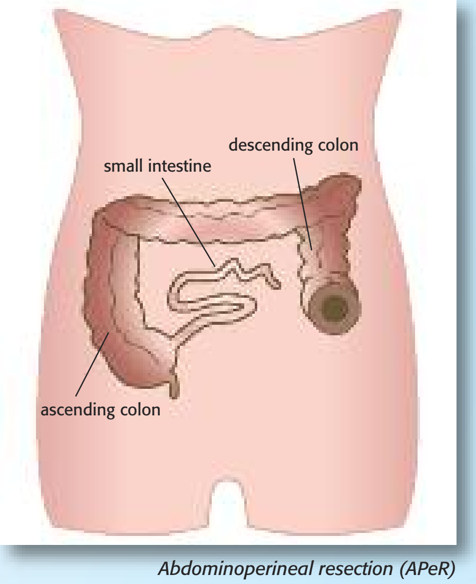
Another potential cause of rectal discomfort is a condition called proctalgia fugax. It can be caused by a cramping of the levator ani muscle, which makes up a large part of the pelvic floor. Proctalgia fugax is a condition that can affect anyone with a rectum, whether they have a stoma or not, and usually presents itself when the person reaches the mid–forties although has been reported in children. It is reportedly more common in women but this may be due to men being more reluctant to report it. The spasming of the muscle can be incredibly painful lasting from a few seconds to twenty minutes or more and can sometimes be mistaken for the need to go to toilet.

Some people find that a warm bath helps to relax the muscles although often the pain will have settled before the bath is ready. Simple relaxation techniques or rectal massage may help until the spasms pass naturally but in some instances further treatment is necessary.

Exercising the perineal muscles (Kegel exercises) may also help. This should be done with an empty bladder and involves contracting the muscles that you use when you try to stop the flow of urine. Either sit in a chair or stand with feet shoulder width apart, contract the muscles for 3–5 seconds then release. Do this 10–15 times per set and 2–3 times per day. As it gets easier you should aim to gradually increase the time you hold the muscle tight (by one second per week) up to 10 seconds; also increase the number up to 25 times per set. When you get to this level, one set per day should be enough.

If these methods fail to resolve the problem, your GP may suggest a calcium channel blocker ointment, nitroglycerine under the tongue or a salbutamol inhaler to try and help but, as with all medications, these are not without potential side effects so must be considered carefully. For persistent and extreme cases, a referral to a specialist pain management service may be needed and procedures such as local anaesthetic blocks or Botox injections could be considered. These are not guaranteed to work and have been known to increase the pain intensity so this must be borne in mind when exploring the options.

Discomfort without a rectum



Abdominoperineal resection (APeR)

Having your rectum and anus removed is likely to cause you some discomfort. Many people that have undergone the operation say that the discomfort experienced at the back end is worse than that in the abdomen. As with any surgical pain though, this should settle down within a few weeks after your operation.

Phantom rectum

Phantom rectum (PR) is the feeling that the rectum is still there or still working after it has been removed. First described in 1968, various studies report the incidence of PR to be between 12% and 68% (about 1 to 7 out of 10 people who have their back passage removed will experience PR). There are several symptoms associated with PR, some more frequently seen than others, and you could experience all, some or none of them if you have had your rectum removed. These are (most common first):

- The feeling of wind or faeces in the rectum
- Urgency – the sudden overwhelming sensation that you need to have a bowel movement
- Muscle cramps
- Pruritus – a severe itching
- Pain

These symptoms can appear right after the surgery but may develop weeks or months later down the line. For most people these symptoms will fade away. However, for about 1 in 3 people who develop these symptoms they could persist for years, if not indefinitely.

It is thought that the nerves that are responsible for sending messages to the brain from the rectum are responsible for the PR sensations. It may be that they have been damaged by the operation or a subsequent infection or perhaps by radiotherapy or chemotherapy. This damage could cause the nerves to send their own messages after the rectum has been removed. An alternative theory suggests that the nerves get used to delivering the messages and continue to do so even after the rectum no longer initiates them.

Pain that is experienced as a result of this is called neuropathic pain. Neuropathic pain can be difficult to treat, as many conventional painkillers such as morphine, do not work well but, if medication is required, over the counter medicines such as Paracetamol and Ibuprofen are a good place to start (please read the accompanying information carefully before using any medications and consult your GP if you are unsure).

Other medications are available through your GP that may help with the neuropathic pain. Drugs that were originally developed to treated epilepsy such as Gabapentin and Pregabalin are often used, as are antidepressant drugs such as Amitriptyline. However, these drugs will not work for everyone and many people experience intolerable side effects.

If you have been suffering with your pain for longer than three months, your GP may be able to refer you to a specialist chronic pain clinic for other treatments to be investigated. A pundendal nerve block involves the injection of local anaesthetic and steroid given through the buttock to numb the pundendal nerve which is responsible for the sensations felt around the lower rectum and perineum (the area between the anus and the genitals). This may relieve your pain for a few days or even up to a few months but it is not guaranteed to work and could, in some cases, make the pain worse so careful consideration is needed.

Complimentary therapies such as massage and acupuncture have been shown to help with neuropathic pain in some cases. It is, however, important to ensure that any practitioners are registered with a professional body relative to their therapy before consenting to being treated.

Rectal discomfort is not uncommon amongst ostomates following colostomy–forming operations regardless of whether the rectum remains intact or not. There are simple measures that you can take to help relieve the discomfort and in many cases this will be sufficient. In some cases, however, medications and further treatments may be needed. If you have tried the simple measures and feel that something else needs to be done please consult your stoma care nurse for help and advice. ■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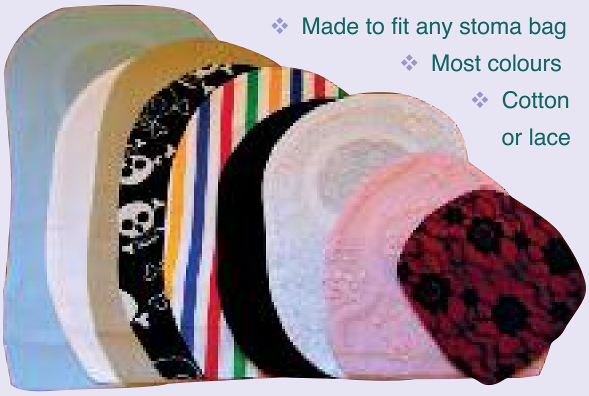


J.O.S.H

Junior Ostomy Support Helpline

This helpline is available for parents or carers of children with bowel or bladder issues.

Our specially selected team of dedicated parent volunteers provide much needed emotional support when it is required.

Helpline:
0800 328 4257

Photo ID Card

The **Colostomy Association** photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

If you would like to apply for a Photo ID card, please complete the form opposite and return it to the **Colostomy Association** for processing with the various enclosures listed below:

- **A copy of your prescription or delivery note as proof of eligibility**
- **Passport photo x 1**
- **Payment – cheque**

Note: Payment can be taken over the telephone if preferred.

Alternatively, the form can be downloaded from our website: **www.colostomyassociation.org.uk**

Please allow 10–14 days for delivery – thank you

National Key Scheme (NKS) Radar Key and Photo Identity Card


Disability Rights UK

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to the **CA Ltd.** Return all required items to:
Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

(If you have any queries please contact the admin team at the **Colostomy Association** office via the following methods:
Telephone: **0118 939 1537** or Email: **cass@colostomyassociation.org.uk**)

National Key Scheme - Key and photo ID card purchase

Title: ________________

Name: ________________

Address: ________________

Postcode: ________________

Tel: ________________

Email: ________________

Please **tick** as appropriate:

☐ I would like to receive a **key** for a charge of **£3.50** (including postage and packing).

☐ I would also like to receive a **photo ID** card for a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

NOTE: Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **CA Ltd.**

DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of disabled toilet facilities. The key is for the personal use of the above named and their designated carer only.

Signature of self or carer: ________________ Date: /   /2017

06 Please cut along the dotted line and return to the address on this form - thank you

Dear Nurse

Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma/Colorectal
Royal Stoke University Hospital
University Hospitals of
North Midlands NHS Trust

Julie Rust became *Tidings* Nurse in December 2004. She has answered readers' letters and e–mails in every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

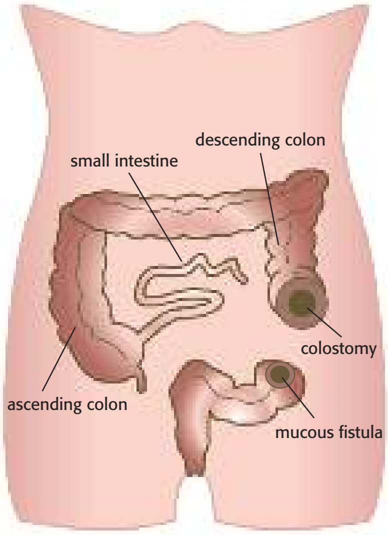
Your medical questions about stoma care management are always welcome and important to us.

Q: *I had my colostomy operation in April 2011. I had previously had polyps removed which were thankfully benign, then an abscess formed and I ended up with a stoma. I also have a mucous fistula lower down.*

I coped quite well and decided I just had to get on with it as no one else was going to do it for me. After about 18 months the area around the fistula got large and the consultant told me it was a hernia. I went into hospital to have it removed and closed, but unfortunately when I was given the anaesthetic I had a cardiac arrest. I came round quickly so no heart damage but of course I was left with my hernia. As I am now 87 they won't risk another operation.

Now I read a lot about parastomal hernias around the stoma but not about the one I have, so I just wondered if anyone else had this problem.

A: A mucous fistula is still a type of stoma and therefore we would treat it as such. When a section of bowel is removed this leaves two ends of bowel, one is brought to the skin surface as the stoma and the other end can either be closed and left inside the abdomen or can also be brought to the surface as a mucous fistula. This fistula can discharge mucus and often a small pouch or a stoma cap is used to manage this.



As you have been told that surgery is not possible another option for you would be an abdominal support. This may help to prevent the hernia worsening and also help to ease any discomfort. Your local stoma care nurse will be able to assist you either by measuring you herself for the support or referring you to either the hospital orthotics department or a company who provide supports.

Q: *For the first eight years after the operation to form my colostomy I had no bother, but for the past three years the problem with passing mucus from my rectum has become steadily worse.*

My consultant doesn't wish to do a reversal operation, mainly because of my age (81) and my state of health. For the past 18 months, I have had bowel irrigation [of the rectal stump] three times a week using the Qufora system (warm tap water) performed by our district nurses. This is a great benefit but the results don't last very long and every night after about three or four hours' sleep I am awakened by pain in the lower back or pains in the legs which result in having to get up and spend the night downstairs trying to sleep upright in an easy chair.

There are other symptoms during the day but as soon as I feel a movement of mucus everything is pain and discomfort–free. I very rarely have any kind of symptom when walking around.

Any advice would really be appreciated. Is there anyone who has experienced similar problems with mucus after a colostomy?

A: This can be quite an irritating problem. You do not describe what the other symptoms are and therefore it may be worth a review by your GP to see if there is anything else he can offer with regards to these.

With regards to the feeling of needing to empty the rectal stump there are a couple of options. The first is to increase the frequency of the rectal irrigation or to get the district nurse to use a small enema given rectally on a regular basis; this would need to be prescribed. Or there is an option of a rectal plug if you are finding you cannot control the discharge but from how you describe it this is not a problem. I hope you manage to find a solution to manage this problem so that your quality of life improves.

Q: *I had rectal cancer which was successfully treated with radiation, chemo and an anal resection three* *years ago. It took a long time to recover from the surgery with a great deal of discomfort during this period. I could not sit normally at all for about four months. I assumed that once the wounds were healed this discomfort would pass but sadly I still have the problem and my doctors seem unable to advise. They tell me it is not something they have come across before and they don't seem very interested.*

I realise it may not be resolvable, but would very much like to know the reason for it. Walking and sitting remain extremely uncomfortable – and it seems to be getting worse not better. Judging by the size and thickness of the external horizontal scar that I have on my tummy I wonder if it could be caused by similar scarring which is internal. The doctors don't seem to think this is likely and they keep mentioning 'phantom anus' syndrome. I am sure it is not this. The feeling is as though I have a very large cork or tampon, stuck half in half out of where my anus was. Physically when examined externally, there is nothing obvious to see or feel, but the sensation is very real. And it makes it hard to sit normally or walk around for long. Since I work full time and am pretty busy this is a tiring symptom to have.

A: This is difficult to advise on as I don't have access to your medical notes and any investigations you may have had done. If you have not had any investigations to try to identify the cause of this problem then it may be worth discussing it with your consultant again.

If there is no obvious cause then a referral to a specialist pain team may be beneficial. I have had patients with this type of problem within my area and they have been able to find a solution to manage this, but it has been a long journey for them.

Unfortunately, this is not a problem that can be easily treated as everyone is different and it may take several attempts to identify the problem and the cause and therefore the treatment plan. I hope you manage to find a satisfactory solution. ■

Emptying a drainable bag

In the last issue of *Tidings*, a reader who had problems bending his knees asked if anyone had any suggestions to make it easier to empty his bag into the toilet. We received three replies:

Regarding the reader's difficulty in emptying the bag when sitting on the toilet. I had the same problem until I realised that it would be much easier if I sat in a reverse position. In other words, face the back of the toilet.

I have had my colostomy for 20 years and have rheumatoid arthritis. I too was having the same difficulties with emptying my bag but have found an excellent solution. I purchased a shower stool and adjusted the legs to the height of the toilet. I can then sit comfortably facing the toilet to empty my bag. I have had no more problems and when I go away, the shower stool is the first thing that goes into the car.

I also have arthritic problems in most of my joints. I have a fold up stool and I put the edge up against the toilet bowl and sit facing the toilet so that my pouch dangles inside the bowl. This way I don't have any mess on myself or anywhere else except where it's supposed to be.

Do you find it difficult to drink bowel preparation solutions?

A suggestion from one of our readers

I've had Crohn's Disease for over 20 years and a permanent colostomy for nine years. The day before I was due to have a colonoscopy examination, I got really worked up and worried that I was not going to be able to drink the MoviPrep to clear out the bowel.

This would have meant that I would not be able to have a colonoscopy which would lead to more pain and discomfort as my Crohn's disease was active. My consultant said that during the colonoscopy he would be able to take a biopsy which would help him to plan the next move. It was essential for me to drink the MoviPrep along with plenty of clear fluids to get the best results.

MoviPrep can be mixed with fruit squash (not blackcurrant as that stains the bowel) and water, but in all the years I've done this it's never been any better, whatever fruit squash I used. Then I found the answer: Volvic juice.

You can buy Volvic juice in most supermarkets or even corner shops. There are a few flavours to choose from: Orchard Apple, Sunny Orange and Lemonade. There is also Berry Medley but due to the colouring I would avoid this one.

When making up MoviPrep, instead of adding sachets A and B to one litre of water, add them to one litre of Volvic juice. It comes in one litre bottles which is perfect. Once mixed you can start drinking it straight away or place it in the fridge to chill until you need it.

It used to take me hours to drink 250ml but when mixed in this way I drank the full litre within the hour as it tasted fine. You still need to drink clear fluids as you would when mixed with water.

I assume Volvic will work with other similar bowel preparation such as Klean Prep and Picolax. It was my consultant who suggested I contact support organisations for people with bowel conditions to share this suggestion so their members could benefit too.

Julie says: "I've not heard of using Volvic, so I would advise patients to check with their own endoscopy unit when they are given the bowel preparation. It is also important to make sure they don't use black or red berry juice."

If you have a general medical question or a query about stoma management:

E–mail:

editor@colostomyassociation.org.uk

or

Write to:

The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

Your questions will be passed on to Julie Rust. Although Julie is not able to reply directly to you, her answers will be published in the next issue of *Tidings*.

Julie's answers to questions about issues such as leakage, rectal discharge, or managing hernias or retracted stomas etc. may not only help you, but may also provide advice and reassurance to others experiencing a similar problem.

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Readers' writes

Do you have a story to tell, experiences or concerns to share with other ostomates, issues to raise? Maybe you have comments and suggestions about *Tidings*.
Write in or e–mail us today. The editorial team looks forward to hearing from you.

Rosemary Brierley

Dear Editor

I've recently had a very nervous few weeks through taking part in the Bowel Cancer Screening Scheme. Thirteen years ago, when I was first sent the kit I contacted the screening centre and explained I had a stoma. They said that made no difference and I could do it anyway. I did, three or four times, with no problems and no nasty surprise – till this time, when they found 'abnormality' in the first pack. They sent another, which was clear, then another 'to be sure'. That time, there was apparently too much specimen, so they couldn't assess it – so they sent a fourth, which was when I 'blew a gasket' and contacted Norfolk & Norwich Hospital who are going to bring my next colonoscopy forward to two years instead of five to 'set my mind at rest'.

A nasty few weeks, I could have done without, but people need to be made aware that stomas bleed easily and the blood can as easily 'contaminate' the specimen. Having spoken to Norfolk & Norwich Hospital, here's the update: The Oncologist and Colorectal Department say poo–stix aren't necessary for stoma patients, who are followed regularly by five–yearly colonoscopies.

Judith

Editor's note: If your colostomy was formed for a reason other than cancer and you are no longer followed up by the hospital and/or do not have regular colonoscopies you are advised to take part in the bowel cancer screening programme.

Dear Editor

I have been interested to read various letters concerning overseas holidays and the subject of travel insurance. I had a bowel resection in 2000 when I was 58 and have been an ostomate ever since. It took some time to come to terms with the new 'way of life' but in the past few years I have travelled extensively around the world with no ill effects from my condition. One or two tricky moments along the way I must admit but overall no problems and nothing that would deter me from travel, albeit I would think twice about venturing to some developing countries mainly due to their lack of 'facilities'.

I have been to the Far East, Australasia, Europe, the Med, the Middle East, all over Africa as well as the USA, Canada, Russia, Cuba, Mexico and the Caribbean. I have met several people who travel without travel insurance, saying it would be too costly for them to take out; this seems a false economy to me as should anything befall these folk then someone has to foot the bill!

I experienced the perfect example of having the necessary insurance when last April whilst on a cruise from Japan to Hawaii I became ill on Big Island, an excruciating stomach ache that developed with no prior warning. I had to get back to the ship's doctor as fast as possible and after examination and an X–ray I was booked into the Hilo Medical Centre on the island. My wife and I had thirty minutes to clear the cabin as the ship was due to sail. Thankfully the hospital was a very up–to–date facility and the doctor/surgeon who saw me was absolutely brilliant.

After further tests and X–rays I underwent an emergency operation that lasted over three hours and it was discovered I had a volvulus of the small intestine, that is a section that was badly twisted, gnarled and about to burst. Just over four feet of intestine was removed, I was stitched up with huge staples and given a private room where I remained for six days whilst recuperating and receiving expert American care.

The insurance company looked after my wife, accommodating her in a nice, four–star hotel overlooking the lagoon and some of the kind nurses took to visiting, taking her shopping, swimming and to local restaurants. When I was discharged a flight, business class, was arranged to Los Angeles and a further business class flight from LA to Heathrow. On arrival I was met by a chauffeur–driven Mercedes that drove us home to Cornwall – Some service! It didn't cost me a penny and on top of that we were able to reclaim the fees for the remaining lost four days of our cruise and three days in San Francisco. I was happy to be assured that my condition had nothing to do with me being an ostomate and no reason could be given for the volvulus occurring.

So, my advice to anyone travelling, don't forget your travel insurance!

Best Wishes
Alan B

Dear Editor

Re: Ordering stoma supplies.

Having assisted my wife (as her carer) for several years I have been involved in the monthly stock control and ordering on her behalf and have to admit it has not been an easy process.

Unfortunately, the GP's surgery combined all her stoma items together with medication on one repeat prescription which did cause some problems, until she ordered medication and stoma items on separate days each month.

Favouring the 'DIY' method, we collected the repeat prescription for stoma care, sending it off in a prepaid envelope to the supplier; a local pharmacy collected her medication prescription. This was working well, apart from the GP's issuing the full prescribed monthly amounts for stoma care, leading to oversupply. This maybe is appropriate for medication, as the

CONTINUED ON PAGE 44, COLUMN 1

Readers’ writes

CONTINUED FROM PAGE 43, COLUMN 3

recommended dosage/course should normally be adhered to. However, as most ostomates realise quite early on, no one day is the same and usage varies from month to month.

I did try to avoid this happening by making up a separate printed list specifying my wife’s required amount of stoma care products for that month, but this was mainly ignored. We then tried missing certain items completely off the repeat prescription list, if we considered there were sufficient in stock until the following month, and this seemed to be working well, avoiding a waste of NHS resources.

Then the surgery decided late last year to introduce the NHS Electronic Prescription Service (EPS) and stoma care ordering became chaotic once again. We found that, after the initial settling down period, EPS works well with medication repeat prescriptions sent electronically to our designated local pharmacy but stoma care has been fraught with problems. In particular, EPS cannot order ‘complimentary’ items from the supplier, and we cannot make a physical check to see if correct items/quantities have been listed. This has led to over ordering when a repeat prescription was accidentally duplicated without our knowledge and only discovered when the courier arrived with a very large box! Out of desperation I have typed in a highlighter “please don’t forward to supplier”, on to the repeat prescription list, and so far it’s been 50% successful!

I really think that EPS is a good method in reducing time and form filling for the patients and NHS staff, but it needs modifying to work with repeat prescriptions for stoma care.

AG

Editor’s note: Delivery companies and pharmacies (if they dispense stoma products in the normal course of their business) must provide Essential Services which includes providing a reasonable supply of supplementary items (disposable wipes and disposal bags) so these do not need to be included on the prescription. Other complimentary items need to be requested by contacting the delivery company direct.

Dear Editor

I have had a stoma for almost two years and early on was told that warming the pouch increased adhesion. Laying the pouch on top of the radiator certainly helped to produce a good seal.

Then we had the bathroom revamped and a towel rail was put in to replace the radiator. It was after that I noticed a problem, just now and again, with pancaking, where waste is confined to the top half of the pouch.

I realised then that I had been laying the pouch over rather than along the rail, causing an internal weld to take place. Now I place the pouch in a towel and drape it along the top of the rail.

David

Dear Editor

I applaud the work of the **Colostomy Association** and your particular, recent ‘Not every disability is visible’ awareness–raising campaign.

I would like to suggest an easy, pragmatic approach for people – who do not have an outwardly obvious disability – when using accessible facilities and one which may pre–empt any adverse comment or irritated muttering if you do.

For just £3.50, I obtained from the **Colostomy Association** a RADAR key which I carry with me at all times. Not all accessible loos require a key, but whether or not they do, I take the key out of my bag and brandish it as if I expect to have to use it (and look surprised when I don’t need to!). I’m sure this helps to silence any critics who either have obvious, visible disabilities themselves and/or those who cynically suspect me of avoiding the usual queue for the Ladies.

Most appliance suppliers offer a ‘Need to Use the Toilet urgently’ card and the **Colostomy Association’s** Photo ID Card would be even more convincing but it’s a sad indictment that solutions like this are necessary. You shouldn’t have to prove or explain that you need an accessible facility.

If challenged, my rehearsed answer, if I ever had to give it, goes something like: “I have a colostomy as the result of emergency surgery which saved my life. I would rather not have it and I would rather not have to use a Disabled loo. I’m sure you would feel the same”.

Finally, I notice in many public places that new toilets are being built as individual, larger cubicles with hand washing facilities inside the cubicle. Perhaps the day will come when this will be the norm and the larger accessible loo becomes for wheelchair users only.

Best wishes
Sue

Dear Editor

I have read *Tidings* over the past few years and realise that having bowel cancer is not the end of the world. There have been many encouraging stories from readers and I have taken heart from them. My operation took place some 12 years ago. The cancer spread to my lungs, but fortunately I recovered and just have

Readers' writes

regular annual checks. I have not climbed Everest or jumped from an aircraft, as some of your readers have, but have flown on Concorde, joined in the Mardi Gras in New Orleans, sung with Tom Jones and Shirley Bassey at Cardiff Arms Park and taken holidays abroad on my own since my wife died.

Your advice and tips regarding flying and customs procedures have been invaluable. I have always used drainable bags and have not had any problems, apart from the odd near miss – well, who hasn't?

There are certain foods like chillies and curries, which I like and was told to avoid, but I must confess that after a few years I decided to risk it and give it a go and really enjoyed them. No ill effects, but I appreciate that we are all different and others may not be so lucky.

So life has gone on as usual, until this year when I was admitted to hospital with a urinary infection. After three weeks, I was discharged with a catheter fitted. Since then I have not been abroad, but have not given up hope, even though I am now all bags and tubes and am 91 years old.

Soon after I had my op, I started writing my autobiography and last year it was published on Amazon Books. I am sure that many of your readers will read this and think to themselves – I may not have the courage to go on safari or swim the channel, but I could write a story of my life. As they say "there is a book in everyone."

Geoff

Please Note: Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

Dear Editor

How about this for an embarrassing moment? I was getting ready to go out and put on my slightly furry coat? Unbeknown to me, my stoma bags were waiting to be cut, on a shelf behind me. I said goodbye to my husband, and set off for an afternoon shopping. I spent an hour in Sainsburys, had wander around my local town centre, finishing up in Marks and Spencer. I noticed two young girls quite close to my back but didn't think too much of it.

When I arrived home, my husband had a weird smirk on his face, and took my shoulders and turned me around in front of the mirror. OMG, to my horror I had not one, but two stoma bags Velcroed to my coat. I'd spent the whole day with two bags hanging off my back. So many people must have seen and probably hadn't a clue what they were. I now understand why the two girls were so close behind me. And not one person told me. Nothing embarrasses me now and maybe a few people had a laugh that day. It certainly made mine.

We want to hear from you

Moved by something you've read in this issue of *Tidings* magazine? Do you have an issue that needs addressing or an experience you'd like to share with our readers?

The **Colostomy Association** regularly receives correspondence from supporters across the UK who would like to share their thoughts, experiences and personal tips.

All letters and e–mails are considered by the editorial team who decide which will be published in *Tidings* magazine.

If you'd like to send a letter to be considered for inclusion on the Readers' Writes page please send an e–mail to:

editor@colostomyassociation.org.uk

or a letter to:

The Editor
Colostomy Association
Enterprise House, 95 London Street
Reading RG1 4QA

Please make sure you include your full name and address and telephone number so we can contact you. Additionally, please mention whether the **Colostomy Association** has permission to publish your letter and whether you would like us to use your full name or just your first name. In the interests of confidentiality, if you do not give us permission to use your name we will publish only your initials.

Not a day goes by without some mention in the news about the civil war in Syria. The conflict has been ongoing for more than six years now and, as with most wars, the civilian population has suffered heavily. Aside from the tragic loss of life and injuries reported in the media, the country's infrastructure has collapsed and its national health system has fallen apart. This has included the destruction of hospitals and clinics, making access to basic healthcare difficult, if not impossible, for most citizens.

Just like the UK, Syria has a large ostomate community. Earlier this year, we got in touch with Hand in Hand for Syria to see if our Stoma Aid Project could help. Hand in Hand for Syria is a UK registered charity that delivers humanitarian aid to Syria on behalf of international non-governmental organisations (NGOs) and governments who do not have access to the country. They have over 300 staff on the ground, working in some of the country's hardest hit and most difficult to reach areas. Over the past six years they have established 8 hospitals in Syria as well as supporting more than 20 clinics and other medical facilities, which they supply with medicines and medical consumables donated in the UK. In 2015, this led to 144,467 patients receiving much needed treatment.

In April we sent our first Stoma Aid shipment to Hand in Hand for Syria. This comprised 60 cartons, containing a total of 25,000 stoma bags cut to fit a variety of stoma sizes, along with sprays, wipes, creams, wound dressings and bandages, underwear and urostomy night and leg bags. These supplies have now been received and are being distributed to ostomates via the hospitals that the charity runs and a further 80 cartons will be sent at the end of May. As you will know from our previous Stoma Aid reports, help of this nature changes lives. So please continue to donate. See below for details.

How you can make a difference

You can help make a difference to thousands of people across the world who cannot afford stoma supplies by either donating supplies or making a financial donation. Please send supplies you genuinely cannot use to Stoma Aid at the following address:

Dean Philps
Stoma Aid
c/o Stone Logistics/PRS Limited
Lorne Mill
Lorne Street
Bolton
BL4 7LZ

The cost of sending unneeded supplies to Stoma Aid can be reduced by using Hermes which has over 4,500 collection points across the UK. Prices start from as little as **£2.70** per parcel and more details can be found about the locations of their Parcel Shops on their website below (or by telephoning the **Colostomy Association** office with your postcode):
https://www.myhermes.co.uk/parcelshop–finder.html

Stoma Aid will accept the following:
All types of stoma appliances for adults and children including:

- Closed bags
- Drainable bags
- One piece bags
- Two piece bags (must include matching baseplate/flange)

Additional Products (which must all be at least 6 months in date):

- Absorbent gels
- Adhesive remover wipes, sprays and swabs
- Aerosols (spray and pump)
- Cleaning wipes, barrier wipes and dry wipes
- Dressings and bandages
- Frames and flange extenders
- Night/drain bags
- Pastes/creams
- Powder
- Seals, rings and washers
- Support belts, briefs and stockings

Stoma Aid cannot accept syringes, deodorants, prescription medications or drugs of any kind.
Stoma bags do not need to be in date but all additional products must be at least six months within their expiry date. Additionally, all two–piece donations must have both the stoma bag and matching baseplate/flange.

DO NOT be tempted to over–order or over–stock your supplies with the idea of sending the surplus to Stoma Aid. We cannot accept donations on this basis. Please only send items that you have ordered in good faith but find that you can no longer use. As we all know, helping the NHS save funds is vital and this in turn could also help prevent GPs questioning the quantity of stoma bags required.

Haven't got any supplies to donate but would still like to make a difference? Why not make a financial donation to Stoma Aid? (Please make all cheques payable to Stoma Aid and send them to the **Colostomy Association**, Enterprise House,
95 London Street, Reading RG1 4QA.

Help Stoma Aid with a Bag for Life

Order our NEW Stoma Aid ‘bag for life’ and help give ostomates worldwide a ’bag for life’.

Our new Stoma Aid ‘Bags for Life’ come in two styles, a cotton Tote Bag at only £2.49 + £2.50 P&P (measuring 38cm x 43cm) and a larger more robust Jute Bag for £4.99 + £2.50 P&P (47cm x 32cm)

An ideal present, both bags make a statement when you are out shopping! The caricature was designed by a professional cartoonist whose work has appeared in a number of famous comics.

All profits from sales will go to Stoma Aid. So help us to continue our support of thousands of ostomates in need worldwide by buying one (or more) of our Bags for Life.

Order Form

To order your **Bag for Life** simply fill in your details below and return it with a cheque made payable to the **CA Ltd** and send to:

Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA

Alternatively, you can order your **Bag for Life** from our online shop at **www.colostomyassociation.org.uk/shop**

Insert quantity of bags required in each box:

☐ Cotton Bag £2.49 each plus £2.50 P&P ☐ Jute Bag £4.99 each plus £2.50 P&P

Title:

Name:

Address:

Postcode

Tel:

Email:

Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA Charity No. 1113471 VAT No. 917079312

NEW

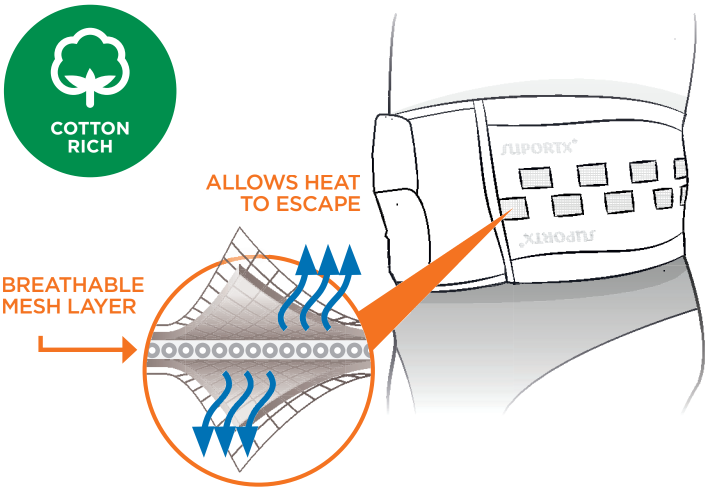
SUPORTX™

Breathable Easy Peel & Tube Belts

The Breathable Easy Peel Hernia Support Belt has been developed to provide abdominal support for a variety of hernias which include ostomy, parastomal, umbilical, epigastric and abdominal scars.

The anti-roll silicone pattern on the elastic bands help prevent the belt from rolling offering exceptional ease of use and comfort.

The belt helps immobilise the stoma pouch or hernia during daily activities whilst providing discretion and a smooth appearance. Furthermore, the belt helps to dampen the noises from the stoma pouch.



Key Features

- Unique Easy Peel Fastening
- Breathable fabric with cotton
- Shaped back (20cm and 26cm only)
- Available in 3 depths 15cm, 20cm and 26cm
- Choice of 3 colours: Neutral, Black or White

Other Suportx products available.

Visit our website to download the brochures

AVAILABLE ON NHS PRESCRIPTION

Suportx offer a **FREE** nationwide fitting service for all hernia support garments call or visit our website on:

☎ **0800 917 9584** **www.suportx.co.uk**

Win up to £25,000 with Unity

50p
From every £1 goes to Colostomy Association

Unity is a lottery with a difference. We receive income directly from the number of lottery players we recruit, so we need your support. For every £1 entry – 50p comes directly to the **Colostomy Association**.

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

How to join – three easy steps

Step one – Complete your personal details - so that we can contact you if you win.

Step two – Select the number of **Unity** lottery entries you wish to purchase per week and how often you wish to play.

Step three – Complete the direct debit instruction or enclose a cheque. Detach the form, put it into an envelope and return to **Unity** to the address shown on the right panel. **Unity** will notify you of your **Unity** lottery number.

If you have any queries please call our hotline on

0370 050 9240

Results & Rules can be checked by visiting

www.unitylottery.co.uk

Or by phoning the Unity winners hotline

0370 055 2291

Calls cost no more than calls to geographic numbers 01 or 02.
You must be 16 or over to enter.

Prizes				
	£25,000 6 digits	£1,000 5 digits	£25 4 digits	5 Prize Entries in the next draw 3 digits

1. Your details (please print in block capitals)

Title: First Name:

Surname:

Address:

Postcode:

Tel: Mobile:

D.O.B.: If you would like to receive correspondence via email, please tick here ☐

Email:

☐ If you do not wish your name to be publicised if you win, please tick here

2. Payment Frequency

How many entries would you like each week? ☐

x

How often do you want to pay? (please tick payment frequency and write amount in box)			
	☐	Monthly	£4.34 Direct Debit only
	☐	Every 13 wks	£13
	☐	Every 26 wks	£26
	☐	Every 52 wks	£52

→ ☐

=

Total Payable ☐

3. Select your Payment method

☐ Payment by Cheque

☐ I enclose a Cheque made payable to Unity
(minimum payment £13)

☐ Direct Debit

Please fill in the form and return to **Unity**
Name and full postal address of your Bank or Building Society.

To: The Manager: Bank/Building Society

Address:

Postcode:

Name(s) of Account Holder(s)

Branch Sort Code: ☐☐ ☐☐ ☐☐

Bank/Building Society account number ☐☐☐☐☐☐☐☐☐☐

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

unity

Instruction to your Bank or Building Society to pay by Direct Debit

DIRECT Debit

Service User Number 4 2 1 1 0 2

Reference: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Instruction to your Bank or Building Society
Please pay **Unity** from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with **Unity** and, if so, details will be passed electronically to my Bank/Building Society.

Signature: Date:

4. Your consent to Play (I confirm I am 16 or over and resident of GB)

16

Signature: Date:

☐ Occasionally, **Colostomy Association** may send you samples and information that may be of interest to you. We do not pass on your details but may use them to keep you informed of what else is available. If you would prefer not to receive these, please tick the box.

Detach the form, put it into a stamped envelope and return to **Unity** at the address shown on the right. They will notify you of your **Unity** lottery number.

Post this form in a stamped envelope to:

The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

T46

The promoter of this Unity lottery is Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA | Registered with Reading Borough Council Registration number: LOT000141

The Unity Lottery, Furness Gate, Peter Green Way, Furness Business ParkBarrow-in-Furness | T: 0370 050 9240 | E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

colostomy association
Helping ostomates since 1967

If you wish to setup a regular donation, please download the form from our website:
www.colostomyassociation.org.uk

Thank you for your support

Single donation

Every donation makes a difference – your support can help change lives across the UK. With your help, thousands of adults and children living with a stoma will be able to receive invaluable support through the Colostomy Association.

Please fill in this form to make a Single donation. Check your details are correct, then return the completed form by post to: Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

Note: Please ensure that we have your correct contact details: full name, address, postal code and telephone number. Thank you.

My Details: Title: Name: Surname:
Address:

Postcode:
Telephone (home): Mobile:
Email:

Optional Information: Date of Birth: Stoma Type: Colostomy ☐
Reason for your stoma: (Please tick) Ileostomy ☐
Year of operation: Urostomy ☐

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

Single donation: I wish to make a **single donation** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Form below** ☐ (Please tick),

Single donation/gift: a donation of £15 (or more) will help cover the cost of all our patient services

☐ (Please tick.) **Yes** I would like to make **a single donation/gift** of ☐£15 ☐£20 ☐£25 ☐£50 or
other amount (please state) £ to the **Colostomy Association**

I enclose my **cheque/postal order form** made **payable** to the **C.A. Ltd** and attach the completed Donation Form in its entirety.

Yes, I require a receipt ☐ (Please tick).

Single donations from individuals, groups and fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.

Thank you for supporting Colostomy Association – with your help – we can change lives!

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ I want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: **Date:** / / 2017

To make a single donation...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you

Registered Office: Enterprise House, 95 London Street, Reading RG1 4QA

Registered Charity No: 1113471

News from Local Support groups

North Notts Stoma Support Group

Stoma? What next! is a leaflet produced by the support group for informing new and existing ostomates of the nature and aims of the group. Copies have been given to the stoma nurses at Kings Mill Hospital, Sutton in Ashfield and local doctors' surgeries. We also have our own web site www.northnottssupport.co.uk and are also on facebook as a closed group.

We are a small friendly group that meets on the second Saturday of every month in Clinic 3, Kings Mill Hospital, Sutton–in–Ashfield from 10.00am to 12.00noon. We invite representatives from the various manufacturers of stoma products; Claire Olley from Oakmed will be with us on 12 August and Vanessa Dosanjh from Coloplast on 9 September. When possible there is a stoma nurse to answer questions.

The meetings are very informal and can cover a variety of topics, not always just about our medical conditions, so, as well as having a more serious side to our meetings, we try and keep it light hearted. On 9 December we will hold our Christmas Fuddle.

For more details contact:
Nicky and Tore Norman
Tel: 01773 715 460,
e-mail: toreno@sky.com

Stoma?
What next!

North Notts
Stoma Support Group
NNSSG

Here to help

Kirby Ostomy Support Group

Meetings are for those with a stoma living within Leicestershire. We offer support to anyone with a colostomy, an ileostomy or urostomy, whether they have had surgery recently or in the past. Members who might have problems are able to discuss them with those who understand. Partners, family members or friends welcome.

Meetings held in the Clinical Education Centre, Glenfield Hospital at least once a month, usually on the third Saturday from 10.30am till 12.30pm; Parking is free in the car park in front of the centre.

Speakers followed by tea, coffee and a general chat:

Saturday 15 July 2017
Michael Lee – Leicester Railways
Saturday 19 Aug 2017
Dawn Buswell – Stoma Care Nurse
Saturday 16 Sept 2017
David Tydesdale – Garden Birds
Saturday 14 Oct 2017
Julie Ede – Bess of Hardwick Hall

For more details contact:
Janet
Tel: 0116 239 2844 or 07464 957 982
e-mail: kosg2013@btinternet.com

Pembrokeshire Stoma Association

Pembrokeshire Stoma Association

We Are Here For You

Support and advice for Colostomates, their families and their carers

We look forward to seeing you!

About six years ago, along with Peter, who had also had an operation for bowel cancer at Withybush Hospital, I decided to form our group with the support of the stoma care nurses. Pembrokeshire is very rural and evening meetings proved to be difficult so we now meet late mornings on dates arranged by the members. Our programme is varied and includes guest speakers. Coffee and tea is provided and members are free to bring their own refreshments.

The next meeting will be on **25 July** from 11am until 3pm.

For more information contact:
Roy Whitfield
Tel: 01437 760 701

Normandy Stoma Group

Meetings held at St Marks Hall, Guildford Road, Normandy GU3 2DA

From 10am till 12noon

Saturday 22 July 2017
Jackie Dudley from the **Colostomy Association**

Saturday 23 September 2017
Elaine Moseley from Trio Healthcare – Healthy Eating

Saturday 25 November 2017
Jo McNair from Hollister

For more details contact:
Jackie Sanders, Secretary
Tel: 07815 603 742
jackie-saunders@hotmail.co.uk

Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

Stoma support groups in your county

Channel Islands

Guernsey
Guernsey Ostomates
Luci Deane 0148 123 6077 /
lucideane58@gmail.com

Jersey
Jersey Ostomy Society
Fiona Le Ber: 0153 4445 076 or
jerseyostomysociety@gmail.com

England

Bedfordshire
Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire
E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297 or
07974 790 558

Bristol
Bristol Ostomy Self Support (BOSS)
Janet on 01934 248 114 or Rob on
0117 966 8021

Buckinghamshire
High Wycombe Stoma Support Group
Wendy Hetherington: 07717 335 884

Milton Keynes Stoma Association
Thia Cooper 01908 679 295 /
mksa.sec@gmail.com

You Are Not Alone Stoma Support Group
Carla 0784 6354 918

Cambridgeshire
Connections Cancer & Colostomy Group
Bev or Sue Scott 0135 386 0356/
0776 695 8811 or Barbara Hunt
0135 386 2133

Peterborough Stoma Support Group – Ostomistics
Alan Wright 0135 465 3290 /
0783 666 1102
http://www.ostomistics.org/

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 0124 436 6170

East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071

Stockport Support Group
Angela Simpson: 0161 320 9400 /
0800 652 6667

Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland
Oops Group
Julie Morrisroe/Carol Younger:
0128 728 4113

Co. Durham
Bishop Auckland Stoma Care Group
Betty: 0138 881 4535 or email:
pgill82171@aol.com

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Durham Stoma Support Group
Katie: 0191 3332184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
The Chairperson: 01726 828 419
or The Secretary: 01872 241 145,
cbcsginfo@gmail.com or website
www.cornw

Cornwall Ostomy Support
Ken Jones: 01872 863 106 or
www.cornwallostomysupport.org.uk

Lanhydrock Ostomist Support Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com or Anna
Rennie: E:anna@thesilverocean.com

Cumbria
Grange Cancer Support Drop in
Marie: 0153 953 3279

Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179

Derbyshire
Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

Devon
Devon IA
Martin Hornby: 01458 251 095 or
email: devon@iasupport.org

Mid Devon Ostomy Support Group
Janice: 07923 975 051 or
01363 776 417 or
jdkelly234@gmail.com

Plymouth & District Bowel Cancer Support Group
Wendy Wilson or Keith Anderson:
07934 922 156 Facebook: Plymouth
Bowel Cancer

Dorset
Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Bournemouth)
Beryl Andrews 0120 248 3303

Colostomy Urostomy Pouch Ileostomy of Dorset – CUPID (Poole)
Jenny Pipe: 0120 274 0440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset – CUPID (West Dorset)
Colin Clare – 0130 585 3238

East Midlands
Newhall Stoma Support Group
Diana Manning: 0128 354 1311 or
Helena: 0793 233 1850

Essex
Connect
Lin Hart 0127 950 5273

Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374

N.E.S.S (North Essex Stoma Support)
Secretary: Brian Waller:
0120 654 0449

Optimistic Ostomates
Carol Booth: 0170 238 5510 or Angela Taylor: 0170 238 5509

Redbridge Ostomists Club
Stoma Nurses – Chris/Lisa: 020 8970 8321

STEPS
Jackie: 0126 845 1937 or email: stepsessex@gmail.com

Gloucestershire

Ladies Big Op Group
Gill Hopkins: 0300 422 4363. Please Note: For ladies with one or two permanent stomas

Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794 182 7393

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Ron Lever 0238 089 3949 / rdlever@sky.com

Solent Ostomates Support Group (S.O.S.)
Sally: 07527 707069

Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com

Wessex Urology Support Group
Adrian Kuczynzki: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 0143 288 0656 or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 0172 776 0981

Stevenage Ostomistics
Judy Colston: 0143 835 4018 / neilcolston@btinternet.com or Alfred: 0176 731 6958

Isle of Man

IOM Bowel Cancer Patient and Carer Group
Heather Norman: 07624 480 973

Stoma Support Group
Carole Cringle stoma nurse: 0162 465 0212

Isle of Wight

Optimistics
CNS's Andie Coates & Amanda Broadbridge 0198 353 4009

Semi–Colon Club
Tony Crowson on 01983 559 326 or Cancer Clinical Nurse 01983 534 180

Kent

Ashford Stoma Support Group
Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 0782 799 7424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Julie Bell: 0777 134 5703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

Royal Tunbridge Bowel Cancer Support Group
Bronwen Tetley CNS: 0189 252 6111 x 2287

Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194 / sogs-uk@hotmail.com

SWAN Stoma Support Group
Heather: 0771 144 5312

Thanet Stoma Buddies Support Group
Phil (Secretary) 0184 358 7769

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 0784 120 6910

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790, www.phoenixgroupbvh.com or eMail: sandrapeet7@aol.com

Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper: 0116 239 2844 / kosg2013@btinternet.com

Lincolnshire

Friends East Coast Support Group
Betty: 0120 572 4120, Sheila: 0120 536 4493

Grantham Support Group
Bobbie/Rachel: 0147 646 4822

Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617

London

Bowel Cancer Newham
Scyana: 0208 553 5366 scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)
Wendy Hetherington: 0771 733 5884

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 0208 510 5318 or 0208 510 7599

Rectangle – Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563

St. Thomas' Hospital
CNS: 020 7188 5918

Surrey & South London Bowel Cancer Support Group
Sue Berry: 0173 755 3134 or John Amos: 020 8668 0796

Merseyside

I.C.U.P.S
SCN: 0151 604 7399

St Helens Cancer Support Group
Office: 01744 21831, Denys Floyd: 01744 884097 or email: contact@sthelenscancersupportgroup.org

Middlesex

Inside Out
Sarah Varma: 020 8235 4110 Bob (chairman): 020 8428 4242

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448 sylvia.ruth.hughes@gmail.com

Northamptonshire

Northampton Ostomy Support Group
Ian: 0780 1316 403 (evenings) or Trish 0770 3188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore and Nicky Norman: 0177 371 5460

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support
Jenny or Kate: 0115 962 7736/ Mrs B Heath: 0115 966 3073

Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable on 0169 123 8357

Staffordshire

Outlook
Moira Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363

James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955

L.O.G.S (Lowestoft Ostomy Group Support)
Mandy O'Shea: 07899 913 617 or Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse: 0163 851 5525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena: 0137 273 5925

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049 or Jackie Sanders: jackie-sanders@hotmail.co.uk or 07815603742. Website: http://www.normandystomagroup.wordpress.com/

Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 0127 355 4407

Chichester Stoma support Group
The Stoma Care Team 0124 383 1527

The Ostomy Friends Group
Jane Quigley: 0132 341 7400 ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker: 0144 444 1881 ext 8318

Tyne & Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com

NHS Molineaux Centre
John Burchell 0191 265 1047

Royal Victoria Infirmary Support Group
John Burchell 0191 265 1047

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com or Bob: 07564 680 803

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group
Michael Slater: wessex.stoma@yahoo.co.uk or on 0172 274 1233

Worcestershire

Kidderminster & District Collossus Support Group
Brendon Drew: 0129 940 0843

Yorkshire

Acorn Ostomy Support Group
Michelle: 0758 069 3155 (After 6:00pm)

Airedale Stoma Support
Sue Hall: 0153 564 6373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 0122 643 2528 or Celia Utley (Chairman) 0122 628 4262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 0148 435 5062

Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or 01924 512 072

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses – Judith Smith and Mary Hugil

Harrogate Stoma Support group
Jacquie: 07768 024356

Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group
Pete Smith: 0798 956 5335 or Pete Rennard: 0793 951 8642 / 0148 279 3966 or Rosanna Grimsby: 0148 280 1575. www.hercosg.org.uk

Northern Ireland

Co. Antrim

Colostomy Association Volunteers Northern Ireland
Chris Wright: 0772 071 7771

Mater Hospital
Karen Boyd – Stoma Nurse: 0289 074 1211 Ext 2329

Royal Victoria Hospital – Belfast
Sarah Haughey/Audrey Steele: 0289 024 0503 Ext 3483

Co. Armagh

Craigavon Area Hospital
Clare Young/Lynn Berry/Janice Garvie 0283 861 2721

Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000 Ext 2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511

Ulster Hospital
Hazel/Martina: 0289 055 0498

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Republic of Ireland

Co. Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

Bowel Cancer Support Group (ICS)
National Cancer Helpline: (00 353) 1 800 200 700 or Olwyn Ryan: (00 353) 1 231 0500

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945

Stoma Care And Recovery (SCAR)
Maggie: 0129 427 1060/ 0781 773 6147 maggie13@sky.com or Rhona: 0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866

Glasgow Stoma Support group
Chairperson: Morag Sinclair 0141 779 1322 or Jackie McChesney 01505 324 052

Moray

Moray Ostomates Support Group
Meggie 01343 552 449 / Kathleen 07789 684 285

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net or 0145 037 4012. Fiona Gentleman: r.gentleman@sky.com or 0145 037 1063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 0165 664 5602 or bridgend.ostomy@gmail.com

Carmarthenshire

Support Group
Iris Williams: Iris.Williams@wales.nhs.uk

Conwy

North Wales Ostomy Support Group
Hazel: 07976 817 246 or Lesley: 07828 837 325

Flintshire

Bag For Life Stoma Support Group In.It.Together
Faye Jones 0785 275 0772

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After 6pm

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis: 01633 791 339 / 07504 713 069

Mid Glamorgan

C.A.S.S Colorectal and Stoma Suport Group
Colorectal Nurse Team on 0168 572 8205

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 0143 776 0701

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

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