

# Ostomy

A U S T R A L I A

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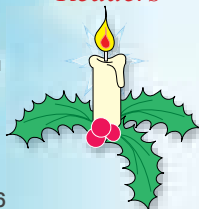
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**Cover Picture:** Spring flowers.  
Photo by Joe Kraus.

## ENUSI IN THIS ISSUE

*Greetings  
To All Our  
Readers*



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has a new mailing  
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# PRESIDENT'S MESSAGE

I write this message at the conclusion of our ACSA bi-annual executive meeting and annual general meeting in Canberra at the end of October. The AGM was attended by 20 of the 22 ostomy associations that comprise the Council and addressed a number of issues. I was impressed by the collegial approach that all associations took to addressing the issues that were raised. Most of those issues are covered in other articles in this December issue of *Ostomy AUSTRALIA*.

There are two issues that I would like to bring to my fellow ostomates in this report. They are:

- the structure under which associations operate; and
- provision of universal access to stomal therapy nurses.

## Association structure

By way of background, in the two months before our AGM, several events occurred which gave clear indication that the Stoma Appliance Scheme (SAS) on which we all rely for our appliances is under government scrutiny. The first indication came from the Department of Human Services (DHS), which reimburses associations for the cost of products distributed to members, using claims prepared by associations from the orders placed by members.

A team from the DHS audit group visited four associations to review the way that associations processed members' orders and prepared the claims for reimbursement of the cost of those orders. The reimbursement includes the 2.75 per cent commission paid to associations to cover their costs in administering the scheme. ACSA Vice President David Munro and I were present during one of those visits. The team showed interest and some surprise at the number of individual associations distributing product. They were also surprised that there was no formal contract with ACSA or the associations covering the SAS, which last year reimbursed \$90 million of government money.

The second event was the change of director in the area of the Department of Health responsible for overseeing the Scheme. The incoming director has previously been involved in the National Diabetes Services Scheme. In comparing the two schemes, she has raised questions about the contractual basis under which our scheme operates, including the contractual relationship between ACSA and individual associations.

The third event was a question to ACSA from the DHS team about the size of financial reserves held by associations. While this information was unable to be provided at the time, it is publicly available on the Australian Charities and Not-for-profits Commission (ACNC) website. Associations need to ensure that they are deploying any surplus they have accumulated over the years in support of their stated objectives. This will ensure that they continue to meet the obligations required to retain ACNC registration.

At the Canberra conference, associations agreed to establish a working party to identify alternative organisational structures for Australian ostomy that would provide a platform for a formal contract with government. The objective of the working party is to recommend to Council a structure that retains the services that the 22 associations deliver to members, but in a form which meets the government's requirement for a formal contractual base.

That working party has been established, using the relevant skills of association members. We are fortunate that among our 42,000 members we have a number of individuals whose background and skillsets can address this challenge quickly and effectively. Your associations will be kept informed of developments as work on the

options progresses. At the latest, a firm recommendation on which option best meets association needs will be placed before the 2017 ACSA AGM.

## Universal access to stomal therapy nurses

At the conclusion of my August message I raised the issue of universal access to stomal therapists. Since then the ACSA executive has had informal discussions with influential contacts in the Department of Health about incorporating stomal therapy services into the scheme. Part of the justification for that outcome would be a reduction in the use of products.

As part of the regular inclusion of products on the SAS, the Stoma Product Assessment Panel (SPAP) reviews the pricing of existing products against newly proposed products. Barrier wipes recently underwent this review when a new no-sting product was proposed at a price substantially below that of existing products.

A decision to reduce the price of all barrier wipes has yet to be finalised and the impact of the decision on ostomates was raised at the appliance officers' meeting that was held as part of the Canberra conference. One association representative noted that more than 80 per cent of the large number of people ordering wipes from their association chose to use the more expensive wipes.

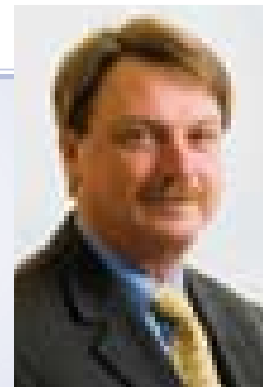
A number of stomal therapists have provided views on the likely impact on ostomates if suppliers of the more expensive wipes withdrew their product. Their response has been that barrier wipes were, in most instances, unnecessary when used with modern appliances. Those therapists had further noted that barrier wipes could, in fact, reduce the effective adhesion of modern base materials because those adhesives depend on reacting with the skin's natural moisture to create and maintain adhesion.

Here we have a clear example of a situation where regular access to clinical advice from a stomal therapist would reduce unnecessary use of SAS products while achieving better outcomes for ostomates. I have had discussions with a number of stomal therapists about the use of a broader range of accessory products. The clear professional advice is that the majority of these products provide significant benefit for a small number of ostomates in specific clinical circumstances, but are not required by most ostomates. This area of the SAS has been reviewed by SPAP and a series of recommendations are before government.

The annual expenditure on this group of products is approximately 25 per cent of total expenditure on the scheme, or around \$23 million. If that expenditure was reduced by half, the savings would, on preliminary figures prepared for the ACSA executive, fund a national scheme for the universal provision of stomal therapy services to all ostomates. That would include quarterly visits in the initial year post-surgery and annual visits thereafter.

We still need to address a number of issues, including obtaining government support, determining who would run such a service, how it would be structured and where we would recruit the stomal therapists to operate the scheme. Like all new ventures, it would have its challenges, but it offers the opportunity to introduce the next major improvement in a scheme that leads the world in supporting ostomates.

**Geoff Rhodes** PRESIDENT



## No change to stoma scheme

On the eve of the ACSA national conference in Canberra, the Australian Government indicated that it was not proceeding with the competitive tender for one-piece pouches listed under the Stoma Appliance Scheme (SAS).

Companies that supply stoma appliances and stomal therapy nurses had been concerned about the possible consequences of the tender that had been called on three sub-groups of one-piece pouches covered by the SAS, and had lobbied against it. ACSA had not been consulted about the tender or involved in its development, but raised its concerns about the possible impact on ostomates and associations.

The government's change of heart was announced in a letter to ACSA President Geoff Rhodes on 18 October. The Department of Health said that "after consideration of matters relating to the tender, it has been decided that the Stoma Appliance Scheme arrangements will continue without change".

Geoff Rhodes subsequently told associations that "ACSA's quiet formal and informal lobbying has paid off with regard to the tender the department had released for products in groups 1, 2 and 3 of the SAS schedule.

"We were able to provide information to the department that demonstrated the tender outcome was unlikely to provide the required savings but would have a negative impact on ostomates."

The idea for a tender was introduced as part of the 2015-16 federal Budget process, and in April 2016 the department announced that the tender would apply to SAS schedule groups 1, 2 and 3, which cover one-piece products. The process was designed to "provide improved value for money for purchasing of relevant stoma products supplied under the SAS".

ACSA made its concerns known directly to the department, arguing that having access to suitable products was important to ostomates' physical, psychological and emotional wellbeing, that individuals often had quite different needs, that changes might increase costs and workload demands on associations, and that the proposed approach might not bring the desired savings.

In its letter of 18 October, the department reiterated that "The Australian Government is committed to ensuring that products supplied under the Stoma Appliance Scheme continue to assist

ostomates to better manage their condition, and allow greater participation in society and the workforce."

The Australia Fund had sent goods to ostomates overseas to an estimated total value of \$275,374, based on weight, in the 2016-15 financial year, the fund chairman, Gerald Barry AM, told conference delegates.

Significant support programs were directed at Indonesia (three sites), the Philippines (two sites), Kenya (three sites), Malaysia and Fiji. A newer program for Mongolia has also continued despite difficulties with parcel delivery.

In the period under review, the fund had sustained an operating deficit of \$3,119. The total cost of running the fund was \$21,525, which exceeded revenue of \$18,405 for the year. This is the first year that the fund has operated at a loss but Gerry Barry did not propose to seek additional funding from ACSA (which makes an annual contribution of \$10,000 to the operation) since available funds in the Australia Fund account were adequate at this stage.

The Australia Fund began in 2001, providing ostomates overseas with appliances and other supplies which are sourced from donations by associations and individuals of obsolete, overstocked and unusable items as well as donations from hospitals, STNs and supply companies.

Gerry Barry told conference the total value of supplies sent overseas in that time was estimated at \$1.354 million, based on the weight of the parcels sent. The cost of sending these goods amounted to \$188,501.

He encouraged all associations to contribute half a day each month to support the work of Australia Fund. This would enable the program to expand its efforts to a wide range of needy ostomates. Reports from overseas destinations confirmed "the immense difference the donated appliances make to the lives of ostomates who have very little support with their medical issues, in addition to the lack of appliances".

ACSA has a new appliance officer co-ordinator, following the decision of Sue Hoyle to step down from the position. Delegates unanimously appointed Hermione Agee, assistant manager at the Ostomy Association of Melbourne, as the new co-ordinator.

*Continued page 6*



Gerry Barry AM reports on the Australia Fund.

## National computer system to launch soon

Despite unanticipated delays, ACSA expected the new national membership, ordering and financial management system to be launched before the end of the year, Geoff Rhodes told ACSA national conference in Canberra in late October.

Development of the Stoma Appliance Management System (SAMS) was also well within budget and this was not expected to change, the ACSA president said.

ACSA decided in 2014 to develop SAMS as a common computer system to serve all Australian associations and allocated \$250,000 to the project. The new system is intended to improve client management, stock management and data security, and to supersede the variety of different applications and versions in use nationally.

Finalising the system for implementation would move quickly in the weeks after conference, after the Ostomy Association of Melbourne had committed its assistant manager, Hermione Agee, to working full-time on the application.

Some associations were keen to begin familiarising their staff with the new system, and ACSA had decided to make SAMS available to these associations in its pre-release form.

It seemed clear that migrating data from existing

systems to SAMS would not present major difficulties. However, it had become obvious that a full-time helpdesk function would be needed to support associations for at least the first two years as SAMS was rolled out around Australia. Associations were invited to nominate suitable candidates for the helpdesk, which would probably need to be up and running early in 2017.

Geoff said SAMS would not initially have the capacity to handle e-parcels—the priority was to get the system bedded down—but that capability could be added later.

Company representatives said that they would be able to improve their service to ostomates if SAMS could provide accurate information that would allow them to order advance supplies from their home companies overseas. It would ensure that they could hold sufficient stock, and also reduce the problem of backorders.

Delegates saw a preview version of the updated ACSA website which has been developed by the national office and is expected to be on line before the end of 2016.

ACSA Administrative Officer Kylie McGrory said the new website would be more modern and would contain much more stoma-related support information than the existing site.

It would include a page dedicated to each association, complete with their contact information, logo where available, business hours and a contact form.

It would also have a means of automatically directing incoming email enquiries to the association concerned. As well, each association would have an email address available through the ACSA website, although this would not replace existing email addresses.

Conference decided not to increase the capitation fee—the sum that associations pay per member for affiliation with ACSA. It will remain at \$1.50 per member, plus GST.

ACSA's operations resulted in a surplus of \$455 in 2015-16, the treasurer, Bob Barsing, reported. This was down from \$6,766.60 in the previous financial year. Total income amounted to \$80,614.86 from sources including advertising revenue and affiliation fees. Major items in total expenditure of \$80,159.85 included salaries and honoraria, publications and a donation to the Australia Fund.

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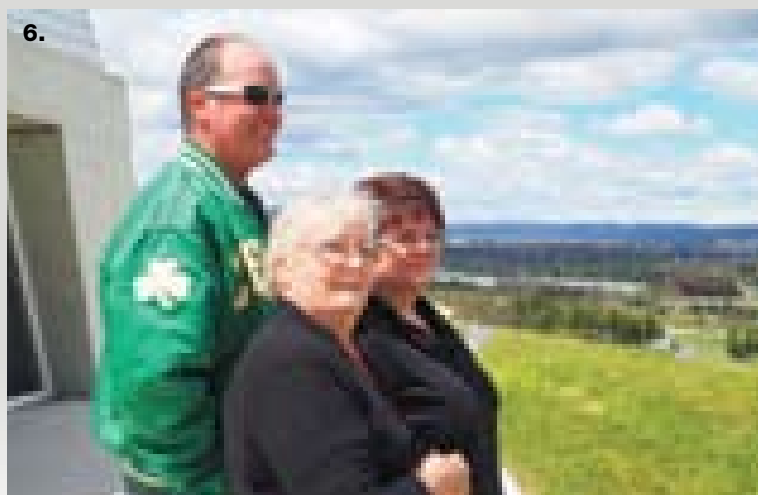
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**1.** Dr Sarah Engledow, Historian of the National Portrait Gallery, talks to members of the Sunday tour group about John Webber's portrait of Captain Cook.

**2.** ACSA President Geoff Rhodes and Administration Officer Kylie McGrory during a conference debate.

**3.** Wendy Taylor, Secretary of the Ileostomy Association of Victoria, and Rosel Robertson, ACT Office Manager, at the welcome function drinks.

**4.** ACT and Districts Association president Horst Kirchner registers Liberty Medical representative Jason Gurton-Edkins at the conference welcome function.

**5.** ACSA Treasurer Bob Barsing, Secretary Rosemary Quick and Vice-President David Munro run through on-line documents at the pre-conference executive meeting.

**6.** Gold Coast visitors (from left) Tim Condon, Jo Wood and Sharleen Condon take in the view after lunch during the Sunday outing.

**7.** Nola Straughair (ACT, left) and Marianne Smith (Colostomy Association of Victoria) admire Evert Ploeg's portrait of Deborah Mailman during the Sunday tour of the National Portrait Gallery.






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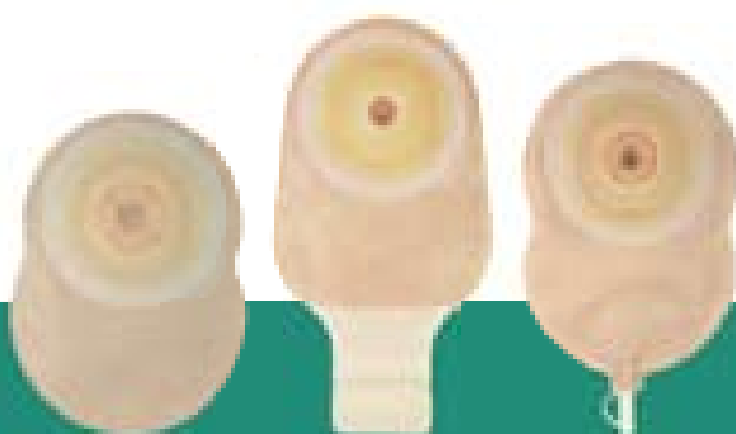
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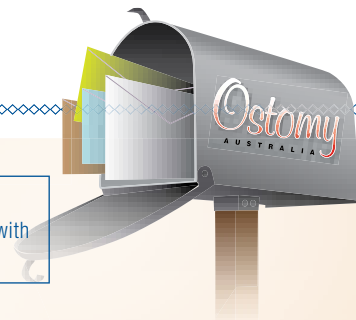
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**Dear Editor,**

Sarah of South Australia in Ask Carmen (August 2016) said she had heard that cholesterol absorption is linked to the large bowel, so people with ileostomies need not worry, and asked whether there is any truth in this.

I'm not able to answer this definitively but I can say that since my total colectomy resulted in an ileostomy 51 years ago, my cholesterol levels have always registered low, on or off the bottom end of the scale.

In the late 1970s, I was told by my Brisbane physician that the reason for my low readings was that cholesterol is absorbed from by the large bowel, and since I no longer had one, my readings would always be low.

Not everyone's experience is necessarily the same as mine, but I have asked a few ileostomy acquaintances about this and their experience is similar.

This automatically leads to the question—are people with ileostomies less likely to die of a heart attack because of their low cholesterol? My speculative guess would be 'maybe'—but does it matter when you factor in the health issues that led to people having an ileostomy carry their own negative impacts on life expectancy? A related question might be—are there bad long-term consequences from having low cholesterol? The only certainty in life is that sooner or later we all die of something.

Some might find comfort in the thought that not having a large bowel might have an upside, but I don't imagine it would result in a rush for bowel-removal surgery by people seeking a cure for heart disease.

If some researcher hasn't already addressed these issues, it would be a fertile field for study. A good place to look for people to study would be the ileostomy component of the 42,000 members of the Australian Council of Stoma Associations. There should be some good statistics to be got there.

**Ray Garske, Queensland**

*Editor's note: Margaret Allen will write about ileostomies and cholesterol in a future issue.*

**Dear Editor,**

I have been a urostomate for 12 years and, apart from the initial few weeks, have used the same products. However, panic set in when I discovered that my bags were on backorder for at least a month. I spoke to my stomal therapist, Joan, and met her the following week to look at an alternative product.

She was so helpful, and after inspecting my stoma (the first time in 12 years I had ever presented for a check-up, as I have no skin problems) she placed the new baseplate and bag on me and explained how it all worked. I went home with a couple of bags and, after she made a phone call to the company, was told that more supplies would be delivered by courier to my home the next day. This duly happened, so I felt pretty relieved that I would have supplies to tide me over. I still had quite a few of my regular brand left and was eking them out.

However, using a different brand is quite an adjustment to make. The tap is different and I seemed to empty far more frequently, probably because I was afraid of leakages. The baseplate was fantastic but the night drain was a different matter altogether. The first night was trouble-free but for some reason on the second night I left the outlet open! The closure was the opposite way to what I was used to. As a result I woke up to a pool of urine on the carpet! Oh well, these things are sent to try us. I was so cross with myself for not checking properly.

I will put in an order for the new product even though I hope to go back to my original product when supplies are resumed. After this experience I think it's useful to have a back-up supply in case it happens again. This is the first time anything like this has happened to me, and I always have plenty of supplies on hand, but for some reason this time I was down to my last box before re-ordering, only to discover the month backorder (Murphy's law). I was in a state of panic, stressed and feeling extremely vulnerable. Thanks to my association for getting me through this situation, and thanks in particular to Joan. She was so calm and came up with all the answers.

**Vivien Causon, Victoria**

**Dear Editor,**

The notes by Irvine Nicholson of South Australia (Tips and Hints, April 2016) were quite comprehensive and an interesting read, and they prompted me to record my own experiences.

In 2009, when I was 67 years of age, I was diagnosed with prostate cancer and underwent the usual period of radiation therapy, which was successful. In 2012, I was diagnosed with bladder cancer and in January 2013 underwent a prostatectomy and cystectomy.

My stomal nurse in hospital introduced me to a one-piece device which I have been using to date and with which I am comfortable. To be fair, I did have my share of

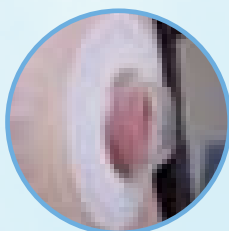


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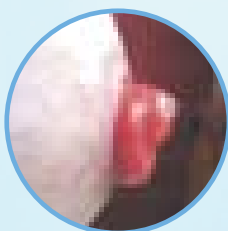
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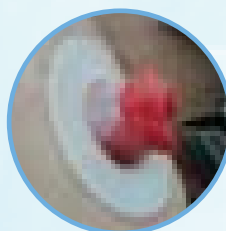
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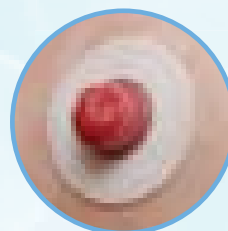
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problems to start with, ending up with a hernia behind the stoma, and having a few 'blowouts' both day and night. The most dramatic was when travelling to Sydney. My wife and I stopped at a motel in a northern Victorian town and I had an accident overnight which resulted in having to pay for a complete unit carpet clean. From that date I have used buckets, cat litter trays (new) and smaller trays to hold the night drainage bag.

In February 2015, I entered hospital for a day procedure to check my ureters. A CT scan had shown the left one was not working properly. I came home nine days later. My surgeon was using a camera probe and inserted a dye to highlight the area. My body went into shock with the dye and into a 'code blue' situation. I spent the next three days and nights in ICU. I had a serious urinary infection with the left ureter not working at all, and there was a massive buildup of fluid. A stent was inserted into the area to drain the fluid and once again all was well. Three months later I underwent surgery to repair the faulty ureter and stitch up the hernia.

I change my one-piece device daily, at shower time in the morning. I place a baby's nappy bag (available in packs of 200 from a supermarket) on the bathroom bench, I use my aerosol spray wipe to remove the device, use commercial wipes (which I cut into four pieces), shave the area in the shower (I am quite hairy), and attach the one-piece before getting dressed.

With all the hospital and recovery time, I have been fortunate to miss less than three months at a time from the golf course. The handicap suffered a bit, but is steadying down now.

**John Watson, Victoria**

.....  
**Dear Editor,**

Thank you to those people who responded to my last contribution on parastomal hernia support (August 2016). As I stated then, I have continued without too much success to make a belt that actually works. It obviously needs more design effort and skill than I have thus far brought to bear on the topic. What I have found to be useful in preventing leaks are those curved shaped patches around the outside edge of my base wafer, together with the 45mm internal seal (ie under the wafer), both from the same manufacturer. In combination these are giving me a more reliable seal and separations and leakages have dropped considerably.

However, I still consider this to be a temporary arrangement and still believe belt manufacturers should be pressed to design a belt that will adequately support parastomal hernias and allow the free flow of waste product. In response to the criticism that a belt with a hole will necessarily cause a stomal prolapse (as STNs believe) I can only say

that this view only allows manufacturers not even to try. I've tried using a belt with a hole with no such problem, and I've got a 44mm stoma.

**Tony Russell, SA**

.....  
**Dear Editor,**

I noted with interest a post by Mr Tony Russell in the April 2016 *Ostomy AUSTRALIA* issue. I not only share the issues that Tony described but have been putting a lot of effort into modifying different support straps to come up with a good working solution. I am happy to report that I finally did it! That is, I have come with a relatively simple but effective modification to the standard elastic strap that does not block stoma output while supporting the surrounding area without tearing.

I am a 54-year-old engineer and for past three years, as a result of a nasty bladder cancer, live with a urostomy. Over the past two years I too have been noticing hardening and expansion of the stoma surrounding area. I have purchased and tried several US made stoma guard products and I have tried a few hernia support garments and straps available on the Stoma Appliance Scheme. Yes, their effect can be at best described as neutral. At the same time the advice from my urologist and stoma nurse is to 'exercise with caution and wear support garments'. So far, so predictable . . . and of course all true.

All this time the engineer in me was determined to find a better solution and I have been tinkering with straps, plastic bottles cut-outs and other materials—and finally I've got it! An elastic strap with a hole that does not tear while providing additional support around the stoma area.

I have been testing the new strap for the past six months in every imaginable condition. It works for me exceptionally well, ticking all the problem areas that ostomates encounter. I feel strongly that it will work for my fellow ostomates.

I have designed and, with the help of my wife, constructed a strap with a hole that is reinforced, and not only holds its shape but provides positive pressure on the parastomal area without stopping the flow. This design is based on two products from the SAS and some parts that we purchase, cut, shape and stitch together.

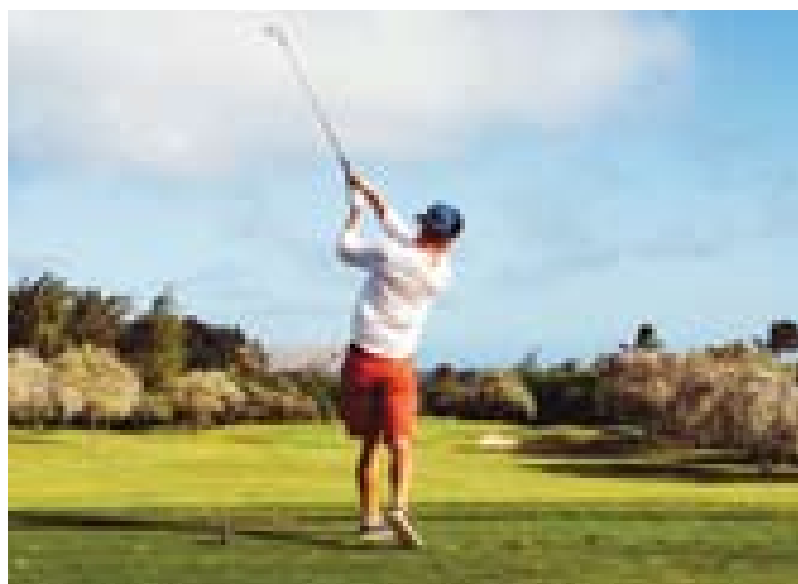
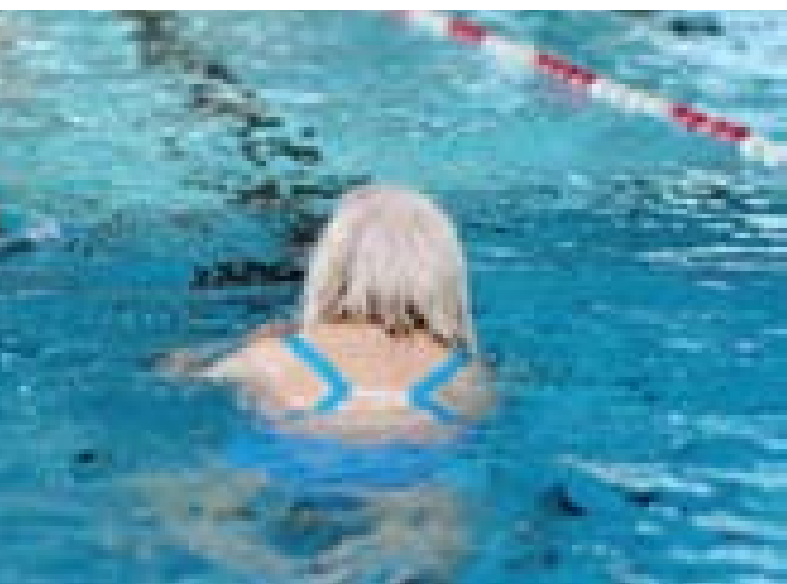
The result is a strap with integrated structure for parastomal support area with a bag cutaway that is further reinforced with a cotton 'rope', stopping tearing of the strap and adding pressure to the appliance baseplate, making it more secure. Making it takes some effort and precision but the result is a significant improvement—something that US stoma apparel makers smugly call 'life-changing'.

**Alec Umansky, Victoria**

*Editor's note: Carmen, our stomal therapy nurse contributor, looks at the question of parastomal hernia support in her column on page 30.*



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# 'Keep a positive attitude and always look forward'

By Tybias Smith

It's coming up 12 months since first being diagnosed with Ulcerative colitis (UC) at a hospital in Belgium. As I write this, I have just been discharged from St Vincent's Public Hospital in Melbourne after the second of three planned surgeries.

My UC story starts after I packed up everything I owned and headed out with just my backpack on another adventure, to Europe this time.

It wasn't long before I started experiencing the quick onset of symptoms of ulcerative colitis. After visiting hospitals in Venice and Paris, at the six-week mark of travelling I found myself in the emergency department of a Belgian hospital, 10kgs down, dehydrated, sick and exhausted. Within a couple of days and after a lot of tests the doctors gave me the answer—it was ulcerative colitis. This was all a bit daunting, with the doctor's response to 'So what is ulcerative colitis?' being, 'Well you have your laptop, you might as well just look it up yourself.'

After two weeks they had got me well enough with medication to be able to fly home, but it wasn't long before the symptoms had returned and I was back in hospital, this time in Mildura. The doctors started IV therapy (Infliximab) and also total parenteral nutrition (TPN) feeding, due to more weight loss. I was flown to St Vincent's Hospital in Melbourne after two weeks. Weighing just on 45kgs, down from 70kgs just three months before the first onset of symptoms, I had doctors in St Vincent's baffled. I was terrified of what would come next. I spent the next four days in intensive care having a horde of doctors and specialists look over me. I spent the next four weeks working with the brilliant team at St Vincent's to get me feeling good, gaining weight and getting back on my feet, and when symptoms subsided I was able to return home.

Within three weeks symptoms came back with a vengeance and everything that the doctors had put in place had failed. While in the ICU, I was on watch for an emergency colectomy, to be left with an ileostomy. At this stage it was the last resort to be sent to theatre and the doctors knew I wasn't in the best state physically and mentally to recover from the operation. But after coming back only three weeks after I had left the hospital, it was decided that we had exhausted all medical options and I was scheduled for surgery to remove my bowel and start the three-step surgical path toward a J-pouch at the end of that week.

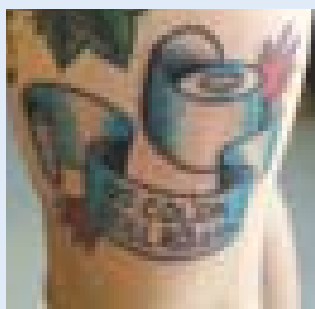
When I came to this fork in the road, the only way I could see to proceed was to embrace the opportunity I had been given



Tybias, right, awarded his jiu-jitsu purple belt, gained since his ileostomy.

and make the most of every situation to come. After surgery and being left with a temporary ileostomy, the next goal was to get back to weight and get back into the Mixed Martial Arts gym. As soon as I could I was moving around and slowly back into kickboxing classes, then slowly working up to getting back into Brazilian jiu-jitsu classes as well. Since the first surgery in October 2015, I have attended three-day camping festivals, spent Christmas in Darwin with my family, got back to working as an electrician for a three-month seasonal seven-days-per-week contract, started a new career training as a barber, spent three weeks island-hopping in Thailand—and have my fitness and body feeling amazing. The key for me is to keep a positive attitude and always look forward, I could have easily stayed at home, felt sorry for myself, complained about life and watched Netflix all day like so many others I've seen on forums online. But I would rather take life by the horns, look forward and not let anything stand in the way of being a better person than I was last year!

I would like to thank everyone at St Vincent's Hospital who helped to save my life, as well as my family, who have been a blessing over the past 12 months.



A new tattoo declares Tybias's positive attitude.

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At the ACSA conference in Adelaide last year, delegates were given a presentation by Kim Chilman-Blair, founder and CEO of Medicine X. She told us that Medicine X produces digital apps that use storytelling to present complex medical information in a way that helps new patients to understand their conditions, and that the company was preparing an app called Colostomy Xplained.

Ostomy Association of Melbourne is always on the lookout for different resources that might be of use to our members so I went to the Medicine X website to see some of the other apps they had produced. They looked interesting—the art was well done and, more importantly, the medical information was fact-checked with professionals working in the field and presented in a way that was easy for a lay person to understand. Each app focused on one patient with the condition and told their story in a frank and engaging way, addressing the fears, confusion and questions they had as they went through diagnosis and treatment.

I made a mental note to check back when Colostomy Xplained was ready to see if it would be something we could promote to our members. In the meantime, I sent an email offering of help if OAM could contribute anything to the project.

Not long after I received an email from Medicine X saying



Robert Saunders - setting a good Xample.

that the person they had lined up to be the case study for Colostomy Xplained had pulled out.

The producers wanted to know if I knew of anybody who matched the criteria and would be willing to be the face of Colostomy Xplained. They were looking for someone who would be able to tell his story, take part in developing the storyboard part of the app and be filmed for the promotional video. Immediately one of our members, Robert Saunders, came to mind—he is kind, articulate,

dedicated to helping ostomates and I knew he would be perfect. All I had to do was talk him into it! Fortunately he agreed to talk to Medicine X and they took it from there. The result is a fantastic app and a great video that will help current and future ostomates understand that they're not alone.

We at OAM are very proud of Robert and what he has achieved in the short time he has been an ostomate. He volunteers at our distribution centre twice a week, has served on our committee and now he is the face of Colostomy Xplained.

You can watch the 'Robert's Story' video on our website, [www.oam.org.au/links.php](http://www.oam.org.au/links.php) and you can download the free Colostomy Xplained digital app featuring Robert's case study at [www.colostomyxplained.com.au](http://www.colostomyxplained.com.au)

Hermione Agee is Assistant Manager at Ostomy Association of Melbourne Inc

## Pathway to a 'new me'

Sometimes, says Debra Walz, "life takes us along unexplained pathways towards a larger goal that even we can't see clearly".

In the case of the Sunshine Coast author, that pathway was defined by the bowel cancer with which she was diagnosed in October 2014, and the six operations that soon followed. One unanticipated result is *A Whole New Me*, Debra's 170-page account of her experiences.

They "taught me a great deal about myself," Debra says, and though she hadn't intended to write a book, family and friends prompted her to tell her story to the wider world. *A Whole New Me* is based on the journal she wrote, initially

for personal reflection only. "I wrote about my feelings, treatment options, surgical procedures and operations and all the things that went along with managing each day of the 12 months following my diagnosis," she says.

Debra notes that many emotions are involved with a cancer diagnosis—"I don't look ill, however there are a multitude of differences in my body now which resonate with other people who have been through a similar experience.

"My book is designed to help people with cancer, their carers, family and friends to understand what is happening—



the internal struggles with acceptance, the feelings of burden upon family and friends, even the level of pain and fatigue. My success and survival has been achieved on many levels, physically, emotionally, spiritually. I adopted a holistic approach to my recovery."

She hopes her book will provide ideas and options for people recovering from chronic or life-threatening illness. "My purpose is to share my story, successes and failures, what worked and what didn't work," she says.

*A Whole New Me* is available in print or as an e-book. More details are available at [www.debrawalz.com](http://www.debrawalz.com)



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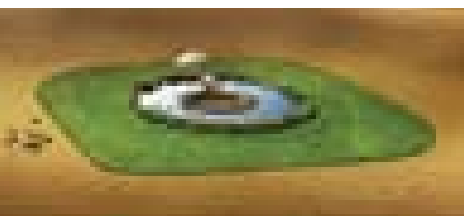
Christopher's story is a common one, with 50% of people with a stoma reporting skin issues around their stoma in their lifetime<sup>1</sup>. At Hollister we believe everyone deserves healthy skin from the start.

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# Australian stoma nurses changing lives in Kenya

By Helen Richards and Sandy Hyde-Smith

**M**ary is a 32-year-old mother of two small children who works part-time as a teacher on a minimal wage. Her husband, a labourer, has no regular work. After weeks of feeling unwell, Mary has been taken to the local hospital with severe abdominal pain and fever. Following emergency surgery she has woken with a cut in her abdomen and an opening (a colostomy) which has faecal fluid leaking on to the bed. She is dazed and confused and drifts in and out of sleep. The nurses have no bags to catch the output. They also do not understand what has happened, so cannot explain things to her. Mary's skin is raw and painful and the smell is overwhelming. There is no support for Mary or her family to understand the situation, no money to pay for the surgery or ongoing supplies. Mary's life has just fallen apart and she spirals into despair . . .

**T**his is a common story in Kenya and in other parts of Africa. Many people require ostomy surgery but lack the support of stomal therapy nurses and have no access to regular supplies of stoma bags. They are resilient yet sad and depressed. They are forced to accept the situation, and invent ways of containing stoma output using whatever is at hand. Sometimes just newspaper, sometimes a binder wrapped around the body, sometimes a cheap plastic bag but without odour control or skin protection. Children with a stoma frequently are ostracised because of the smell and leakage and not allowed to attend school. Nurses too lack skills or knowledge and often consider a stoma as a wound which just keeps leaking.

In Australia, where there are more than 40,000 people with a stoma, there are stomal therapy nurses (STNs) in all major hospitals and in other institutions and regions. In Kenya, with a population of more than 47 million, countless numbers of stomas are created for congenital abnormalities, diseases such as cancer and typhoid, trauma such as rape, motor vehicle accidents, knife and gunshot wounds and pressure injuries. Until 2013

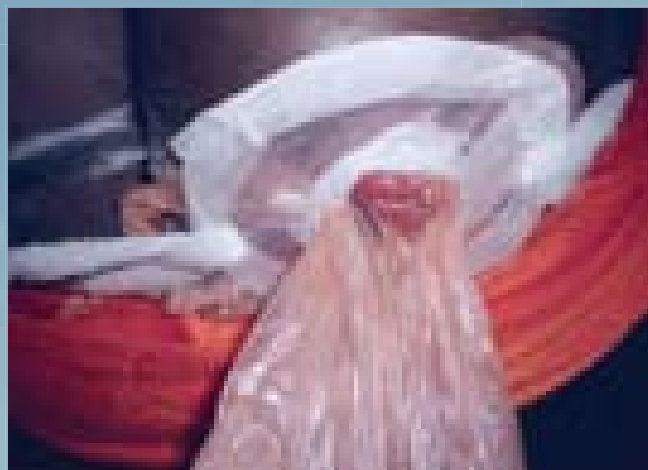
no specialised nurses were available to care for these people.

Now this situation is changing, thanks to the efforts of Australian STNs working in the Australia-Kenya Twinning Project. Already there are passionate, dedicated African nurses with new skills and knowledge who can provide the love, care and information that their patients deserve.

In 2008 staff from the Nairobi Aga Khan University Hospital School of Nursing approached the World Council of Enterostomal Therapists (WCET) for help with stoma care education, at a time when Adelaide STN Elizabeth English was WCET President. Short stoma courses were held in ensuing years but when Elizabeth visited Kenya in 2011, it was obvious that Kenya was ready to establish formalised training. Discussions began to set up the first WCET-recognised stoma, wound and continence nursing education program (SWCNEP) in sub-Saharan Africa.

Boosted by an educational grant of \$US20,000 from ConvaTec, tutor scholarships from WCET, student scholarships from ACSA's Australia Fund, financial support from the Australian Association of Stomal Therapy Nurses (AASTN) and donations from a variety of Australian sources, the Australia-Kenya Twinning Project was set up, supported by AASTN and WCET. Ten STNs from various parts of Australia volunteered their services and in November 2013 the first program began in Nairobi with 18 Kenyan and two Tanzanian students. Those completing the course gain a certificate recognised internationally.

Since its inception the project's main aim has been to set up a sustainable training scheme that can be controlled and conducted by Kenyan nurses. The twinning project planned to train three separate groups of Kenyan nurses in the specialty areas of stoma, wound, continence and professional development.



A makeshift stoma bag, typical of those used when supplies are not available.

Graduates of the first programs would have the opportunity to be mentored as tutors so the program could be sustained once the Australian project was completed. Already 39 registered nurses have completed the first two courses and a further 14 are due to graduate in May 2017. They come from all over Kenya, with two from Tanzania, and one each from Togo and Botswana.

Over the past three years 16 Australian STNs have volunteered: six original team-members are still involved.

Graduates of the Kenyan programs now have the official title of Stoma Wound and Continence Nurse (SWCN) to recognise the span of their knowledge. Those who wish to become tutors have been nick-named 'the KT's' (Kenyan tutors) to differentiate them from the Australian tutors. Currently 18 KT's from the first two programs are being mentored in an advanced program with master classes planned for 2017. These nurses are the future of stoma care in sub-Saharan Africa and will advance the stoma, wound and continence nursing when the twinning project ends in May 2017.

To attend the mentorship program, KT's from remote areas have to travel long distances by bus and stay in Nairobi for the nine weeks of the course. To support KT's, especially those from remote areas who may spend 13 hours on a bus to Nairobi on hazardous roads, the Merle Boeree Memorial Scholarship has been set up. Merle Boeree was a passionate STN from Adelaide who cared for many

patients and trained many nurses. She was involved in the initial planning for the Kenyan project but sadly was too sick to attend and died in 2014. Her loving spirit lives on with these beautiful Kenyan nurses who can already see the difference they are making in the lives of their patients.

The twinning project would not have succeeded without Australian STNs giving their time and expertise free of charge—but a venture such as this needs finance. Ongoing fundraising is needed to support the existing and future programs. More educational aids and text books will be needed, as well as funds for safe accommodation and travel costs.

Australian team members have been passionate about fundraising. They have distributed 'loose change' money boxes, written letters, held talks, spoken at meetings, asked industry for educational material, sold cakes, jam and other items all to boost funds. They sincerely thank the AASTN for donating the proceeds of its last conference, the Aga Khan Hospital for funding remote Kenyan nurses, and all other contributors. But to complete the dream and to help many more patients, the program is seeking support from those who know how life-changing this experience can be. Many small contributions help us to make a big difference, not just to the patients we see in Kenya, but to the nation's infrastructure. Contributions go directly

to an educational training program that directly touches many people.



Author Helen Richards with some of her African students.

If you would like to support new students, tutors and the program's general costs, log in to the internet with the code [gofundme.com/8jx3jde4](https://gofundme.com/8jx3jde4) If you would like to contribute to the Merle Boeree fund to support Kenyan tutors, please log on with the code [gofundme.com/2gnupk98](https://gofundme.com/2gnupk98)

More detailed information can be found on both these links or by contacting the authors.

The Australian team thanks ACSA's Australia Fund for sending donated products to ostomy support groups to ensure that the poor patients in Kenya and other developing countries can continue to access free products. Many patients are so poor that they don't even have a spare 100 Kenya shillings (\$1) to feed themselves or the family, let alone cope with medical expenses.

If you as an ostomate would like to correspond directly with a Kenyan ostomate, please email [eenglish@bigpond.com](mailto:eenglish@bigpond.com) This is another personalised project we would like to develop.

**D**ay 5 after surgery, Mary is isolated in her bed. Devastated and ostracised, she cannot know how her life will progress. Other patients hold their noses and keep their distance. Amina, the newly trained Kenyan SWCN, returns to work after her days off and knows she can make a difference. She approaches Mary with compassion and understanding. Mary is washed and cleaned and Amina explains and teaches stoma bag application. For the first time since surgery there is no odour, Mary's skin is protected and her dignity maintained. Amina sits and holds her hand. She explains the surgery and provides stoma bags for ongoing care. She also links Mary to the local support group where donated bags can be obtained and there is information about purchasing bags if she can afford them. Amina arranges to speak with Mary's husband and family to allay their anxiety and answer questions about daily routines and, with Mary's permission, intimate aspects of life. She also gives Mary the opportunity to talk with another ostomate so positive experiences can be exchanged. For the first time since her surgery, Mary has the desire to continue life, knowing that her situation can be managed and that a stoma has saved and not ruined her future. Amina's training has made a tangible difference in a situation that would otherwise have held little hope.

We are making a difference. Nobody chooses the life they are born to, and the situations that arise from that. However, we can help with knowledge and education, and with a passion to make a difference. This is why we go back.

Any contribution to help our work, no matter how small, will touch a life in a tangible way.

The authors, Helen Richards, STN, Wollongong Private Hospital, NSW, and Sandy Hyde-Smith, STN, Melbourne, Victoria, are members of the Australian Stomal Therapy Nurses Kenyan Team.



Vicki Patton, an original member of the Australian team, training two nurses in Kenya.

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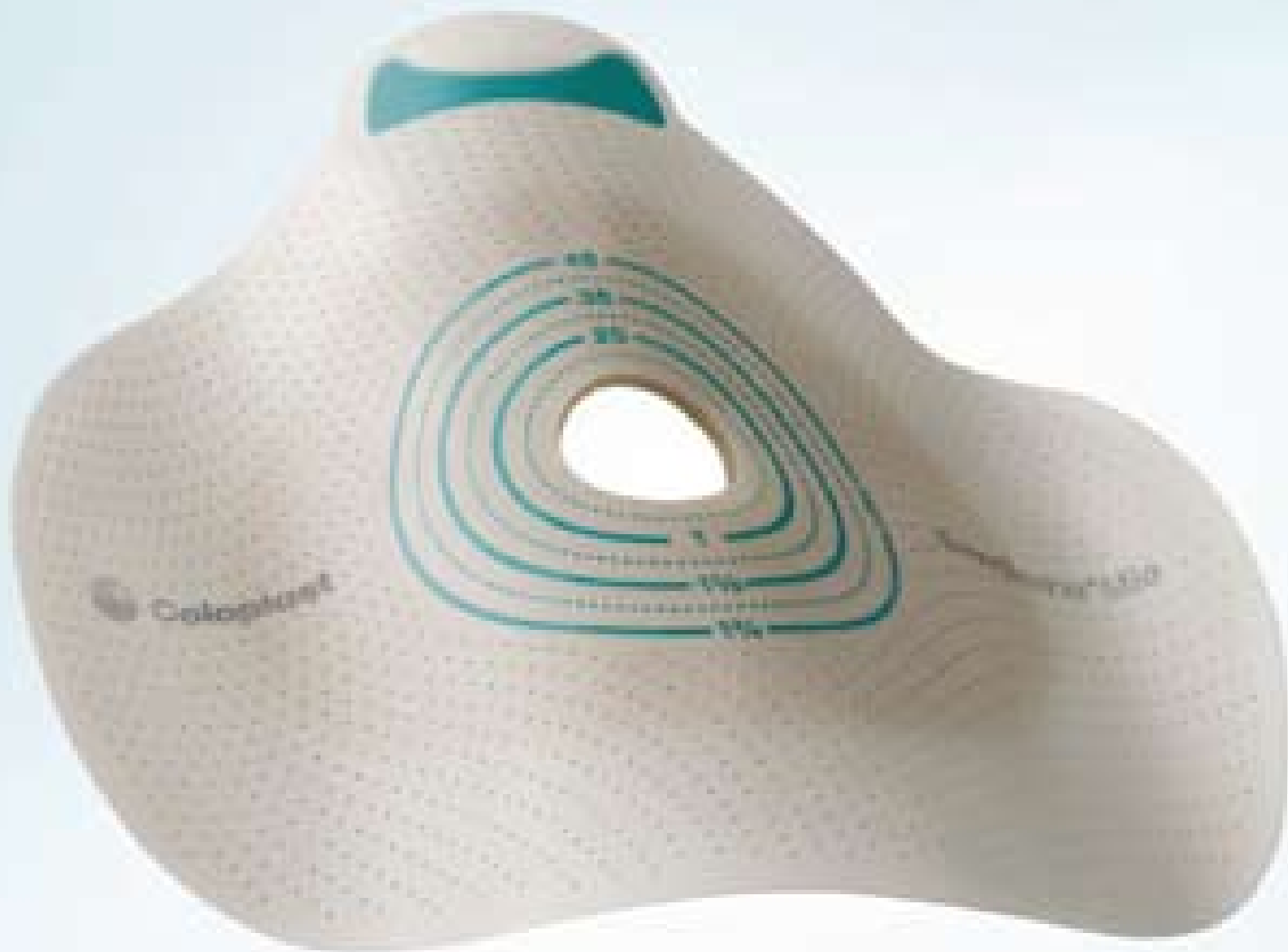
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***An emergency during a holiday in India left Udesh Kumar with a temporary ileostomy - an experience that brought lessons worth sharing.***

I am a senior citizen, 71 years of age, of Indian origin, living with my wife and children in a south-eastern suburb of Melbourne. While on a holiday to India last year I happened to develop sudden profuse rectal bleeding, so much so that I lost about a litre of blood within the span of an hour!!

I immediately rushed to a well-regarded hospital in Delhi where they performed both a colonoscopy and upper endoscopy procedure but could not identify the source of the bleeding. I had lost almost half of my body's blood—about three litres—before the doctors concluded that I was bleeding from my small intestine and diagnosed my condition as angio-dysplasia, an uncommon disease leading to massive multipore bleeding from a section of the intestines.

I was rushed to the operating theatre where they removed about a metre of my small intestine and half of my colon—the bleeding region—a procedure termed a right hemi-colectomy with double-barrel stoma. However, God's will and my gastrointestinal surgeon's skill saved my life, despite all odds and so much of blood loss. A stoma bag was then placed on my abdomen.

As luck would have it, within a week, while still in hospital, I developed a cardiac problem, probably triggered by my recent blood loss! After my condition somewhat stabilized I flew back to Melbourne where I underwent coronary angioplasty. My cardiologist placed two stents in one of my coronary arteries, following a 70–80 percent blockage. He also put me on blood thinners, as a result of which no elective surgery could now be performed on me for the next six months!

That's where the story of my brief encounter with ileostomy begins.

During these six months, from November 2015 to early May 2016, my stoma output was not only watery but quite high, about 1500 mls a day. This required stoma

bags to be drained every two hours or so, day and night.

This was indeed a difficult period when I had to maintain a strict dietary regime to control my stoma output and also maintain a healthy electrolyte balance to prevent any dehydration during the summer months. Stoma bags would start leaking abruptly—sometimes within an hour of fixing them, for no apparent reason.

## MY EXPERIENCE WITH ILEOSTOMY: AN AFFAIR TO REMEMBER

By Udesh Kumar



Here, the advice of my stoma nurses, both at my local hospital and at the Ostomy Association of Melbourne (OAM), was very useful. The dietary controls they suggested helped me to regulate the thickness / viscosity of the stool, although the output continued to be around 1500 mls per day, despite all dietary precautions.

They also experimented with various types of barrier rings before finally identifying one that suited my odd convex-shaped stoma opening, so the bags could stay on for three days at a stretch without leaking. My bags, however, had to be changed in a lying-down position (not standing or sitting) to adhere properly. So my wife had to fix them all the time—God bless her for her patience!

During these few months, I learnt a few things about the ileostomy and how to manage it, which I would like to share with other ostomates in the hope that some of my experiences and counter-measures

will be helpful to others.

- The more the intake, especially fluids, the higher the stoma output, so eat judiciously.
- Chew your food thoroughly. In India we say, chew food 32 times (once for each tooth).
- Consume health foods and avoid junk food. The stoma nurses' advice is very useful here, as they can guide you on what types of food to eat and to avoid, depending on your specific problem.
- Maintain a record of your intake and output. This is important, as each person's response to a food is unique so it becomes easy to establish which food causes a problem.
- Try to educate yourself and research your specific issues on medical websites—this may give you fresh insight.

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- Drinks like coconut water, buttermilk during summer and green tea during winter help to maintain your electrolytes (sodium, potassium, chloride, etc.) and also reduce dependence on hydrating solutions.
- Eating bananas, rice, yoghurt, psyllium husk before each meal help to thicken stoma output.
- Aerated drinks, beer, red wine, wholemeal bread, raw fruits and vegetables are a big no-no if you have a loose bowel action.
- Regular exercise, under the supervision of a physio-therapist, is helpful in preventing muscle loss and reduces the occurrence of body cramps.
- Above all, as far as possible, try to maintain a lifestyle that is as close to what existed before the surgery so you don't regret the unfortunate episode.

Maintaining a positive attitude towards life helps you to achieve a healthy state of mind, which is very important when facing your changed circumstances. In my case,

the practice of yoga and meditation, and socialising with people as before, helped a great deal.

With all these controls and countermeasures, I could maintain a near-normal lifestyle during this period.

Finally, the six-month moratorium was over in early May 2016, the blood thinners were temporarily suspended by my cardiologist, and I underwent the stoma closure surgery successfully.

With God's grace, I have recovered well and came back to my normal life within a few weeks.

I would sincerely like to thank my family members, my surgeon and stoma nurses, whose compassion and care helped me cope with this challenging phase of life. A special thanks to ACSA and OAM and its volunteers for their support. The whole support and care system is so well designed that it takes care of the members' requirements to the last detail. May God bless them all for the good work (read God's work) being done by them! ●

## A key to comfortable travel

*When Debbie Warwick travelled from her home in Queensland to the Blue Mountains in NSW, the trip provided some unexpected discoveries.*

I have been an ostomate for more than a year now—and what a time it has been. In mid-2016 I went to the Jenolan Caves and this experience set me on a whole new learning curve.

Public toilets would have to be the biggest trial I have found. Travelling from Ipswich to the Blue Mountains, a 14-hour drive, led me to a discovery that I wanted to share with other ostomates who might find themselves in the same situation.

Firstly, I now carry a discreet backpack to the toilet that contains skin lotion tissues, disposable waterproof "blues" that you may be able to purchase from your stoma association, spare plastic bags, baby wipes and spare clothes

Secondly, I was told about a most valuable website from which I have since purchased a master key to access

National Public Toilets across Australia. Yes, there is a site where you can purchase a key for \$20 and the website gives you a link to all the available sites for your route.

If I had had this information for my trip, I could have planned my rest stops to coincide with these facilities. It also gives the toilet facilities in towns and cities.

Other ostomates might already know of this but for those who do not, please look it up and I can guarantee that travelling will be made a whole lot easier.

I also discovered that my seat belt caused leakages so I purchased a cheap travel pillow, the type that goes around the neck, and made it into a doughnut that sat on top of my ileostomy site. This cushioned it from pressure caused by the seat belt.

As well, I have learnt that your stomal therapy nurse can organise a travel certificate that you can present at airports and security terminals. It has your personal details and explains that you have had a surgical procedure that has created a stoma. It also has other

important information that outlines your circumstances.

To apply for a master key to Australian National Public Toilets, the web site is: [www.masterlocksmiths.com.au/mlak.php](http://www.masterlocksmiths.com.au/mlak.php)

The site with information on toilet facilities around Australia is: [toiletmap.gov.au](http://toiletmap.gov.au)

When you log into this site, you register and then access the information you require. If you have an iPhone, you can also get the free National Public Toilet Map app.

I have found this information invaluable when travelling. Knowing the simplest things has helped me maintain my dignity and sanity when travelling.

I have more travel planned, so I am sure that I will find a lot more experiences that I have not yet faced. Stay tuned! ●





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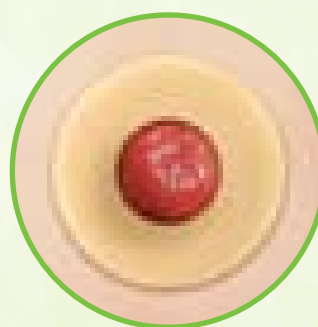
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# I'm proud of my bag

By Josie, 15, from Victoria

'Not again,' I groaned. At 11 years old, I was at school when I tried to make a run for the toilet. But before I could, I lost control of my bowels. Born more than four weeks premature, my parents Evelyn, 39, and Anthony, 40, became concerned when I'd go for up to 16 days without doing a number two. 'Don't worry she's just got lazy bowels,' the nurse assured them.

But by the time I was two, they secured an appointment with a gastroenterologist. A biopsy revealed I had an abnormally large bowel. 'It's likely the cause of her premature birth,' the doctor said. 'There isn't much we can do.'

From then I started a vicious cycle of laxatives, doctors' appointments and constant stomach pain. When I was 11, Mum received the call that I'd had an accident at school. I hadn't told her it had been going on for months. Instead I'd been throwing away my underwear and claiming the

dog chewed them off the line. I was so ashamed.

After an emergency appointment I was sent for a test which would evaluate the pressure and reflexes in my bottom. Doctors discovered my sphincter muscles were paper-thin, my brain was also sending signals to squeeze instead of relax. I would get so bloated that nurses would say I looked pregnant. No wonder I was in so much pain!

For the next two years I endured regular Botox injections to my muscles under a general anaesthetic, with limited success. The turning point came when, after months of discussion, doctors agreed to fit me with a colostomy bag. I was thrilled—there was a cure in sight.

In December 2014 I had the surgery. I was amazed. My pain was gone and I could finally take Pilates classes and go horse-riding. I even wore a bikini and showed off my bag. I've never been so happy. I feel free!

## Social media keeps young ostomates in touch

By Lillian Leonard, Treasurer of YOU Inc.

Social media remains the chief source of communication for Young Ostomates United Inc. — the Facebook page is increasingly active. Updates on the YOU webpage include an overview for colostomy irrigation and travel tips for the ostomates who irrigate. This can be viewed at [www.youinc.org.au](http://www.youinc.org.au)

The group's annual general meeting was held in August and the next get-together will be the Christmas luncheon on Saturday, 3 December, at Doncaster Shoppingtown Hotel, Melbourne. The event will begin from 11am. A meeting is planned in February 2017 at the Nurses Memorial Centre, Melbourne. The keynote speaker will be a physiotherapist and the address will be followed by a panel discussion about the social and physiological issues facing young ostomates.

## Book will bring colour to children facing Mitrofanoff procedures

The world is about to get a little bit more colourful for children with complex urological conditions, thanks to a book being produced to help young people undergoing Mitrofanoff procedures.

Lisa Naeher, a stoma/urology clinical practice consultant at the Women's and Children's Hospital in Adelaide, has been awarded the second national Hollister Mitrofanoff Support Australia Scholarship for her project to produce colouring books for children undergoing a Mitrofanoff procedure.

The Mitrofanoff procedure is performed on children and adults who have complex urological conditions. It enables the emptying of the bladder by intermittent catheterisation.

The \$3,000 scholarship, sponsored by Hollister, will enable Lisa to develop a colouring book to help children to relax, understand their bodies, and learn about the surgeries they will undergo and the procedures they will use.

Lisa Naeher said going to hospital could be an overwhelming experience for children and parents.

'The colouring book is being designed to provide simple



Lisa Naeher, left, receives her scholarship cheque from the CEO of Mitrofanoff Support Australia, Janelle Solomon.

information and will be used as a tool to assist children and their parents to understand the procedure and ongoing catheterisation," she said.

"This is a project that I have been keen to get off the ground for a number of years. The Hollister MSA Scholarship will enable the colouring book to be developed and distributed to brighten the lives of children undergoing this procedure."

The chief executive of Mitrofanoff Support Australia, Janelle Solomon, who presented the cheque to Lisa, said the colouring book would fill "a significant gap

in the current resources available for discussing complex urological conditions with children".

"We are thrilled to be involved with this exciting project and we look forward to working with Lisa to make the colouring book available to all children's hospitals and urological specialists in Australia."

Copies of the colouring book will be available from mid-2017 through hospitals, specialists and Mitrofanoff Support Australia's website, [www.mitrofanoffaustralia.org.au](http://www.mitrofanoffaustralia.org.au)

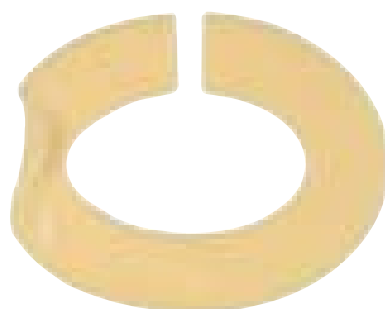
Applications for the 2017 scholarship will open early in 2017. ●

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One of my tasks as the Administration Officer for the Australian Council of Stoma Associations Inc is to answer queries generated through the ACSA website. It always amazes me that a good number of these originate from countries other than Australia, ostomates in the UK and Asia being the most frequent enquirers. Generally, the bulk of these queries relate to requests for support or for information about product availability and reciprocal health care agreements for travellers intending to visit our wonderful country.

In contrast, one of the more common enquiries that I receive from Australian ostomates is, 'I need to use XX product for my stoma but, because it's not on the Stoma Appliance Scheme (SAS) schedule, I have to buy it. It's a stoma-related product that I need to manage my stoma so why can't I be reimbursed for it through the Stoma Appliance Scheme?' The short answer is that, unless a product has been approved for inclusion on the SAS schedule, it is not a subsidised scheme product and therefore will need to be purchased.

Enquiries such as this highlight that, while the range of products listed on the SAS Schedule is incredibly generous and extensive, not every product that may be required or available for use by an ostomate is accessible through the SAS. In fact, considering the plethora of stoma-related products which are available to ostomates internationally, the number and range of stoma products available through the Australian scheme is limited to some extent. So who ultimately decides what is available to Australian ostomates through the scheme, and what is the listing process? Before considering this question, it is essential to understand the framework of the Stoma Appliance Scheme itself.

The scheme is an Australian Government program that helps eligible people living with a stoma to better manage their condition by providing access to a range of subsidised stoma-related products. The scheme began on 1 October 1975 and is legislated under Section 9A of the *National Health Act (1953)*. The scheme is administered by the Department of Health and the Department of Human Services on behalf of the government. The Department of Health has overall policy responsibility for the scheme and manages the SAS schedule which details all stoma-related products which are available through the scheme. The Department of Human Services processes scheme claims and payments and is responsible for registering new participants. To participate in the scheme an eligible person must join one of 22 approved stoma associations and pay an annual fee.

To make a product available under the SAS, the manufacturer or supplier must first apply to list the product on the schedule. To be eligible for consideration, the product must be registered on the Therapeutic Goods Administration (TGA) Australian Register of Therapeutic Goods (where relevant) and must fulfil a clinical need. The application will seek to list the item either as a 'benchmark' product (where an existing 'comparator' is listed on the schedule and the product is no worse than the comparator) or a 'premium' product (where evidence indicates that the product is superior to comparators). The application is submitted to the Department of Health for consideration by the Stoma Products Assessment Panel (SPAP).

This independent technical advice panel is appointed by the department to review applications requesting inclusion on the schedule. The SPAP consists of an independent chair, clinical and economic experts, a consumer representative, a non-voting representative of industry and a non-voting representative from ACSA. The primary role of individual voting members is to apply their skills and experience to consider applications for listing new products. The SPAP considers applications once every financial year.

From its considerations the SPAP will recommend whether a product should be listed on the SAS schedule and, if so, at what price. If the recommendation is positive, the Department of Health will advise the Department of Finance and the Minister for Health and seek approval to make a listing submission to Cabinet. If the listed is approved, it will be included on the next SAS schedule and will be available to SAS participants from that schedule's release date.

Australia's ostomates are fortunate that the Australian Government is prepared to fund the SAS to the tune of almost \$90 million annually. They are also fortunate to have 22 associations that manage the distribution of the products available through the scheme. Those associations continue to rely on support from volunteers to facilitate the distribution process.

The scheme delivers generous benefits. For this to continue, ostomates need to ensure that they restrict use of their use of available products to those that are essential for effective stoma management. Overuse of products on the scheme could lead government to impose more restrictive conditions or reduce benefits.

Please send your questions via email to [feedback@australianstoma.com.au](mailto:feedback@australianstoma.com.au) Alternatively, hard copy submissions may be sent to The Editor, *Ostomy AUSTRALIA*, PO Box 3378, Weston Creek, ACT 2611






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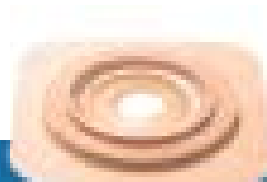
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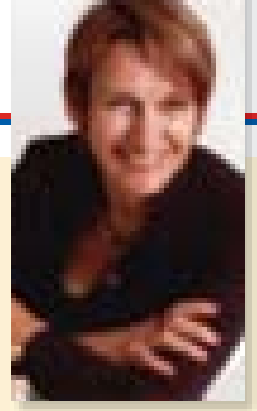
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### Parastomal hernias - cause for caution

Unfortunately parastomal hernias are common occurrences around stomas. To create the stoma the muscle is cut to pull the bowel through. This creates a weakness in the muscle wall which sometimes enlarges. Loops of bowel push through and form the hernia bulge. The larger the hole in the abdominal wall and the weaker the muscle is, the larger the hernia will become. Basically this is a form of 'incisional hernia'.



Supporting the bulge by wearing a stomal support belt may assist in preventing enlargement and may help to reduce the ache and dragging sensation that some people describe. The belt is not meant to constrict but support.

Some people complain that wearing the belt inhibits the flow from their stoma into the stoma appliance. Not wearing the belt quite as tightly should alleviate this, as could using a lubrication substance inside the colostomy bag—this would help the faecal matter to slide down into the bag. It is thought that having a hole in the belt for the bag to protrude through puts a lot of pressure on the area around the stoma and might increase the effect of the muscle weakness, and so make the hernia worse.

For this reason, in Australia none of the stoma support garments available through the Stoma Appliance Scheme have holes made in them.

**Dear Carmen,**

Where do people without a large bowel fit into the topical subject of large bowel microbiome and one's immunity and general health?

**Peter Thimios,** Queensland.

**Dear Peter,**

As you rightly comment, there has been a lot in the media around the role of gut microbiota in whole-body health and immunity.

My understanding is that if you don't have your large bowel (colon) then obviously you won't have the same colonies of healthy microbiota to protect and sustain you. We do know that most people who have their large bowel removed seem to survive and live happy and healthy lives. There is some evidence that taking supplementary probiotics may be helpful in replacing the missing microbiota and maintaining a healthy balance of bacteria, especially for people who have internal ileoanal pouches and are prone to pouchitis. Apart from this I can't really answer your

question. Maybe we should ask our nutritionist, Margaret, what she knows about this area.

**Sincerely, Carmen**



**Dear Carmen,**

Thank you for your advice regarding the yellow pustules on my stoma (*Ostomy AUSTRALIA* April 2016) and many thanks to Margaret Weise for suggesting using silver nitrate to combat this condition (August 2016). I have since used silver nitrate with splendid results. The condition has completely disappeared and, so far, shows no sign of returning. I now accompany each bag change (every three days) with a dab of Betadine around the edge of my stoma, waiting until this dries before using a dry cloth to mop up any moisture/mucus and then applying the bag. The silver nitrate I use is in the form of a gel, comes in a tube and was obtained from eBay under the heading "silver nitrate". I would suggest that care needs to be taken that no gel is applied where the bag has to stick but apart from that its use is straightforward.

**Tony Lanning**

**Thank you, Tony,** for sharing your positive experience with using silver nitrate and Betadine to address your pustules. My concern is still that you would involve a qualified health professional—a stomal therapy nurse—to assess the skin around your stoma and the appropriateness of your current appliance. Most ostomates with a correctly fitting bag will not experience any skin issues and certainly they should not be using strong anti-microbial substances such as Betadine and silver nitrate on their skin indefinitely.

**Sincerely, Carmen**



**Dear Carmen,**

I'd like to ask about treatment, management and long-term prognosis for pre-sacral abscesses, which seem to be a common potential complication from bowel cancer surgery.

I've had a permanent ileostomy for about 11 years and suddenly developed a pre-sacral/para-sacral abscess while overseas recently. This saw me admitted to the emergency unit four days after I returned, with a temperature over 40°C and uncontrollable shakes. Hospital treatment involved insertion of a percutaneous drain for about 10 days, plus intensive antibiotics.

Since discharge from hospital I still have about 10 or 12 uncontrolled leaks a day, some large, some small, through a hole in the bowel wall caused by a rupture

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following reversal of the temporary ileostomy 10 years ago. The surgeons are OK with this situation, and advise there is no easy fix, and that I need to learn to manage the condition. They don't want me on continuous antibiotics. I monitor my temperature daily, just before going to bed, to help understand what the normal range is for me, and hopefully to provide early warning if the situation deteriorates.

However, I don't want to have to deal with continence pads 24/7, and the ever-present risk of a large uncontrolled leak of pus from the abscess, through my anus, for the rest of my days.

Are there any medical professionals who can advise on how to manage or treat pre-sacral abscesses? What is the general prognosis—can they be cured, or do they likely involve the situation I've described for the rest of one's days?

**Bryan, Melbourne.**

**Dear Bryan,**

I would have to say, considering the enormous amount of surgery that is performed in the abdomen and pelvis, that the development of abscesses in this region is pretty low. I have no idea what the statistics are. In your case the abscess developed many years after the surgery and with quite dire consequences for you.

All bowel surgery is 'dirty' surgery. Sometimes there is peritonitis involved—that is, infection in the abdominal cavity with pus or faecal matter in what is meant to be a sterile internal space. Further, foreign bodies in the form of staples and suture material are used and are left holding internal bits together. These can become foci for infection over time.

The usual way for draining these abscesses uses CT (computed tomography) guided insertion of tubes. The purulent fluid is drained away, antibiotics may be used and then everything clears up and most people are not left with a hole leaking pus for the rest of their days. It sounds as if this is what you have had, although it also sounds like the source of your infection has not been adequately dealt with.

I don't know why you had your ileostomy created. It may be that it was for Crohn's disease, and perhaps this event is related to this. I suggest that you seek a second opinion about this situation.

**Sincerely, Carmen**



### **Bendigo's contribution recognised**

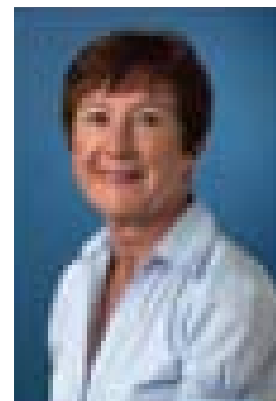
Gold Coast Ostomy Association has pointed out that the article 'Big Developments for PNG Ostomy Association' in the August 2016 edition of *Ostomy AUSTRALIA* mistakenly stated that Bendigo Ostomy Association had donated \$1000 to the PNG Ostomy Association cause.

"Bendigo's valued donation was in fact \$5000," Gold Coast President Warren Rayment says. "We very much regret this unintended oversight and apologise for any confusion it may have caused."

## **A busy time before Christmas**

By **Carmel Boylan**, president, Australian Association of Stomal Therapy Nurses.

By the time you are reading this you will be looking forward to the Christmas festivities and hopefully some time with your families. In Perth that will mean warm weather, which we hanging out for. Despite growing up in Ireland I can say with hand on heart that this has been the coldest winter I remember since moving to WA 30 years ago.



The executive committee had been awaiting developments on the tender for one-piece stoma appliances. In April I wrote to the Minister of Health on behalf of the AASTN to voice our concerns in regard to the potential consequences for the ostomate and the stomal therapy nurses of a reduction in appliance choice. I have received acknowledgement of our letter, and we now know that the government is not going ahead. I acknowledge the work ACSA also undertook in this regard.

The AASTN website ([www.stomaltherapy.com](http://www.stomaltherapy.com)) has been updated with current details of stomal therapy nurse services. It outlines which areas hold an out-patient clinic. I encourage you to access this information should you need to find a stomal therapy nurse in your area. Please remember that all stomal therapy nurses welcome your call and if not in a setting to see you themselves, they can direct you to the appropriate nurse. The website also has a number of educational pamphlets that you may like to read or discuss with your stomal therapy nurse.

Our Queensland colleagues are busy preparing for the National Conference in March 2017.

I don't envy them the workload but look forward to the opportunity to network and learn of new developments in the world of stoma, wound and continence management.

This year the Western Australia Stomal Therapy Nursing Education Program is being run at Curtin University with clinical placements organised by the AASTN (WA). The Graduate Certificate (Wound Ostomy Continence) is divided into two semesters—Advanced Clinical Nursing Science 1 (Acute and Chronic Wounds) and Advanced Clinical Nursing Science 2 (Ostomy and Continence).

Nurses from all across Australia are currently completing the course and it has proven a great success, with enquiries already coming in for next year. Hopefully some of you will get to meet the newly qualified stomal therapy nurses in the near future.

That is all my news for now. I would like to wish you all a Merry Christmas and look forward to catching up in 2017.



➤ Simon, colostomy

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# Salt balance essential for ileostomates

*Margaret Allan is a nutritionist who advises both ostomates and the general public on diet and health-related matters. She is the director of the consultancy Nutrition for Ostomates.*



In the last edition of *Ostomy AUSTRALIA* (August 2016), Sarah from South Australia asked some great questions in the journal's 'Ask Carmen' column. They were initially answered by Carmen and were referred to me for further discussion.

Sarah's first question was whether there are any long-term heart health repercussions for ileostomates consuming a high salt diet. Sarah is young, with a permanent ileostomy, and is concerned that long-term ingestion of salt to replace intestinal losses may affect her arteries and heart function over time. Great question Sarah! Thanks for submitting this to Carmen.

To fully answer this question, I need to provide some background information to set the scene, as follows:

- Salt is made up of 40 per cent sodium and 60 per cent chloride.
- Both sodium and chloride are absorbed by the colon.
- Water is also primarily absorbed by the colon.
- Adaptation of cells in the small intestine after resection of the colon enables some absorption of sodium, chloride and water.
- The kidneys regulate sodium, chloride and water concentrations in the body.

Australian Dietary Guidelines stipulate limiting foods that contain added salt as well as moderate use of salt at the table and in cooking. However, these guidelines are not aimed at people who have had all or part of their colon removed. When the colon is fully intact and absorption of sodium in the intestinal tract is normal, the amount of sodium that is excreted via the kidneys is approximately equal to the amount consumed on a given day, which maintains appropriate blood levels of sodium. When sodium levels in the blood rise from a person consuming salty foods, thirst prompts the person to drink fluids until the sodium-to-water ratio is



restored and blood sodium levels are returned to normal. Then the kidneys excrete both the excess water and excess sodium together to maintain balance in the body.

Salt is made up of both sodium and chloride, and has been linked to high blood pressure and an increased risk of cardiovascular events. However, sodium in salt has some important functions in the body, such as regulating water balance and enabling muscles to contract via generation of nerve impulses. Therefore it is important to ensure that sodium intake is adequate for the body's needs. Lack of sodium can have a negative impact on body function as well, and is referred to as *hyponatraemia*.

Sodium supports water balance by directing where water is stored in the body and how much is excreted via the kidneys. Fluids such as water in the body maintain blood volume, which in turn maintains blood pressure, which is an important indicator of heart health. If blood volume and therefore blood pressure drop to too low a level, signals are released which stimulate the reabsorption of sodium by the kidneys. The kidneys initially filter all the sodium out of the blood, then via precise mechanisms return the exact amount of sodium that the body needs for proper functioning. Water follows sodium, which in turn stimulates water reabsorption by the kidneys as well. This process then restores blood volume and blood pressure to normal.

# abiggerlife.com

**We're here for anyone whose life has been touched by a stoma**

Whether you have a stoma or you're a relative, parent or carer of someone who does, you're not alone.

Lots of other people have been through the same things and asked the same questions. Which is why it's so helpful to have access to an informed, supportive community. And here it is.

## abiggerlife.com

is a free, independent online resource offering professional healthcare advice, a user forum plus lifestyle tips on everything from food and hygiene to routines and relationships.



We do have 'a bigger life' than just having an ostomy.  
Laura Zappulla

### New ostomate

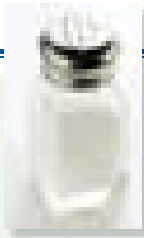


**Casper**

So I am two weeks away from having my survey ileostomy - any advice? What to take to hospital?, recovery - starting to break out!.....

Our members are sharing and learning about their experiences.

**Join in today. [www.abiggerlife.com](http://www.abiggerlife.com)**



Lack of sodium in the blood has few signs or symptoms if it is mild, so there is no immediate evidence when sodium intake is inadequate and blood levels are becoming low. However, if sodium intake is not increased, brain and muscle fatigue, loss of appetite, nausea and abdominal cramps may develop. More serious consequences such as agitation, confusion, impaired mental function and incontinence may result if sodium depletion continues. It can even progress to seizures and coma.

As indicated above, sodium is normally absorbed by the colon; therefore a total colectomy resulting in permanent ileostomy leads to progressive adaptation of the small intestine to take on some of the functions of the colon, such as sodium, chloride and water absorption. However, an adapted small intestine might not absorb these nutrients to the same degree as normal colonic tissue, and the fluid nature of ileostomy output also means that more sodium, chloride and water are lost in this process. Additionally, vomiting and diarrhoea can lead to indiscriminate loss of sodium from the body, and tea, coffee and carbonated drinks can lead to even further sodium excretion. Because sodium is an important nutrient for good health, it is important that sodium intake by ileostomates through salt is sufficient to compensate for these factors and enable appropriate functioning in the body.

Salt depletion from loose and watery output can also lead to dehydration, the signs of which include blurred vision, feeling dizzy or faint, fatigue, unquenchable thirst, dry mouth (indicated by the tongue sticking to the roof of the mouth, or difficulty talking because of dry mucous membranes), headache, pins and needles in the hands and feet, or cramps. If dehydration is not rectified, renal failure may develop.

I have previously written in *Ostomy AUSTRALIA* about the importance of hydration for ostomates: this article is available on my website, **[www.nutritionforostomates.com.au](http://www.nutritionforostomates.com.au)** For ileostomates who are dehydrated, using plain water to increase fluid intake without simultaneously increasing sodium intake can also lead to hyponatraemia. This is why it is advisable to drink oral rehydration solutions that replace electrolytes such as sodium and chloride, rather than drink plain water.

The dietary guideline to limit salt intake therefore is more relevant to urostomates, and colostomates who have had only a small section of their colon removed. Ileostomates, on the other hand, are

advised to use salt liberally in their cooking and at the table, as well as consuming salty foods to ensure sodium concentrations in the body are adequate for optimal functioning.

There is always a risk of going too far and consuming too much salt, which may also have consequences, but there is much less risk of this occurring for ileostomates than for colostomates and urostomates. High sodium intake can lead to calcium excretion, which may affect bone mineral density over the long term. Due to its role in fluid balance, too much sodium in the blood may also cause water retention, which can lead to swelling or oedema and an accompanying rise in blood pressure, resulting in hypertension.

A person may also be more susceptible to increased blood pressure from high salt intake if their parents have high blood pressure, or if the person has kidney disease, diabetes, or is over 50 years of age. People who are overweight also appear to be more sensitive to the effect of salt on blood pressure.

The risk for ileostomates, in particular, is not consuming enough salt to compensate for intestinal losses rather than consuming too much. Drinking oral rehydration solutions when dehydration is developing or blood sodium levels are becoming low is preferable. Colostomates and urostomates, on the other hand, need to be mindful of salt intake to reduce the risk of high blood pressure and cardiovascular events, especially later in life.

So the question is: How do you know if you are consuming too much salt for your body's particular needs and circumstances? One method is monitoring blood sodium levels via a blood test, and the other is to keep an eye on blood pressure to make sure it is not getting too high.

I also recommend ensuring adequate hydration, addressing kidney health to facilitate appropriate retention or excretion of sodium as needed, as well as maintaining a healthy body weight. There are many dietary and supplemental strategies that ostomates can apply to support all these health goals. If you require assistance in achieving any of them, please contact me via my website at **[www.nutritionforostomates.com.au](http://www.nutritionforostomates.com.au)**

Sarah also asked a great question about cholesterol which I will address at a later stage, so stay tuned!

Wishing you good health and happy days,

**Margaret** ●



# National Directory of Ostomy Associations

Please contact your association (from the list below) for all ostomy issues relating to membership, appliance supply and/or *Ostomy AUSTRALIA* journal distribution.

## AUSTRALIAN CAPITAL TERRITORY

### ACT & DISTRICTS STOMA ASSN INC.

Second Floor, ACT City Health Centre,  
1 Moore St, Canberra City, ACT 2600  
Postal Address: GPO Box 1260,  
Canberra City, ACT 2601  
Telephone/Fax: (02) 6205 1055  
Website: [www.actstoma.org.au](http://www.actstoma.org.au)  
Operating hours:  
1st & 2nd week of each month Mon,  
Tues, Wed. 10.00am - 1.00pm  
Office Manager: Rosel Robertson  
Email: [actstoma@alphalink.com.au](mailto:actstoma@alphalink.com.au)  
Secretary: David Ramsay

## NORTHERN TERRITORY

### CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House  
25 Vanderlin Drive, Casuarina  
Postal Address: PO Box 42719,  
Casuarina NT 0811  
Mon to Thurs 8.30am - 2.00pm  
Phone: (08) 8944 1800  
Fax: (08) 8927 4990  
Email: [ostomy@cancernt.org.au](mailto:ostomy@cancernt.org.au)  
Web: <http://nt.cancer.org.au/>

## WESTERN AUSTRALIA

### WA OSTOMY ASSN INC.

15 Guildford Rd, Mount Lawley 6050  
Telephone: (08) 9272 1833  
Fax: (08) 9271 4605  
Enquiries email:  
[waostomy@waostomy.asn.au](mailto:waostomy@waostomy.asn.au)  
Orders Email:  
[orders@waostomy.asn.au](mailto:orders@waostomy.asn.au)  
Operating hours and appliance  
pickup: Mon, Tues, Thurs 9.00am -  
1.00pm  
Secretary: Jess Whitehouse

## NEW SOUTH WALES

### NSW STOMA LIMITED

(formerly *Colostomy Assn of NSW*)  
Unit 5, 7-29 Bridge Road,  
Stanmore 2048  
PO Box 164, Camperdown 1450  
Operating hours: Mon to Thurs  
9.00am - 4.00pm and  
Friday 9.00am - 2.00pm  
Office Manager: Mrs Jenny Kemp  
Secretary: Peter De Luca  
Telephone: 1300 OSTOMY or  
(02) 9565 4315  
Fax: (02) 9565 4317  
Email: [info@NSWstoma.com.au](mailto:info@NSWstoma.com.au)  
Website: [NSWstoma.com.au](http://NSWstoma.com.au)

### OSTOMY NSW LTD

Unit 6, 555 Princes Highway  
Kirrawee NSW 2232  
Postal Address: PO Box 3068  
Kirrawee NSW 2232  
Operating hours: Mon to Thurs  
9.00am - 2.00pm  
Telephone: (02) 9542 1300  
Fax: (02) 9542 1400  
Email: [orders@ostomynsw.org.au](mailto:orders@ostomynsw.org.au)  
Website: [www.ostomynsw.org.au](http://www.ostomynsw.org.au)

## QUEENSLAND

### GOLD COAST OSTOMY ASSN INC.

PO Box 703 Labrador 4215  
8 Dunkirk Close, Arundel 4214  
Telephone: (07) 5594 7633  
Fax: (07) 5571 7481  
Email: [gcoa@bigpond.com](mailto:gcoa@bigpond.com)  
Operating hours:  
Tues & Thurs 9.00am - 3.00pm  
Office Manager: Norm Kelly

### NTH QLD OSTOMY ASSN INC.

Shop 4, 52 French Street, Pimlico  
Telephone/Fax: (07) 4775 2303  
Fax only Mondays & Thursdays  
All correspondence & orders to:  
PO Box 1017  
Hyde Park, Castletown 4812  
Operating hours:  
Monday 9.00am - 4.00pm  
Thursday 9.00am - 3.00pm  
Email: [admin@nqostomy.org.au](mailto:admin@nqostomy.org.au)  
Secretary: Gwenda Williams  
A/H (07) 4775 2303

### QLD OSTOMY ASSN INC.

(formerly *QLD Colostomy Assn*)  
22 Beaudesert Rd, Moorooka 4105  
PO Box 198 Moorooka 4105  
Operating hours: Tues & Thurs  
9.00am - 3.30pm  
Admin (07) 3848 7178  
Fax: (07) 3848 0561  
Email: [admin@qldostomy.org.au](mailto:admin@qldostomy.org.au)  
Web: [www.qldostomy.org](http://www.qldostomy.org)

### QLD STOMA ASSN INC.

Unit 1/10 Valente Close, Chermside  
4032  
Telephone: (07) 3359 7570  
Fax: (07) 3350 1882  
Website: [qldstoma.asn.au](http://qldstoma.asn.au)  
Operating hours: Mon to Thurs -  
8.30am - 2.30pm  
Last Saturday of each month -  
8.30am - 12.30pm  
Closed Fridays and Public Holidays  
Emergency No: (07) 3359 7570  
PO Box 370, Chermside 4032  
Email: [admin@qldstoma.asn.au](mailto:admin@qldstoma.asn.au)

### TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

Education Centre, Blue Care Garden  
Settlement, 256 Stenner Street,  
Toowoomba 4350  
All correspondence to:  
PO Box 7314, Toowoomba MC 4352  
Telephone: (07) 4636 9701  
Fax: (07) 4636 9702  
Operating hours:  
Tues 9.00am - 3.30pm  
Secretary: Bob Schull  
Telephone: 0418 717 199  
Email: [bob.schull@bigpond.com](mailto:bob.schull@bigpond.com)

### WIDE BAY OSTOMATES ASSN INC.

88a Crofton Street, Bundaberg  
West, QLD 4670  
Operating hours: 8.30am - 3.00pm  
Tues, Wed, Thurs.  
Telephone: (07) 4152 4715  
Fax: (07) 4153 5460  
Appliance Officer: Trina McRae  
Email: [wbostomy@bigpond.com](mailto:wbostomy@bigpond.com)

## SOUTH AUSTRALIA

### OSTOMY ASSN OF SA

(formerly *Colostomy Assn of SA*)  
1 Keele Place, Kidman Park 5025  
Telephone: (08) 8235 2727  
Fax: (08) 8355 1073  
Email: [colosa@colostomysa.org.au](mailto:colosa@colostomysa.org.au)  
Website: [www.colostomysa.org.au](http://www.colostomysa.org.au)  
Distribution of supplies: Mon - Fri  
10.30am - 2.30pm  
Secretary: Ruth Horne

### ILEOSTOMY ASSN OF SA INC.

73 Roebuck St. Mile End. SA 5031  
Telephone: (08) 8234 2678  
Fax: (08) 8234 2985  
Office hours: Mon-Fri 10am - 2pm  
Distribution times: Tuesdays  
10am - 2pm, 1st & 3rd Tuesday  
evenings 7pm - 8pm.  
Secretary: Dawn Osborne  
Telephone: (08) 8268 3645  
Email: [ileosto@bigpond.net.au](mailto:ileosto@bigpond.net.au)

## TASMANIA

### OSTOMY TASMANIA INC

Amenities Building,  
St. Johns Park  
St. Johns Avenue, Newtown 7008  
PO Box 280, Moonah 7009  
Telephone: (03) 6228 0799  
Fax: (03) 6228 0744  
Operating hours:  
Mon 9.00am - 3.00pm  
Tues 9.00am - 1.00pm  
Sec/Treas: Sue Hoyle  
Email: [admin@ostomytas.com.au](mailto:admin@ostomytas.com.au)

## VICTORIA

### BENDIGO & DISTRICT OSTOMY ASSN INC.

43-45 Kinross Street, Bendigo 3550  
All correspondence to:  
PO Box 404, Golden Square. 3555  
Ostomy Rooms: (03) 5441 7520  
Fax: (03) 5442 9660  
Operating hours:  
Tues, Wed, Thurs 10.00am - 2.00pm  
and second Tues of each month from  
9.00am - 3.00pm  
Secretary: PO Box 404,  
Golden Square, VIC 3555

### COLOSTOMY ASSN OF VIC.

Suite 221, 2nd Floor, Lift 3,  
Block Arcade, 98 Elizabeth Street  
Melbourne 3000  
Telephone: (03) 9650 1666  
Fax: (03) 9650 4123  
Email: [colostomy@mail2me.com.au](mailto:colostomy@mail2me.com.au)  
Operating hours:  
Monday to Thursday 9.00am -  
2.00pm  
Stomal Therapy Nurse  
Wednesday 9.30am - 2.00pm  
Contact: Kathleen Allan

### GEELONG OSTOMY INC.

6 Lewalan St. Grovedale VIC 3216  
Postal Address: PO Box 1069  
Grovedale VIC 3216  
Telephone: (03) 5243 3664  
Fax: (03) 5243 6335  
Email: [goinc@geelongostomy.com.au](mailto:goinc@geelongostomy.com.au)  
Website: [www.geelongostomy.com.au](http://www.geelongostomy.com.au)  
Operating hours: Monday, Wednesday,  
Friday 9.30am - 2.30pm  
Administrator: Karen McKenzie

### ILEOSTOMY ASSN (VIC) INC.

Suite 322, 3rd Floor, The Block,  
98 -100 Elizabeth Street,  
Melbourne VIC 3000  
PO Box 32, Flinders Lane VIC 8009  
Telephone: (03) 9650 9040  
Fax: (03) 9650 1723  
Email: [ileovic@onestream.com.au](mailto:ileovic@onestream.com.au)  
Web Site: [www.ileostomyvic.org.au](http://www.ileostomyvic.org.au)  
Operating hours:  
Mon. Wed. Fri. only, 9am - 2pm.  
Secretary: Wendy Taylor

### OSTOMY ASSN OF MELBOURNE INC.

Burwood Industrial Park  
Unit 14, 25-37 Huntingdale Rd  
Burwood, VIC 3125  
Telephone: (03) 9888 8523  
Fax: (03) 9888 8094  
Email: [enquiries@oam.org.au](mailto:enquiries@oam.org.au)  
Website: [www.oam.org.au](http://www.oam.org.au)  
Operating hours: Mon to Fri  
9.00am - 4.00pm  
STN by appointment only Tuesdays  
and alternate Thursdays  
9.30am - 2.30pm

### PENINSULA OSTOMY ASSN INC.

12 Allenby Street, Frankston 3199  
Telephone: (03) 9783 6473  
Fax: (03) 9781 4866  
A/H Emergency only: 0417 011 075  
Operating hours:  
Mon & Thurs 10am - 3pm  
Secretary: Alexandra Terdich  
Email: [poainc1@bigpond.com.au](mailto:poainc1@bigpond.com.au)

### VICTORIAN CHILDREN'S OSTOMY ASSN.

Equipment Distribution Centre,  
Royal Children's Hospital,  
Level Basement 2 (green lifts),  
50 Flemington Road,  
Parkville, 3052  
Telephone: (03) 9345 5325  
Fax: (03) 9345 9499  
Operating hours:  
Mon to Fri 8.30am - 4.30pm  
Orders: 24 hours' notice  
Coordinator: Mrs Lilian Damiani

### WARRNAMBOOL & DISTRICT OSTOMY ASSN INC.

279 Koroit St, Warrnambool 3280  
Telephone: (03) 5563 1446  
Fax: (03) 5563 4353  
Email:  
[warrnamboolostomy@swh.net.au](mailto:warrnamboolostomy@swh.net.au)  
Operating hours:  
Friday 12 noon - 4.00pm  
Secretary: Heather Love

# National Directory of Ostomy Support Groups

## NEW SOUTH WALES

### ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec.  
Venue: Hilltop Accommodation Centre,  
600 Keene Street, East Albury NSW  
Contact: Alex Watson 0428 578 385

### BATHURST

Meet on the first Tuesday of March, June, September & December at Daffodil Cottage  
Contact: Louise Linke  
(02) 6330 5676

### BROKEN HILL

Meet: Every 3rd month or as required.  
Venue: Broken Hill Hospital Conference Room.  
Contact: Tarndra (08) 8080 1333

### CENTRAL COAST

Meet: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting. For further information, phone the Stomal Therapy Service on (02) 4320 3323

### COFFS HARBOUR

Meets 2:00pm to 3:30pm  
2016 meeting dates to be advised.  
Venue: Sawtell RSL Club, First Avenue, Sawtell.  
Ostomates & friends welcome.  
Contact Mandy Hawkins STN on (02) 6656 7804

### EUROBODALLA REGION

Meets first Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11am  
Venue: Laughter Room, Moruya Hospital.  
Phone: Betty (02) 4476 2746

### FAR NORTH COAST

Meet at Lismore Workers Club 225 - 231 Keen St. Lismore.  
11.30am - 2.00pm  
1st Saturday March, July, December.  
Contact: Marie: (02) 6686 7248

### FAR SOUTH COAST

Bega & Surrounding Areas  
Meets second Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11.00am at a different venue each time. Flyers are sent to Ostomates 10 days beforehand.  
Inquiries:  
Eileen. Phone: (02) 6492 2530  
Geraldine. Phone: (02) 6492 2366

### GRAFTON & DISTRICT

Meets first Thursday of each month from 9.00am to 11.30am  
Contact: Anne: (02) 6641 8200

### GRIFFITH & DISTRICT

Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)  
Enquiries: Barry (02) 69635267 or 0429 635 267  
Email: ann.bar@bigpond.com  
Karan: 0434 785 309

### HASTINGS MACLEAY

Meet: The Old Hospital at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.  
Inquiries: Neil 0427 856 630 or Glennie (02) 6583 7060

### ILLAWARRA

Meets: 10.00am to 12 noon.  
2016: Wednesdays 17 Feb - 13 Apr - 15 Jun - 17 Aug - 19 Oct - 14 Dec.  
Venue: Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525.  
(Xmas luncheon venue to be advised)  
For further information contact Helen Richards CNC STN (Wollongong Private Hospital) on (02) 4225 5046 (Mondays only) or Julia Kittscha CNC STN (Wollongong Hospital) on 0414 421 021

### MANNING/GREAT LAKES

Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.  
Venue: Skills for Life Building, 5-9 Elizabeth Ave. Taree NSW (wheelchair accessible)  
Website: www.mglostomy.co.cc  
Contact: Karla MacTaggart on (02) 6592 9469

### NEWCASTLE DISTRICT

Meet at 1.30pm on the last Saturday in Feb - May - Aug (AGM) - Nov.  
Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.  
Enquiries: Geoff (02) 4981 1799 or Diane 0409 156 325 or Maree (02) 4971 4351

### ORANGE & DISTRICT

Meet: Mar - June - Sept - Dec From 12 noon.  
Venue: 15 Oliver St, Orange. NSW  
Contacts: Louise: (02) 6330 5676 and Joanne: (02) 6362 6184

### SHOALHAVEN

Meet: 2.00pm. 2016 meeting dates to be advised.  
Venue: Nowra Community Health Centre, 5-7 Lawrence Ave, Nowra.  
Contact: Margaret or Tracey on (02) 4424 6300

### SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).  
2016 meeting dates to be advised. For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

### SYDNEY - PENRITH AREA

Meets: 2.00pm. 2016 meeting dates to be advised.  
Venue: Learning and Development Centre at Nepean Hospital, located behind the multistorey car park in Somerset Street. Entrance via the rear side door.  
Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

### SYDNEY - NORTHERN AREA

Meet: First Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Rd. Wahroonga.  
Contact: San Cancer Support Centre (02) 9487 9061

### TWEED

Meets: third Tuesday of March, June, September and December from 12 to 2pm.  
Venue: South Tweed Sports Club.  
Contact: Jane Bright on 0409 671 162

### WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00am to 11:00am.  
Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga  
Enquiries: David (02) 6971 3346 or 0428 116 084  
Baz (02) 6922 4132

## VICTORIA

### BAIRNSDALE & DISTRICT

Available for people to talk to and for home visits in the local area.  
Contacts: Janine: 0418 854 562  
Derelle: 0448 458 997  
Email: bdosg@hotmail.com

### BENALLA / WANGARATTA

Meets 2.00pm on the third Monday of each second month.  
Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug - Dec and Benalla Masonic Centre, Cnr Benalla St. & Walker St, Benalla in Feb - Jun - Oct.  
Contact: Rex Nankervis (03) 5762 2080  
Email: rexsmarn@bigpond.com

### MILDURA

Meet: Every third month  
Venue: Mildura Base Hospital Conference Room  
Contact: Tarndra (03) 5022 3333 or Norma 0409 252 545

### MOUNT WAVERLEY

Our support/social group meets bi-monthly on the fourth Wednesday; alternately at Mount Waverley Youth Centre or at a local restaurant for a luncheon.  
Contact: Ron Butler on 0403 163 327 or crocite@gmail.com

### SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on (03) 5655 2628 for more information.

### SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre  
Enquiries: Norma Murphy 0409 252 545

### WARRNAMBOOL & DISTRICT

Meets at 10.30am on the second Friday of the month in Feb - Apr - Jun - Aug - Oct - Dec.  
Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool  
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093  
Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

## WESTERN AUSTRALIA

### ALBANY

Meets at Albany Hospice conference room, 9.30am to 11am on the first Friday every three months.  
For details, contact Terry (08) 9847 4701 or 0428 502 530

### GERALDTON

Meets: 2.30pm last Saturday every second month.  
Venue: Bluff Point CWA Rooms  
Contact: Dawn Hall: (08) 9921 8533

### PERTH (WAOA)

Venue: 19 Guildford Road, Mt Lawley  
Weekends: third Saturday of every month 11-1pm.  
General: fourth Tuesday of every month 2 - 4pm.  
New Members: second Tuesday of every month 2 - 4pm.

## QUEENSLAND

### BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre, 10 -18 Mt. Warren Blvd. Mount Warren Park QLD.  
Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107

### BRISBANE

Brisbane Ostomate Support Visitors Service (BOSVS) is a new ostomate visitor service operating in the Greater Brisbane Area.  
Phone: (07) 3359 6500.  
Website: qldstoma.asn.au/bosvs.htm  
Operating Hours: 7 days, 8am to 8pm.  
Operated by Qld Stoma Assn and Qld Ostomy Assn.

### LOGAN

Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre Corner Wembly & Ewing Roads  
Contact: Logan Hospital Stomatherapy Unit, (07) 3299 9107

### MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov).  
Venue: Gordon White Library on Phillip Street, Mt Pleasant.

Contact: Graham Stabler for further information on 0428 776 258 or email: [grahamstabler@bigpond.com](mailto:grahamstabler@bigpond.com)

#### REDCLIFFE

Meets first Tuesday each month at 10.00am in the Shillam Room, Redcliffe Cultural Centre - off car park Irene Street, Redcliffe. Enquiries: Dorothy Douglas (07) 5495 1335

#### ROCKHAMPTON

Meet: 1.30pm third Saturday, Feb - May - Aug - Nov. Venue: Community Health Centre, Bolsover St. Rockhampton Contact: Frank & Marge Noy Phone: (07) 4921 0728

#### SOUTH BURNETT

Meet second Tue. each month at 10am. Venue: Nanango Community Health Centre, Brisbane St. Nanango. QLD Contact: Anne Davoren Phone: (07) 4171 6750

#### SUNSHINE COAST

Meets at the Small Meeting Room, Library Support Building, Cotton Tree, Maroochydore on the second Monday of every month from February 2016, commencing at 10am. Enquiries: Winifred Preston (07) 5476 6313 or [presto1849@hotmail.com](mailto:presto1849@hotmail.com) Evon Fuller (07) 5447 7158 or [eful@bigpond.com](mailto:eful@bigpond.com) Laurie Grimwade (07) 54459008 or [sid.and.laurie@gmail.com](mailto:sid.and.laurie@gmail.com)

#### WIDE BAY

Meets from 1.00pm to 3.00pm on the third Thursday each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West. For information please contact Heather James: 0406 472 486 or leave a message on (07) 4152 4715

#### TASMANIA

"SEMI COLONS" - a support group for men and women impacted by Colorectal cancer. Meets in Hobart on the third Thursday of every month, from 2.00pm to 3.30pm. Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on (03) 6212 5715

#### NORTH & NORTH-WEST

**North:** Meets 10.00am on the first Monday of Mar - Jun - Sep - Dec at the Cancer Support Centre, 69 Howick Street, Launceston. **North-West:** Meets 10.00am on the second Monday of Mar - Jun - Sep - Dec at the Ulverstone Senior Citizens Club, 16 Edwards Street. Contact: Adrian Kok (03) 6326 4664

#### SOUTH AUSTRALIA

##### CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov.

When: 2pm. Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End. Information: Val: (08) 8381 1646

#### FLEURIEU

2016 meeting dates to be advised. Meet: 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor. Please contact Sue McKay STN for further information on 0412 692 418

#### SOUTHERN

Meet: First Wednesday of Feb, April, June, Aug, Oct, Dec. When: 2pm. Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs. Information: Val: (08) 8381 1646

#### NORTHERN TERRITORY

##### DARWIN

Meet: 5.00-6.00pm on the first Tuesday of every month. Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810 Contact: Marg Lavery: (08) 8944 1800

#### YOUTH GROUP

Doris Steyer, Telephone: (02) 4296 5354

#### YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623 Web: [www.youinc.org.au](http://www.youinc.org.au) Email: [helshae@hotmail.com](mailto:helshae@hotmail.com) Facebook: Young Ostomates United

#### BOWEL GROUP FOR KIDS INC

Tel: (02) 4659 6067 or 0431 857 188 Email: [enquiries@bgk.org.au](mailto:enquiries@bgk.org.au) Web: [www.bgk.org.au](http://www.bgk.org.au)

#### PARENTERAL NUTRITION DOWN UNDER

Secretary on (02) 9987 1978 Email: [contactpndu@gmail.com](mailto:contactpndu@gmail.com) Web: [www.parenteral-nutrition-down-under.webs.com](http://www.parenteral-nutrition-down-under.webs.com)

#### MITROFANOFF SUPPORT AUSTRALIA

PO Box 256, South Melbourne, Victoria 3205 Email: [info@mitrofanoffaustralia.org.au](mailto:info@mitrofanoffaustralia.org.au) Web: [www.MitrofanoffAustralia.org.au](http://www.MitrofanoffAustralia.org.au)

## Stoma Appliance Scheme Product Suppliers



#### AinsCorp

PO Box 572, Niddrie, Victoria 3042  
Toll Free Number: 1300 784 737  
Email: [service@ainscorp.com.au](mailto:service@ainscorp.com.au)  
Website: [www.ainscorp.com.au](http://www.ainscorp.com.au)



#### Dansac

PO Box 575, Port Melbourne, Victoria 3207  
Phone: 1800 331 766  
Email: [customerservice@dansac.com.au](mailto:customerservice@dansac.com.au)  
Website: [www.dansac.com.au](http://www.dansac.com.au)



#### Coloplast

PO Box 240 Mt Waverley Vic 3149  
Freecall: 1800 653 317  
Email: [au.care@coloplast.com](mailto:au.care@coloplast.com)  
Website: [www.coloplast.com.au](http://www.coloplast.com.au)



#### ConvaTec

PO Box 63, Mulgrave, Victoria 3170  
Freecall: 1800 335 276  
Email: [connection.au@convatec.com](mailto:connection.au@convatec.com)  
Website: [www.convatec.com.au](http://www.convatec.com.au)



#### Future Environmental Services

PO Box 319, Blairgowrie, Victoria 3942  
Phone: +61 3 5985 2828  
Email: [health@futenv.com.au](mailto:health@futenv.com.au)  
Website: [www.futenv.com.au](http://www.futenv.com.au)



#### Hollister

PO Box 599, Port Melbourne, Victoria 3207  
Freecall: 1800 335 911  
Email: [customerservice@hollister.com.au](mailto:customerservice@hollister.com.au)  
Website: [www.hollister.com/anz/](http://www.hollister.com/anz/)



#### Nice Pak Products

Free call: 1800 506 750  
Email: [healthcare@nicepak.com.au](mailto:healthcare@nicepak.com.au)  
Web: [www.nicepak.com.au](http://www.nicepak.com.au)



#### Omnigon Pty Ltd

PO Box 171, Moonee Ponds, Victoria 3039  
Freecall: 1800 819 274  
Email: [info@omnigon.com.au](mailto:info@omnigon.com.au)  
Website: [www.omnigon.com.au](http://www.omnigon.com.au)



#### 3M Australia

Locked Bag 19, North Ryde NSW 1670  
Phone: 136 136  
Website: [www.3m.com.au](http://www.3m.com.au)



#### Statina Healthcare Australia

3/30 Leighton Place, Hornsby, NSW 2077  
Toll Free Number: 1300 365 404  
Email: [sales@statina.com.au](mailto:sales@statina.com.au)  
Website: [www.statina.com.au](http://www.statina.com.au)



# OSTOMY SEMINAR

FREE PARKING  
 NEAR THE LIGHT RAIL  
 FREE SHUTTLE BUS  
 LOCAL ACCOMMODATION  
 TRADE DISPLAYS  
 LUCKY DOOR PRIZES  
 NURSE ACCREDITATION  
 POINTS WILL APPLY

**SATURDAY 1<sup>ST</sup> APRIL 2017**  
**JOIN US FROM 8AM - 3:30PM**  
**@ SOUTHPORT SHARKS CLUB**  
**CNR MUSGRAVE & OLSEN AVENUES**

MORNING TEA & LUNCH INCLUDED

**\$20 ENTRY**

## MEDICAL PANEL

WE WILL BE HOSTING A MEDICAL PANEL DISCUSSION MID-MORNING WHERE THE EXPERTS WILL ANSWER & DISCUSS YOUR QUESTIONS. OUR EXPERT PANEL IS: MODERATOR PROFESSOR LES BOKEY, UROLOGIST SCOTT MCCLINTOCK, COLORECTAL SURGEON DR ISABELLA MOR, DIRECTOR OF IBD CLINIC GCUH DR JOHN EDWARDS, STN SHERYL WAYE

## GUEST SPEAKERS

ACSA PRESIDENT GEOFF RHODES, COLORECTAL SURGEON PROFESSOR LES BOKEY, FOUNDER OF UGA OF AMERICA KEN AUKETT, COLORECTAL SURGEON DR ISABELLA MOR, CLINICAL NURSE ANN ROBINSON, GCUH PHARMACIST LIZ COOMBS, UROLOGIST SCOTT MCCLINTOCK, PAIN SPECIALIST DR LEIGH DOTCHIN, GASTROENTEROLOGIST GCUH DR JOHN EDWARDS, STN'S SHERYL WAYE AND KARA TORNAY

\*\*\*\*\* BETWEEN 8 & 10PM 10PM ON WEDS. WITH \$20 REGISTRATION FEE \*\*\*\*\*

## REGISTRATION FORM

MAIL TO: JON MACPHAIL - PO BOX 793 LABRADOR QLD 4215  
 8 DUNKERK CLOSE ARUNDEL Q 4214 | gooa@bigpond.com | 07 5584 7633

NAME: \_\_\_\_\_ EMAIL ADDRESS: \_\_\_\_\_

ADDRESS: \_\_\_\_\_ PHONE NUMBER: \_\_\_\_\_

PLEASE TICK YOUR CLASSIFICATION:

- ☐ DOCTOR    ☐ STUDENT  
☐ NURSE    ☐ AMBULANCE  
☐ OSTOMATE    ☐ \_\_\_\_\_

PLEASE INCLUDE YOUR  
 SW REGISTRATION FEE  
 WHICH IS PAYABLE  
 BY CASH, CHEQUE  
 OR CREDIT CARD

☐ CASH    ☐ CHEQUE    ☐ CREDIT CARD

NAME ON CARD: \_\_\_\_\_

CARD NUMBER: \_\_\_\_\_

EXPIRY DATE: \_\_\_\_\_ CCV: \_\_\_\_\_



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