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Australian Council of Stoma Associations Inc
ACSA

2016 ACSA Conference
Canberra 19-22 October

National Directory of Ostomy Associations

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Cover Picture: Visitors enjoying the exhibits at the National Portrait Gallery, Canberra. Photo by Brett Boardman, courtesy of the National Portrait Gallery.

IN THIS ISSUE

Index to Advertisers:

The ACSA Journal "*Ostomy* AUSTRALIA" was established in 1992 through the inaugural sponsorship of ConvaTec Australia. The journal is published three times per year and is available free to every member of an Australian Ostomy Association.

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If you do not wish to receive future advertising, we suggest that when you respond to any advertisement, you tell the company you do not wish to receive future advertising. Most of the companies have assured us that they will comply with your request. If you do have any problems, contact the company concerned or advise the Editor of *Ostomy* AUSTRALIA.

Please take this advice into account when responding to company promotions and competitions.

Consumers of stoma appliances are entitled to lodge a complaint with the Therapeutic Goods Administration if they have concerns regarding the way in which appliances are advertised. Any such complaints should be directed to TGA Complaints Resolution Panel, PO Box 764, North Sydney NSW 2059.

PRESIDENT'S MESSAGE

I started writing this report during the last week of a nine-week holiday in Europe which started in mid-April. This period coincided with the release of the Department of Health tender for products listed in Groups 1, 2 and 3 of the Stoma Appliance Scheme. I am very appreciative of the way in which David Munro and the ACSA Executive team handled the various issues that arose in my absence as a result of the tender.

All of my messages since I became president have noted that the SAS is going to be subject to change and that it is up to us, the ostomates who benefit from the scheme, to manage the way those changes impact us.

I was surprised and horrified that the primary response to the release of the tender was, to quote Chicken Little, "The sky is falling". That response appeared to be led by the suppliers to the scheme who have a vested commercial interest in maintaining the status quo.

The ACSA Executive has recognised that changes to a scheme which costs the government over $85 million a year to support 45,000 ostomates is inevitable. The cost of the scheme has been increasing at a far greater rate than inflation at a time when governments of all political persuasions have been looking for savings.

The government decision to implement a pilot tender for a subset of products on the scheme was taken without consultation with ACSA, nor has that decision been endorsed by the ACSA executive. We didn't know a tender was to be introduced until it was announced in the 2015 Federal Budget. We had no input in selection of Groups 1, 2 and 3 as the pilot products and we had no input into the development and release of the tender.

However, once the tender was published, the executive has engaged with the department to ensure that tender conditions provided an opportunity for suppliers to propose the greatest variety of products. Significant beneficial changes to expand the scope of the tender were a direct result of submissions made by ACSA on behalf of ostomates. The executive has also been engaging with the department to ensure that the tender outcomes, once implemented, are reviewed early and with broad criteria that ensure all impacts on ostomates are identified, analysed and resolved.

At the time I am writing this message the tender outcome will not have been announced. I have no idea which products will have been proposed by suppliers or those that have been selected by the Department of Health Tender Evaluation Panel. What I do know is ostomates will still have access to a range of products in these categories. I also know that any significant gaps in the products available after the tender is finalised will be identified by the ACSA executive.

We will work with the Department of Health and their expert advisors on the Stoma Product Assessment Panel to address all identified gaps and ensure that any issues are resolved. We will be in a position to apply that influence because ACSA has maintained independence from the suppliers' commercial interests and has retained credibility with the government managers of the scheme.

Associations and ostomates need to recognise that change to a 40-year-old scheme is inevitable. Collectively we need to rise to the challenge and work collaboratively with government to explore ways to make the scheme more financially efficient whilst maintaining and expanding the clinical and social benefits to ostomates. That collaboration should also extend to including the scheme's suppliers whilst recognising their commercial interests will not necessarily coincide with those of ostomates or the government that ultimately pays for the appliances they supply.

Finally, I was disappointed that the executive, in my absence, had to respond to a number of accusations that the executive, and I personally, had been involved in establishing the tender concept and had been involved in developing the tender. The executive has always worked to ensure the scheme delivers the best outcomes possible for ostomates.

To date, the Stoma Appliance Scheme has focused entirely on delivery of appliances and accessories to ostomates. The scheme does not cover the clinical support services that are essential to maintain ostomates' health and wellbeing. A number of those support services, including universal access to stomal therapists and nutritionists, are not covered by Medicare or private health funds.

It is possible that ACSA could work with government to use any savings made through a reduction in the cost of appliances to fund universal access to clinical services that are not currently funded by government. The commitment of some associations to fund stomal therapists is a worthy start, but access to their services is not universal.

We have a world-leading program which provides ostomates with universal access to over 2500 appliances and accessories. Perhaps now is the time to ensure ostomates also have universal access to the professional clinical services which will ensure that the appliances they use deliver the best health and quality-of-life outcomes.

Geoff Rhodes PRESIDENT ●

Pioneering Victorian ostomy support group closes

By **Lilian Leonard**

Readers of *Ostomy* AUSTRALIA will be sad to learn that Melbourne's Northern Ostomy Support Group, formerly the PANCH Ostomy Support Group, held its last meeting in April after almost 30 years serving ostomates in the Victorian capital.

It all started in June 1987, when Lilian Leonard, a stomal therapy nurse, hosted a special meeting for people who had undergone ostomy surgery at Preston and Northcote Community Hospital (PANCH) in Melbourne's northern suburbs. This function was held as part of Stomal Therapy Week, which was added to the calendar of health events for the first time that year. This was the start of 11 years of the support group being based at PANCH, with quarterly meetings averaging 30 to 50 members attending. At the time it was the only ostomy support group in Victoria, a pioneer organisation with a wonderful group of ostomates who worked tirelessly and with a passion to offer support with friendship in a relaxed atmosphere. So many wonderful people have contributed to the group. Lilian had formed the Young Ostomy Support Group YOU in 1989, and the two groups shared many happy memories together, always incorporating Stomal Therapy Week in June, hosting a community awareness day incorporating fashion parades, holding an information booth in Bourke Street, and other communal activities. Both PANCH OSG and YOU gave their own special support to each other.

The group moved to the Northern Hospital when PANCH was relocated in February 1998. Location had changed but the values remained the same – "support and friendship". When Lilian moved to East Gippsland, Genevieve Cahir took over the hospital's stomal therapy department. With Genevieve's expert guidance and Joy Walker as president, the group's name changed to the Northern Ostomy Support Group (NOSG). It now met in Preston to assist the elderly members who lived in that area. With the sad passing of Joy Walker in 2010 the group has struggled, despite the best efforts of the treasurer, Peter Farmer. Thus, in April 2016, the NOSG held its final meeting with the group's funds being transferred to YOU Inc. as per the constitution.

Sir Edward (Weary) Dunlop twice was a guest speaker at the PANCH OSG, in 1988 and again in 1991. He enthralled everyone with his stories of his time as a POW in World War II, saving lives by giving prisoners with dysentery lifesaving stomas. Therefore it seemed appropriate for YOU Inc. to donate $500 to the Sir Edward Dunlop Research Foundation in memory of Joy Walker and PANCH OSG.

For me personally the closure of the group felt like losing a dear friend, but to all the wonderful members who were part of this group it was an honour to share these special times with you. How can we forget Cec Sellars, Ivy York, Ted Brown, Thelma Hosking, Shirley Hutcheson, Joseph and Ida Dolinko, Vi Osmond, Heinz God, Vince Capobianco, Margaret and John O'Brien, Don Peckham and Julie Little, just to name a few.

In 1993 Lilian Leonard was awarded an Advance Australia Award for her outstanding contribution in community services, which included the formation of PANCH OSG and Young Ostomates United, which is still a viable self help group for younger ostomates.

●

Drop us a line!

Ostomy AUSTRALIA needs your stories, experiences, helpful hints, etc

Please send your submission in MS-Word or PDF document format via email to:

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Hard copy submissions may be posted to:

The Editor, *Ostomy* AUSTRALIA
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Please ensure that your contribution does not specifically name any doctors or nurses, unless they have agreed in writing to his/her name being published. Refer to them as 'my surgeon' or 'my doctor'.

Similarly, try to avoid specific use of an appliance company's name when it may suggest advertising in articles and letters.

Remember, all contributions must include your name and address. However, if you do not wish your name published, please say so in your letter, and only your initials and State will be printed in the journal.

Electronic copies of this journal and several earlier issues are available to ostomates and others via the ACSA website and internet search engines.

Like to be on the front cover of this journal?

We are keen for the front cover of our journal to better reflect the resilience, achievements and enthusiasm of Australian ostomates – babies and children who are not only cute but brave and resilient; young adults who are coping with rigorous daily routines; older adults who are out there making the most of life.

Readers are invited to send in their digital photos along with a narrative relating to the photo subject.

Photographs must be high-resolution JPEG files and preferably in portrait aspect (i.e. vertical format).

We are unable to use hard-copy photos as scanning does not deliver images with sufficient clarity and sharpness.

Written permission from all people shown in the photos should also be provided.

LETTERS TO THE EDITOR

Dear Editor,

I would like to contribute a few words of encouragement to all ostomates. After suffering ulcerative colitis since age 12, when the only pain reliever given at the time was an Aspro, in 1977, at age 32, immediately after the birth of my second child, I underwent a procto-colecto-ileostomy at Hornsby hospital, from end July to October.

After leaving hospital it didn't take long before it was back to farming, riding, milking, fencing, ploughing, haymaking, challenged by droughts, floods and bushfires, and farm tragedy, which left my girls, my great neighbours and myself to manage a farm for four months. In between, there was caring for children, showing horses, farm produce, cooking, flowers, then more recently professional singing, poetry and song writing, still exhibiting at local shows. I became a counsellor, working in both mental health rehab and disabilities, and have come to the conclusion and firmly believe that each and every one of us, in no matter what circumstances, is able to overcome adversity.

I always looked to my husbands and my parents, and their ancestors, and to others, as to how and by what means they were able to recover from tragic events in their lives, finding that mine paled in significance to theirs.

Some 15 years ago I was diagnosed with Crohn's, recently underwent surgery for obstruction and contracted septicaemia. This was followed by a tumour on heart. That was removed, and at present I'm awaiting surgery for a swollen limb.

Whatever the outcome I feel I have had some wonderful experiences, and what I find heartening to know is that I was born in a country where I have been able to access medical and surgical needs from ostomy associations, and I am deeply indebted to volunteers, staff, the Australian government and taxpayers who supply a great many needs to myself and other ostomates, enabling us to manage our condition and as a result enjoy and full and meaningful life.

A letter of gratitude from ostomates to these organisations and government bodies would surely provide a well-deserved motion of many, many thanks for their efforts in enabling ostomates to live with dignity, whereas in certain other countries this is not the case.

Maree Samways, NSW

Dear Editor,

The letter by Vanessa about Velcro closures [No More Velcro Closures Please, April 2016, Your Say, In Your Own Write] is correct for some brands but it does not apply to the brand I use. I found it impossible to get a clean seal with one brand I used.

Like Vanessa, I have had an ileostomy for many years. At first I used a two-piece appliance with a drainable bag with a clip and no filter. When working in rainforest and nearby cleared areas in the tropics for several years, I didn't change the bag or baseplate for four days, returning home to change them.

I had to change brands because the manufacturer started supplying bags with large holes in them. For several recent years I have used a two-piece appliance with a filter and Velcro fastener, with excellent results.

For the last few months I have been waiting two days (instead of one day) to change about 50 per cent of the bags. The Velcro fastener always provides a perfect seal, despite the fact that the effluent is sometimes not much thicker than water. Filter performance isn't always perfect, but has never been a serious problem. The filter does work better than some other brands I tried.

Jim Skinner, Queensland

Dear Editor,

I have always appreciated the opportunity to read of other people's experiences as they adjust to various circumstances associated with their stomas. Frequently I read of people who have difficulties with Velcro closures on their drainable bags. I thought I must be lucky. I have never had a leakage from the Velcro closure, even when near to explosion level of contents and air. Why? And why do others struggle so?

From the first day I used my Velcro model, I thought I was in heaven—so easy! I took careful note to close it correctly as per the instructions. I can't see any way in which it could leak. Am I lucky?

As for emptying, I open over the toilet bowl, drain, then clear the contents by running my fingers down either side of the bag, finishing off with toilet paper to clean the edge and a little way inside.

Maybe those experiencing difficulties would

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benefit from personal guidance from a stomal therapy nurse if there is one in your area. This could highlight why the problem is occurring. I have found the customer service staff of the product company a great source of information.

Talk to someone – I'm sure they could help.

Isobel Davie, Victoria

Dear Editor,

I write not as an ostomate for over 15 years but as a volunteer for over 12 years.

In the past few years the size of the average order has increased to alarming amounts compared with previous years. This has been more evident in the case of wipes, seals, paste and powders than pouches, with some exceptions.

I use a two-piece system and receive 10 baseplates a month, which I find adequate. We had a customer receiving 60. Before you dream up some scenario to justify this, we received back 250.

Some of the returns defy logic. Three unopened boxes of a popular seal is not unusual. Why people keep ordering when they are on their original order is hoarding. To give an example: if I had continued to order my original supply of wipes I would now have 1000 stockpiled.

One area that is a bad example is the proliferation of support garments. How many people are ordering them without getting professional advice? This could be more hindrance than help.

With the Health Department trying to save money, the rising costs could endanger the whole scheme. Think about it.

Keith McIndoe, Queensland

Dear Editor,

I consider myself a fairly new user of products, as I only had my stoma this year. I do understand all products need good packaging but recently was thrown by the amount on a pair of essentially underwear. They were wrapped as follows: In my box of supply, then in a plastic film, then a sturdy box followed by another plastic bag. I wondered at what cost to the environment and government this came to me. I can't even donate the box a local childcare centre for craft, as I feel funny about children asking what was in the boxes.

Bronwyn Kelleher, Victoria ●

Timely diagnosis important with bowel cancer

There was a need for all Australians to make awareness of bowel cancer symptoms a health priority, and for general practitioners to ensure timely investigations and diagnosis, according to the chief executive of Bowel Cancer Australia, Julien Wiggins.

He was commenting on the results of the My Bowel Cancer… My Voice survey, a national study of people diagnosed with bowel cancer. The results of the study were released by Bowel Cancer Australia in conjunction with Bowel Cancer Awareness Month.

The survey found that although three quarters of respondents had presented to their GP with signs of bowel cancer, one in five felt the symptoms were not taken seriously.

The survey of nearly 300 patients found that:

- nearly one in five respondents—18 per cent—were told their symptoms were related to something else, including irritable bowel syndrome or haemorrhoids;
- some 41 per cent were investigated for another condition before bowel cancer was diagnosed;
- almost one in five—or 19 per cent—felt that they had initially been misdiagnosed;
- a similar number were told they were too young to have bowel cancer;
- and some new mothers were initially told that their symptoms were related to pregnancy.

Mr Wiggins said that timely diagnosis was critical for improved patient outcomes. "We know Australians hold GPs in high regard, however people need to feel confident knowing their symptoms or concerns will be taken seriously," he said.

"We need to reduce the number of repeat GP visits and hospital emergency presentations prior to a bowel cancer diagnosis."

His remarks follow the survey finding that 40 per cent of respondents paid two or more visits to a GP before they were referred to a specialist. Some 9 per cent required five or more visits before they were referred, and 7 per cent presented to a hospital emergency department.

The need for timely intervention was emphasized by Bowel Cancer Australia's director, Associate Professor Graham Newstead AM, a colorectal surgeon.

"It is important to be suspicious of symptoms," he said. "If they are suggestive of bowel cancer, then referral for colonoscopy within four weeks is recommended.

"Our research shows more than half of respondents had late-stage disease at the time of diagnosis, when bowel cancer is more difficult to treat and survival rates begin to sharply decline—50 per cent at stage three and 16 per cent by stage four.

"Nobody knows your body better than you, so be aware of symptoms, act on any changes, and if something still doesn't feel quite right, be persistent until you are confident that bowel cancer has been ruled out. Don't be afraid to seek a second opinion," Professor Newstead said. ●

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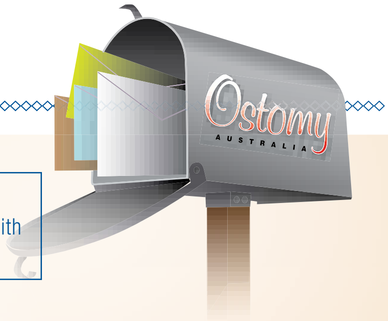

More on parastomal support belts

*Submitted by **Tony Russell**, Adelaide*

Following on from my previous article concerning difficulties with parastomal hernia belts which support the hernia but don't allow a free flow of waste product, I have been contacted by two ostomates who have acknowledged the same problem, and I thank them for their responses.

It would appear that separate manufacturers in both the UK and USA have developed belts which are designed to address the problem and I have gone on line to study their approaches. Both appear to work. The American design in particular is very well thought through, however both are very expensive, the UK one at $A130 and the other $US140. I am not allowed to mention any trade names in this magazine but the US one was developed by a pharmacist, himself an ostomate of course. You may wish to have your STN investigate these products. A further aspect to all this is that of course the belts currently available are free via our association and are paid for by government funding. Given the vast numbers of ostomates in Australia with this problem, surely the government should be approached with a view to adding these belts to the existing allowance. Whose job is it to make this approach ?

On another tack, I have been working with a friend to modify my existing belts along the lines observed in the overseas models and am trialling one at the moment. The main points of design are:

a: where to place the hole, which may vary from person to person;

b: how big does the hole need to be to allow proper fitting of the pouch to the base plate; and

c: how much belt is required around the hole to maintain adequate support for the hernia (the width of the hole comes into this calculation as well).

A properly sized hole also assists with adhesion of the base plate. At first we made the hole too big, forgetting that as you put the belt on, it stretches—and so does the hole! A six-inch-wide belt seems to be the optimum width, allowing about two inches of material above and below the hole; any less and the support strength is lessened. Our work on this continues, but my earlier query remains— "why is this problem not being addressed by our association and suppliers to Australia?"

A related issue is that of ensuring good adhesion, even under pressure from within the appliance. I have found that baseplates can often come loose in the event of a large discharge from the stoma. I am using those adhesive crescent shaped add-ons available through the association with great effect. Half on the edge of the baseplate and half on my skin and the seal is very much better and longer lasting. It solves another of my long standing problems. Ask your STN.

Tony Russell's account of difficulties with his parastomal hernia ("Trouble with Hernias", Your Say/In Your Own Write, *Ostomy* AUSTRALIA April 2016) touched a chord with his fellow ostomates, as the responses in this section show—they provide a resounding answer to Tony's comment that "I can't be the only ostomate with this problem. I would be interested to hear from anyone who reckons they've cracked it".

There are some ingenious approaches designed with the hope of providing support while allowing a stoma to function. This is clearly a matter of concern for more than a few ostomates. But some contributors urge caution; and as we observed in an Editor's Note in the April edition, most stomal therapy nurses in Australia are opposed to cutting holes in hernia belts, since they believe that pressure to the surrounding area may cause a prolapse.

As noted in an earlier journal, "Research indicates that if a hole is cut in the support garment, it will then mimic the situation that caused the hernia in the first place, so it cannot minimise the hernia risk. Hernias may sometimes be forced through the stoma pouch opening in support belts with holes and replicate the original cause of a hernia."

STNs will give their views in forthcoming editions.

EDITOR

• •

Belt changed my life

*Submitted by **Graeme Norton**, Coober Pedy*

I had a similar problem as Tony without the hernias.

I was reading the *Ostomy* AUSTRALIA August 2015 tips and helpful hints, what Bob from the Northern Territory had to share with us, after reading his section I promptly set about to purchase two of the support belts.

After reading Tony's problems I thought maybe the support belt I use might be of help to him.

The belts come from America but what support! They are very comfortable, have an adjustable hook and eye connection, and changed my life in many ways. They are available over the Web.

I can't understand why these belts cannot be made here in Australia.

• •

Continued page 12

Continued from page 10

We are all unique

Submitted by ***Allan Williams****, Queensland*

In response to Tony Russell's letter in April's journal, I also have had a parastomal hernia (left side) for almost three years and have the exact same problems associated with it. How I cope with it may be of help to others. Being a golfer, I wear elasticised support underwear when playing, and they are only worn for the duration of the game, otherwise the same problems that Tony has occur occasionally.

As the ostomate's individual problems are unique to them, I guess that it would be a manufacturer's nightmare to cater for all. I also thought about cutting a reinforced hole in the support underwear, but by all accounts that would only increase the problem. Another thought is to have a bra-like appliance made that would fit under the lower part of the hernia, below the stoma, to support it from the effects of gravity, though attaching it to the body would take some thought.

Regarding the ostomy appliances; I have tried quite a few different types, and only one has been successful so far. It is a two-piece, with the non-drainable pouch adhering to the wafer with the manufacturer's adhesive. I have to doctor the wafer by cutting six small V-shaped slots around the circumference so that it sits neatly around the hernia. The same procedure would also work with a pouch that could be drained.

I have also tried a brand that has these slots already built into the appliance, but they were unsuitable for me. I also use two boomerang-shaped elastic sticky tapes around the circumference of the wafer to stop any occasional leakage that may occur. They cover the slots and adhere to the skin as well. These are also manufactured for that purpose.

Also, I apply one of those ring-shaped seals. This goes on first, before the wafer, as my stoma is rather large (40 mm), and I need to enlarge the hole in the wafer, so I guess my appliance is actually five-piece. The procedure is—ring seal first, followed by the slotted wafer, then the two 'boomerangs', and finally, the pouch. This works for me, and I have had very few problems since using this method. Of course, one must watch what one eats.

……

Will a change help?

Submitted by ***Nancye Turner****, Queensland*

I totally agree with Tony Russell's article 'trouble with hernias'.

Everything you say is true, as I experience the same baseplate leakage with the support belts.

In my next order I am going to try a different brand of hernia underwear, as the ones I have tried cause the same problems as the belts.

Thanks for your informative letter Tony. Let's hope someone listens, as we are not the only ones who have this trouble.

……

Caution is needed

Submitted by ***David Paterson****, Queensland*

Tony Russell's story in relation to hernia support took me back to a story that *Ostomy* AUSTRALIA editor Noel Dillon did back in 2003. Back then I did extensive experiments with hernia support belts.

I agree totally with the editorial comment to Tony that this should be treated with caution. My first attempt was to purchase a commercially made belt from a surgical company in Brisbane.

It was well made and felt really good, however when I arrived home I had a prolapsed stoma, something I'd never experienced before.

This got me thinking and I went on to make my own. The belts that I experimented with had two layers, the first to support the hernia and second to support the stoma itself.

The end product looked or was in fact a bum bag—pardon the pun. I used it for some time. It was useful. It not only gave me support and carried my supplies, it allowed me to go shirt less with confidence.

That's something that I did at that time and I guess worked at that time. I would really caution Tony, and suggest if there is enough desire for such a product then ostomates should pressure manufacturers to design a product that would suit all.

It's really not that straightforward—look at our different shapes ages and life styles.

I am attaching a photograph showing a sample of what I used. In the foreground is a removal liner made from wetsuit material that made washing easier. It's a bit hot and sweaty here in Queensland. ●


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2016 ACSA Conference

The 2016 National Conference of the Australian Council of Stoma Associations will be held in Canberra from 19 to 22 October.

The venue will be the centrally located Canberra Rex Hotel, an establishment with long historic connections with the capital and its political life. The Rex, which has recently received an extensive refurbishment, is located on Northbourne Avenue, about 10 minutes' walk or a short bus ride from the city centre—buses leave from stops within 100 metres of the hotel. It is within easy reach of the popular restaurants and cafes along Mort and Lonsdale Streets, with city-centre shopping a few blocks further on. Major attractions like Parliament House, the art galleries, the National Library and the War Memorial are a short drive or bus trip away.

Conference business will begin with the ACSA executive meeting on **Wednesday, 19 October,** to finalise the agenda for the plenary conference sessions. The first event for most delegates will be the welcome function on **Thursday, 20 October,** to be held in the ballroom from 5pm to 7pm. There delegates will have an opportunity to register for conference, as well as renewing acquaintances and making new contacts.

The conference working sessions will begin at 9am on **Friday, 21 October,** with the annual general meeting. The official opening is set down for 10.15am. Reports, presentations and discussions will occupy the remainder of Friday. Delegates are free to make their own arrangements on Friday evening.

Saturday, 22 October, will be dedicated to the ACSA annual meeting. The morning program will include an address by Professor Ross Hannan, a leading cancer researcher at the Australian National University's John Curtin School of Medical Research. Professor Hannan will talk about cancer—its history from ancient times, its prevalence in modern societies and some of the work being done to combat the disease. The annual conference dinner will be held at the Rex on the Saturday evening.

Those who choose to join the delegates' post-conference day trip on **Sunday, 23 October,** will enjoy a varied program that will begin with a presentation of selected works in the National Portrait Gallery collection by the gallery's Historian, Dr Sarah Engledow. The party will then enjoy a coach tour around some of Canberra's most remarkable embassies before the tour winds up with lunch in the Margaret Whitlam Pavilion at the National Arboretum—a venue that offers splendid views across the city and the southern alps.

Supplier companies have been invited to set up trade stalls for the duration of the conference.

More details are available on the ACT & DSA website, **www.actstoma.org.au** ●

Preliminary program

Wednesday, 19 October
ACSA executive meeting

Thursday, 20 October
5pm: Welcome function

Friday, 21 October
8am: Registrations
9am: Annual General Meeting
10.15am: Official opening
Evening: Free

Saturday, 22 October
9am: Annual Meeting
11am: Address by Professor Ross Hannan, John Curtin School of Medical Research
Evening: Conference dinner

Sunday, 23 October
9am: Delegates' day trip—National Portrait Gallery, embassy tour, lunch at the National Arboretum

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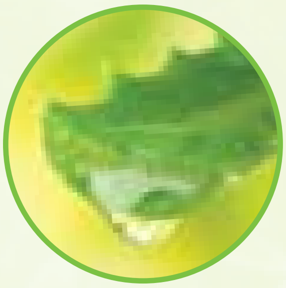

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What happens if I run out of intestine? Do I die?

By Karen Winterbourne

Those were my questions to my gastroenterologist in 2003 following my third unplanned small bowel resection for Crohn's disease (CD) and the diagnosis of Short Bowel Syndrome (SBS). I actually don't remember my gastroenterologist's exact answer, but I do remember being reassured that he had something else up his sleeve should I 'run out of intestine', and life wasn't going to end quite so quickly.

I'd had CD for 13 years at that stage, and it was becoming more aggressive. The start of SBS with this last surgery had its own new challenges, including kidney stones and, at the start, diarrhoea like you wouldn't believe—I just had to think about, or smell, food and I would need to run to the toilet. Dehydration was an issue, too, so there were even more dietary issues.


Karen ready to travel while infusing PN (long haul flights can require infusing in-flight due to dehydration and time of day). The bag of PN and the infusion pump are in the backpack, connected and infusing into Karen's Central Venous Catheter.

Three years on, with severe malnutrition and anorexia, and rampant CD causing incredible pain, I needed more surgery—this time a permanent colostomy. From the doctors' perspective, there was nothing more they could try to postpone more surgery—the CD had gone too far. For me, the main driver for this surgery was relief from pain, so I welcomed it.

No sooner had I had surgery and begun the recovery process than the CD came back again in another location, causing more havoc. I was very poorly and, as a result, the colostomy surgical wound broke down, requiring a much slower recovery. I eventually returned to what was by that stage part-time work, but couldn't stay out of hospital for long. So I was instructed to stop work altogether.

I needed yet another small bowel resection just six months after the colostomy surgery, but without some extra oomph, no-one had much hope of me surviving. It was then that I discovered the 'something else' my gastroenterologist had up his sleeve—parenteral nutrition (PN)! I was put on PN in hospital to prepare for surgery. Parenteral nutrition is food in a liquid form which is delivered via a catheter (tube) into a vein close to the heart when there is a problem with the digestive system. The nutrients are in a bag of sterile solution which is infused through the intravenous catheter. All connections and procedures must be aseptic to minimise infection risk from bacteria entering the bloodstream.

Calories and nutrition!! Exactly what I was needing. I had the surgery, but the result was intestinal failure. I was left with only 20-35cm of small bowel, which means I was never going to be able to absorb sufficient nutrients from food to live. So I was then taught how to infuse PN myself, so that I could do it at home (home parenteral nutrition, or HPN) for 10-11 hours overnight, every night, for the rest of my life.

I admit it was very daunting at first and took a good while to get the hang of it—HPN is a highly complex life-support therapy and there are dangers involved, but it means I'm alive! By God's grace, I've been alive for nearly 10 extra years as a result of HPN and I'm celebrating life! Not only do I have sufficient nutrition, but I've also been incredibly blessed in that the once increasingly aggressive CD, which was close to taking me out, is in remission!

I've also been blessed that, overall, my 10 years colostomy experience has been good. I certainly never want to go back to the level of pain I had before. I did have another CD surgery over four years ago in which they cut off the last bit of large bowel and reformed the stoma in the same site. I've had the usual 'mishaps' that come with a stoma, some CD ulcers, and have annoyingly strong peristalsis which, with a high-output colostomy, causes leakage. All that said, my stoma is a wonderful blessing as I really don't know how I would cope with the high-output diarrhoea if I didn't have it.

On the other hand, life on HPN is pretty extreme. It's not well-known or understood. There are only about 220 adults and children of all ages on HPN across Australia and New Zealand. Short Bowel Syndrome makes up a significant portion of these, but there are also other causes of intestinal failure (IF) requiring HPN, including gastroparesis, chronic intestinal pseudo obstruction, hollow viscous myopathy and many other weird, wonderful and sometimes very rare digestive disorders.


Karen preparing to connect up to PN - sterile procedures are essential.

As *Ostomy* AUSTRALIA and the various stoma support groups dotted around our country offer support for those living with stomas, Parenteral Nutrition Down Under (PNDU) was established seven years ago to specifically support those living with HPN across Australia and New Zealand. I've found PNDU to be a wonderful source of support, friendship and information.

PNDU is celebrating Home Parenteral Nutrition Awareness Week during 7-13 August to help raise awareness and understanding in the community of HPN. If anyone would like to know more about HPN or IF, please visit **www.pndu.org** or **email contactpndu@gmail.com**

The SAS tender – facts and background

By Peter Fuller

The Commonwealth Government's decision to run a competitive tender for one-piece pouches listed under the Stoma Appliance Scheme (SAS) has caused considerable concern to members. The tender project has also been the subject of some misunderstanding, and a considerable amount of misinformation.

This article aims to dispel some misconceptions. It explains what the tender process involves, and what the Australian Council of Stoma Associations' (ACSA) National Executive has done since May 2015, when the government announced that the Department of Health would conduct a pilot competitive tender. In April 2016 the department announced that the tender would apply to three sub-groups of products covered by the SAS. All are one-piece pouches of different types.

At the outset, it is worth making a few specific points:

- The tender is going ahead, though its original timetable has been extended.
- At the time of going to press, no decisions had been taken about what products will be affected, because tenders were still being evaluated.
- Where products are no longer listed under the SAS, the department has given an undertaking that there will be a "reasonable" transition period.
- Products in the six remaining sub-groups, including two-piece pouches, are not affected by the tender and will continue to be available under current arrangements.
- For ostomates and associations, the operation of the SAS will not change.
- The quality of products available is unlikely to fall, given that existing listing regulations will still apply.
- There is no indication that the tender result has been pre-determined. The department has said that it "does not have a target number of suppliers or products for inclusion on the procurement panel".

Why a tender? What will it achieve?

The Request for Tender (RFT) that the Department of Health issued on 6 April this year sets out "to establish a limited panel of suppliers of relevant stoma products (SAS Panel) through a competitive process to provide improved value for money for purchasing of relevant stoma products supplied under the SAS". As such, it is in line with the approach taken by successive governments over recent decades to apply market disciplines to government services and test the market for the most cost-effective outcomes.

The RFT covers one-piece closed and drainable pouches, and one-piece urostomy pouches in sub-groups from SAS groups 1, 2 and 3—the three groups that cover one-piece products. More than 150 different one-piece pouches are currently listed in these three groups. The RFT does not apply to all one-piece products now listed.

The tender process was still under way at the time that this edition of *Ostomy* AUSTRALIA was published. The tender closing date was extended twice, but finally closed on 24 June. At that time it was not known when evaluation would be completed or when the "panel" of successful tenderers—the supplier companies whose products will be listed—would be announced. As a result, there was no indication of what one-piece products would continue to be available, or which companies would supply them. We won't know this until the process is complete.

ACSA's response

ACSA was not consulted about the tender or involved in its development, but since the May 2015 announcement the executive has consistently raised its concerns with the Department of Health about possible impacts on ostomates and associations. The department said those concerns would be considered throughout the tender process.

Where possible affects on ostomates are concerned, ACSA argued that it can take years for an ostomate to find a suitable product, and that being forced to change to something less suitable can have adverse physical, emotional and psychological consequences.

ACSA asked the department to take account of several matters, including the different physical abilities of pouch users, differing sizes and shapes of ostomies and ostomates, the personal challenges of living with an ostomy, the influence of climatic conditions, the capability of carers and availability of expert stomal therapy support. ACSA recommended that, when clinically justified, an ostomate should be able to access suitable products if no successful tendered product was suitable.

It also said the pilot program should use a number of criteria to determine whether the trial had achieved the desired cost efficiencies, including whether its implementation raised costs in other parts of the scheme. ACSA suggested that a transition of at least six months would be required for ostomates needing to change product.

ACSA expressed concern that the project might increase the workload on associations having to deal with changed member requirements, and might also increase cost pressures on them.

ACSA asked the department to make a number of changes to the tender document, including that there be a minimum of two size options for one-piece closed and drainable pouches, and that pouches offer clear or opaque options, or have a viewing window.

The executive also voiced concern that the panel arrangements set out in the RFT would deny SAS participants access to any new improved products for up to six years. On this point the department said on 19 May that suppliers with "new or innovative products with clinical or cost-effective benefits" could apply to have them included in the new arrangement.

More detailed information on the tender process can be found at the ACSA website, **http://www.australianstoma.com.au/images/Summary_Tender_4_June_update.pdf.** The web entry is updated regularly. ●

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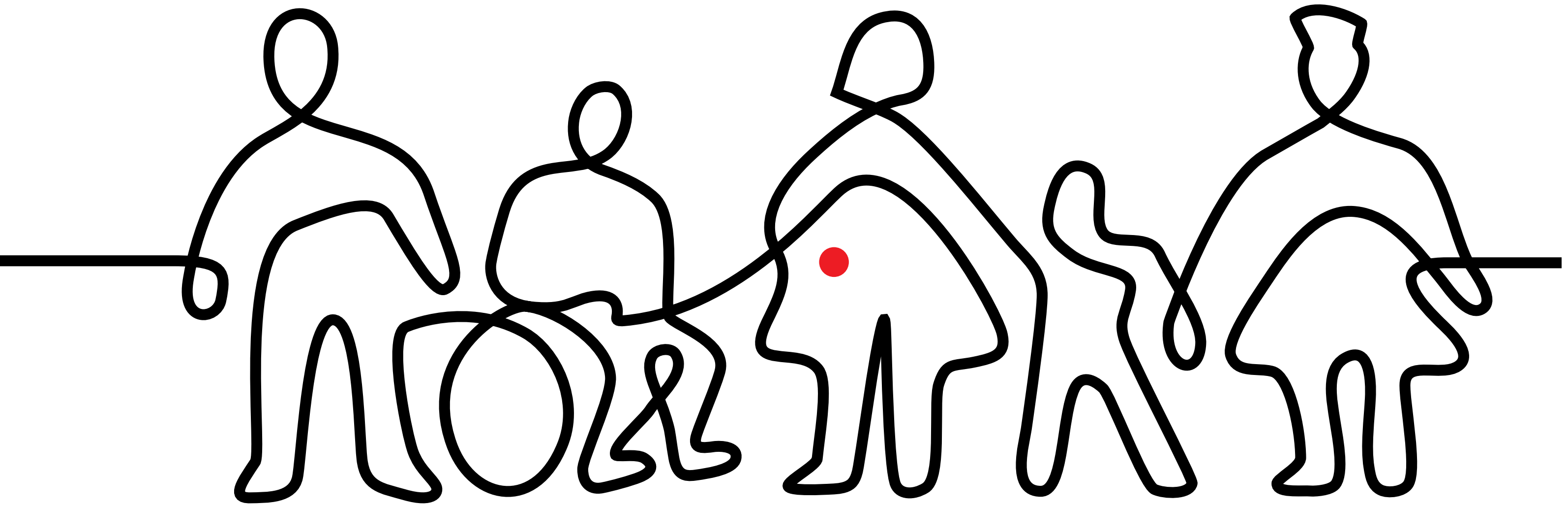
Questions about life with a stoma?



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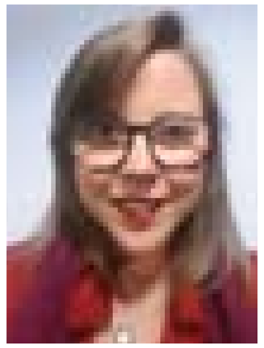
Skin Irritation?

Did you know around 80% of people who have skin irritations do not seek help?[3] Just because you have a stoma it does not mean you have to live with skin irritations.

Call and speak to Karen if you are having issues.



Lifestyle: Travel/Sports/Intimacy?

Having a stoma should not prevent you from living the life that you want. As part of the Coloplast Care program we have information around lifestyle including eating out, travel advice, sports, and general socialising after ostomy surgery.

Call and speak to Courtney if you have any questions.

Sources:
1. Ostomy life study 2014. N=+4000 people with a stoma. UK, DE, NL, FR, IT, BE, SE, AU, JP, US, CA.
2. Coloplast lab test: data on file.
3. Ostomy skin study.

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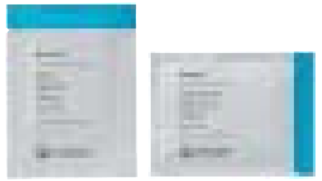

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Ostomy won't stop you from keeping up the pace

By Robin Lisle

After suffering with ulcerative colitis for about four years, and despite numerous treatments, as well as hospitalisations, after some poor pathology results my gastroenterologist said that my situation had become life-threatening and required immediate surgery. An inspection by the surgeon confirmed the poor state of my bowel but he delayed the operation to put me on a course of antibiotics to try to get me into better condition for the operation.

Three weeks later I had a total colectomy. I was 55 years old, working in a job I loved, and had a very supportive wife—our adult children had moved on. My stay in hospital was painful and debilitating, but no worse than for other patients after a major operation. I was given care and attention from the stoma nurse, who made sure that I understood what I needed to do to look after my stoma. She gave me the confidence to leave hospital and fend for myself.

Robin Lisle in the 2016 Canberra Marathon.
Photo: www.Marathon-Photos.com

My recovery from this operation was unremarkable. I handled the new situation reasonably well but had to call on my wife to help when changing my appliance when my stoma was extremely active. My local G.P. became alarmed when, after three weeks of recovery, I was on the roof of my house cleaning gutters. He thought it would be much safer if I returned to work and driving to and from work—a trip of 90 kilometres—rather than being left to my own devices at home. I had six months to allow my bowel to respond to the new situation (I always had a spill-over of inflammation into the small bowel and rectum) before having the ileostomy reversed, if everything was OK. During this time I had two accidents with my bag leaking, one being when carrying a box (light but bulky) against my abdomen. The bag came off, spilling its contents over me and the floor of the shop I was in (ulcerative colitis makes you immune to such minor mishaps).

My corrective surgery came as scheduled, but still with hope that my gut would further improve, and that this would be the end of surgery for me. This time I had an extended stay in hospital because my digestive tract did not want to start operating and medical staff decided to insert a tube into my stomach to relieve the pressure. This horrendous action had an immediate effect: with a 'belly full of stitches' and two nurses holding me up, I threw up all the contents into my bed. This action did not immediately restart my system, but a few days later the stomach pump was no longer needed and I was able to go home. My recovery was more traumatic this time, since instead of a stoma to deal with I had a big hole in my abdomen to treat and heal before I could get back to work.

Life returned to normal after I got back to work, except that I had very regular colonoscopies, as I still had inflammation in the ileum and rectum. After a couple of years of this, it was decided that I could deal with this without anaesthetics, and this was correct, as I felt only mild discomfort during the procedures and I was able to see the samples being taken from the inflamed areas. My pathology results were up and down for about 15 years, but gradually deteriorating.

At 65 years of age, and working as hard as ever, I had an opportunity to take up running. As I was sick of being sick, I picked up the challenge. Having time to focus on myself always made me feel unwell, but being fully occupied by working and training for running events kept me fully occupied. I found it was exhilarating to be up at 4.30am to run before going to work, rain/frost or cold, and having to stop when I was injured made me aware of how important the exercise was to me. Being able to compete at events gave me a lift that is often known as a "runner's high", which lots of people experience. In 2010 I retired from my workplace.

In 2013 my gastro finally said, "This cannot continue, your pathology tests are alarming, don't muck around any longer, see the surgeon immediately." My chance of developing cancer from colitis had reached a critical point, and though at 71 years of age I was not keen to take the next step, eventually I committed to having my rectum removed and a permanent ileostomy in place.

This operation was harder to handle, even though I was superbly fit. My age was now impacting on my recovery, and wellbeing. Another reluctant bowel remained inactive again, forcing me to have the stomach pump treatment again with the same result as previously. I also had a bleed in the middle of the night which the medical staff could not stop, so the surgeon arrived at 1am to get the situation under control. The staff were wonderful through this episode. Two stoma nurses at this hospital cajoled, pushed, pampered, and flattered me enough to be able to leave hospital with the knowledge that they were just a phone call away.

My supportive family were not about to let me rest. A special belt for stoma patients was purchased from the USA to allow me to run again. A month after leaving hospital I saw my surgeon, and then started running again (very slowly). A hundred days after my operation I was able to run 15kms, a short time later I started running at my usual 5km Parkrun event on Saturday mornings. Ten months after surgery I competed in the Sydney Half-Marathon, finishing in less than two hours and third in my age group. I had hoped to do a marathon but other health issues and running injuries dogged me through the next year, and curtailed my activities to one more half-marathon and a number of 5km events. The only part of me not letting me down was my stoma!

I have had issues with my stoma, with little ulcers around the stoma. The stoma therapist has been very supportive and helpful in dealing with this. I have been to the stoma clinic a couple of times and know I have help any time. My wife and I have been travelling extensively for the last 25 years or so, and six months after my operation we planned to accompany our son and his family to South Africa for a big running event in which our son was competing. I had some good advice from various stoma nurses for this six-week trip. Unfortunately shortly after arriving in South Africa, I started having trouble with my bags leaking, and burning of my skin around the stoma. It was due to running, as I had a foot injury and was doing very little running—it had little to do with diet, as I am very fussy with what I eat.

Of course, travelling with two young children made me likely to catch their colds, which I did, with telling effect. The coughing was excruciatingly painful and I now have a hernia. I could hardly wait to see the stoma nurse to sort things out, which she did, very smartly. The stoma had shrunk by at least two sizes, and was withdrawing into the abdomen. Convex bags and smaller openings fixed the leaking and burning—don't worry about the hernia. Pain when coughing has eased with the maturing of the stoma and surrounding area. I have had two leaks in two years with the new bags, both caused when the stoma withdrew inside the abdomen, with difficulties the stoma has in pushing out an obstruction.

A new year, 2016, brought new hope: I was training for another marathon. I had lots of doubts that I could do this, but with the encouragement of family I entered the Canberra Marathon in April. The least of my concerns was my stoma. It has never been an issue running—it is the rest of the body holding together during the training for this 42.195k. event. I was able to complete the event in 4hrs.39min, well inside my goal time, and with few sore spots. Of course I had a couple of issues after running this distance, but none of them related to my stoma. At 74 years I hope to run a few more marathons and continue travelling, as I am not restricted by my ileostomy.

Don't use your stoma as an excuse not to exercise—it is beneficial to nearly everyone. ●

Perth team shows ostomates can beat the limits

By Natasha Batten

The WA Ostomy Association team, from left, Kim Hamilton, Marina Papalia, Natasha Batten, Erin Goodwin, Melissa Gregory, Laine Pileggi and, in front, Kirsty Stringer.

Early on the morning of May 22, 2016 members of the WA Ostomy Association support group participated in an annual event, HBF's "Run for a Reason".

The purpose of this event is to complete a set distance course around Perth, a 4km or 12km walk or run, or a half-marathon. It aims to raise money for and awareness of your chosen charity.

The team was composed of new and not-so-new ostomates, temporary ostomates or former ostomates who recently had reversal surgery.

We were also joined by very supportive family and friends, and even a baby happily pushed in the stroller. The team, appropriately named "Ostomates", completed a 12km walk in just over two hours. The team raised $7963.65 for our chosen charity, Crohn's and Colitis Australia.

Our reason for this run (or walk) was to raise awareness of this illness and to prove that there are no limits with having an ostomy.

Thanks are due to team captains Laine and Melissa for organising the team, and team members Marina, Kirsty, Kim, Erin and Natasha, along with family and friends, for completing this walk, raising money and raising awareness for this important cause. ●

Big developments for PNG Ostomy Association

By Warren Rayment, President, Gold Coast Ostomy Association

The April 2015 issue of *Ostomy* AUSTRALIA highlighted the rather depressing, almost non- existent state of ostomy welfare in Papua New Guinea. The article by Janet Yaki, founder of the PNG Ostomy Association, focused on the dire straits of ostomates who were compelled to resort to 'other things to do the job of ostomy bags as surgical appliances are not readily available in PNG '.

The article pointed out that the majority of ostomates in PNG are from poor communities in rural areas and shanty settlements within urban areas. Janet spoke of the commendable objectives of Janet and the newly created PNG Ostomy Association to alleviate this grim state of affairs and bring about positive change—no easy task in light of the superstition, sorcery, magic and poisoning which pervade PNG society and where sickness is blamed on other people's doing.

The Association's key objective 'is our dream to see that the four regions of PNG will have centres where ostomates can have easy access to their daily ostomy supplies and professional counselling services'.

The awareness, interest and support this exposure generated has been most heartening and has led to some very constructive measures which have helped advance the PNG ostomy cause. In addition, the Gold Coast Ostomy Association's adoption of the PNG Ostomy Association's quest as a project has given the cause momentum.

ACSA member associations have also committed valuable help in the way of providing returned unused appliances, and this has enabled sporadic but substantial deliveries to PNG. A Port Moresby based company, Curtin Bros, has played its part by transporting the goods free of cost via its Townsville division. Financial donations in 2015 from Brisbane ostomate Brian Brent ($5000) Bendigo Ostomy Association ($1000) and the Toowoomba Association ($1000) have enabled new product to be purchased for Janet to distribute. It has also allowed the PNG Association to acquire much-needed office equipment.

Perhaps the most significant development to alleviate the plight of PNG ostomates stemmed from the visit by Gold Coast Ostomy Office Manager Norm Kelly to PNG in late 2015. Norm managed to have fruitful discussions with parliamentary and public officials and also make contact with Greg Neville, the CEO of Matrix Constructions (PNG) Ltd.


Above: Greg Neville.

Greg, a well-known PNG figure, wields useful influence in the local political and social scene. He was taken by the desperate nature of ostomy welfare in PNG and decided to exert pressure where it counts. He also committed valuable corporate help through his company organisation. His welcome and overwhelming intervention has dramatically aided and hastened the PNG Ostomy Association cause. Developments from this and other sources can be summarised as follows:

- Continuing periodic stock deliveries sourced from ACSA member associations.
- New accommodation. Courtesy of his company, Greg has generously provided Janet with a container which is located in the Matrix Constructions compound. It has been painted, air conditioned 24/7, and had shelving installed. A desk and chair have been provided and Janet has a key for round-the-clock access. Donations have allowed the purchase of a printer/ copier and laminator. Janet now has a member history file, member provider forms and a filing cabinet.
- Greg has also committed to provide Janet with a 12-seater bus and driver.
- He is also negotiating with the Prime Minister and Department of Health for the association to set up suitable premises in the main hospital precinct. The premises would contain male and female showers and toilets, an office, a community room and a packing area.
- Plans have been drawn up and there is growing confidence that setting up the premises will be achieved without protracted delay. When the new premises are ready to be occupied and operate, Gold Coast Ostomy intends to send a delegate to assist Janet with the initial set-up.

This crucial support at local level, together with the strong backing of the Gold Coast Ostomy Association and ACSA members, has enabled the fledgling PNG Ostomy Association to make serious inroads into the plight of the country's ostomates over the last two years. Janet's quest is ongoing and we will continue to give her all possible support. ●

Below, inside the new accommodation.


NEW

Jean, still dancing despite a testing life.

By The Reynella Writers, Reynella Neighbourhood Centre.

When using the words courageous, tenacious, inspiring and fastidious, a tiny 94-year-old woman with an infectious smile doesn't usually come to mind. Phyllis Jean Croxton (Hay) is all of those things and more. She has tackled all that life has thrown at her.

Born into a large family in Adelaide in 1921, her first real trauma came when she was just 12 years old. A tragic accident left her with third degree burns to her face, shoulders and upper body, destroying her dreams of continuing with her dancing.

Although she might have felt that her life was over, she continued working hard at school, despite cruel taunts, and then learnt her trade as a seamstress.

After World War II broke out and Jean's brothers all went overseas to fight, she worked for the Red Cross, helping the returned soldiers at the Royal Adelaide Hospital. There she met her future husband, Ron. It was after he returned to active duty that her next trauma would further test her.

At the age of 21 she received the devastating news that she had bowel cancer. This happy, healthy, petite young woman faced an uncertain future.

Jean would be the second-youngest person to have such surgery in Adelaide, but this offered little hope. The first young patient had not survived.

The surgery was successful, but the life she had known changed forever. Unlike today, there was very little help with the emotional struggle she faced. Even after surviving the surgery Jean was given only 18 months to live. Her hopes of becoming a wife and mother seemed a thing of the past. Is it any wonder that life just seemed too hard for her?

Determination came to the fore again. Painstakingly, she learnt how her body worked, and what she could or could not eat, with cleanliness being her main concern. Through trial and error Jean established a program of nutrition and careful management for her digestion. She learnt to care for her own stoma. She diligently irrigated her bowel thrice weekly and then covered her stoma with cotton wool, newspaper and one piece of plastic, (a new invention at the time). There were no bags back then. She still follows this irrigation procedure.

Jean Croxton, whose courage and determination are an inspiration to ostomates.

Together with her returned-soldier husband, whom she married in 1945, Jean raised the daughter of her sister Alma, who had died during childbirth. Life since has been a series of small achievable goals—watching baby Frances grow, seeing her start school, finish school, get a job, get married and have her own children.

One notable highlight for Jean came in 2000, when she carried the Olympic torch and handed it to Rodney Marsh.

Many things have changed with ostomy procedures now. There is help and support for all who go through it, but Jean has been an inspiration to us. She summed it up when she casually let on that, even at 94, she sometimes dances around the kitchen while cooking her meals.

That says it all. ●

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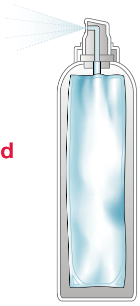

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Ostomy questions and answers

A summary of a discussion with Professor Ian Hayes

Q: What is an ileoanal pouch/J pouch?

A: An ileoanal pouch or a J pouch is a surgical technique that has been around since the 1980s for patients who have had the whole colon and rectum removed for familial polyposis or ulcerative colitis. In this technique the small bowel is joined to the anal sphincter zone and a reservoir or pouch is created as part of it to perform a similar function to the rectum. If the technique works well, the patient would use their bowels four to six times a day. However, sometimes the functional outcome is less good.

Q: Why isn't J pouch surgery performed for Crohn's disease?

A: The problem with Crohn's is that the disease can recur in the pouch, which can be a very complex situation.

Q: What causes IBD/inflammatory bowel disease?

A: The cause is unknown at this stage. The disease is an auto-immune disease where the body mounts an immune response against itself.

Q: Where does ulcerative colitis occur?

A: UC is usually confined to just the colon as distinct from Crohn's disease, which occurs anywhere from the mouth to the anus.

Q: Drugs versus surgery for UC?

A: The medical or drug-based treatments for ulcerative colitis have improved greatly and now the mainstay of treatment for UC is drug treatment. Surgery comes into play when a severe emergency happens or if the drugs fail to control the long-term symptoms of the disease or if the lining of the bowel develops pre-cancerous or malignant changes.

Q: Risk of bowel cancer in UC?

A: When UC involves the whole colon for more than 10 years there is a slightly increased risk of abnormal cells or even cancer. That is why we do ongoing colonoscopy screening for patients with long-term UC.

Q: Can you have a temporary ileostomy permanently?

A: Yes, occasionally circumstances arise where it was hoped that a loop ileostomy would be temporary but it ends up remaining long-term.

Q: What is a fistula?

A: A fistula is an abnormal track between two parts of the body. A common example would be anal fistula, which can occur with Crohn's where there is a track between the anal canal and the surrounding skin that leaks pus and mucus. A much more complex example would be an enterocutaneous fistula, where there is an abnormal unplanned track between the gut and the skin of the abdominal wall.

Q: Why can a person who has had an ileostomy for many years for UC develop a fistula around the stoma?

A: This feature would suggest that the condition may actually be Crohn's. This is a rare circumstance and there could be other explanations.

Q: Can Total Parenteral Nutrition (TPN) help when a diseased small bowel is operated on?

A: Sometimes if a person has very low stores of nutrition it may be necessary to use TPN to build up their strength prior to surgery. However this is a rare scenario and would only apply to very sick patients who are unable to absorb enough nutrition through their gut.

Young Ostomates United Inc. Update May 2016

Professor Ian Hayes, a colorectal surgeon at the Royal Melbourne Hospital, was the guest speaker at the Young Ostomates United Inc annual general meeting on 9 April. He was more than happy to answer our many and varied questions, as the accompanying Q & A report shows.

It was pleasing to meet new members, many from our closed Facebook page which now has more than 120 members. YOU Inc. remains a viable support group for young people and children, which is encouraging for the small but hard-working committee. Copies of our financial statement and reports are accessible on our webpage, **www.youinc.org.au** thanks to our IT guru, Mike.

— Lilian Leonard on behalf of the YOU Inc. Committee

Professor Ian Hayes, centre, with members of Young Ostomates United Inc. after his talk on 9 April.

Q: How much small bowel is required to absorb nutrition?

A: Generally it is said that a patient can just about manage with as little as 1 cm of small bowel per KG body weight. Thus an 80 KG person would need at least 80 cm small bowel remaining. Most people in the normal state have two or three metres of small bowel.

Q: Is there an increase in bowel cancer with colitis?

A: With longstanding extensive colitis there is a slight increased risk of bowel cancer.

Q: How much surgery is being performed for IBD?

A: There is less surgery performed than previously because of improved drug treatments. Fewer ileoanal pouches are being done. There is still a role for surgery in treating anal problems such as abscess and fistula. Abdominal surgery is still required for perforation, obstruction, fistula and inflammatory bowel disease not responding to drug treatment.

Q: What types of support are offered to patients with IBD when they need to make a decision about having a stoma?

A: Besides the normal doctor, nurse and stomal therapy services in our public hospital, most of our surgical units do not have any other specific counselling services dedicated to IBD patients. Groups such as YOU have an important role in filling these gaps.

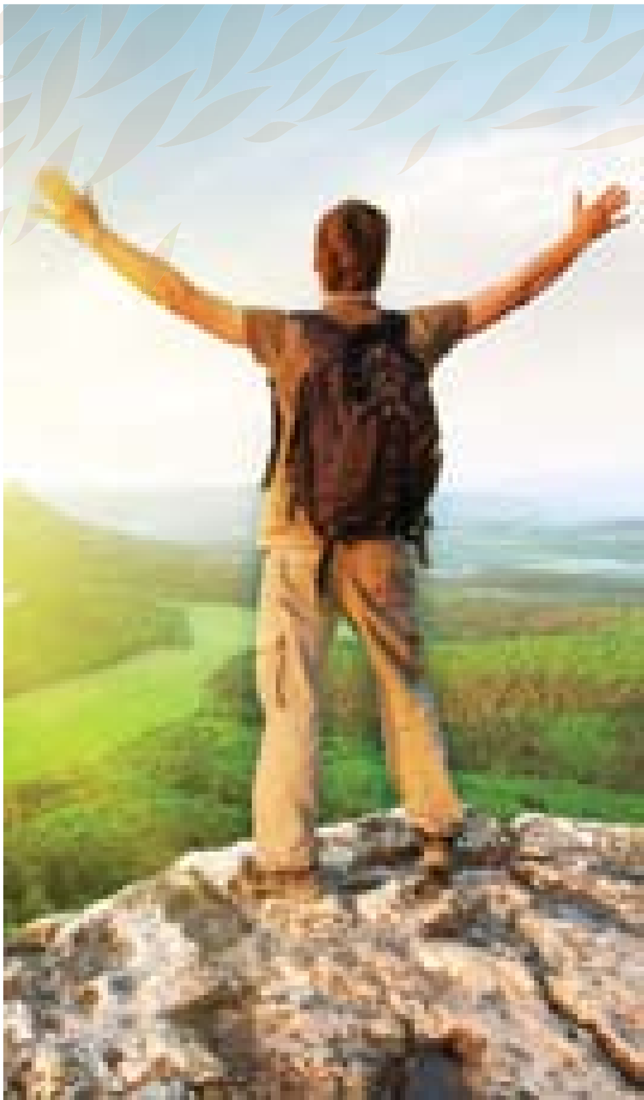
Q: Why is a colostomy given rather than an ileostomy for a slow transit bowel?

A: It is relatively rare for patients to have surgery for slow transit. More often an ileostomy would be used but there are circumstances where a colostomy could be used.

Q: Prior to having surgery for UC/J pouch, what does a young girl need to do to ensure that she can become pregnant? Will she need a caesarean section?

A: It is important to consult an obstetrician on these matters prior to surgery. Often a caesarean would be preferable to avoid injury to the anal sphincters. Often the colorectal surgeon will be asked to be present at the caesarian section to help deal with any bowel adhesions that might be discovered.

Compiled by Professor Ian Hayes with the assistance of Anna Epifanio and Lilian Leonard. ●



“Ask Kylie” A.C.S.A. Administration Officer

MEMBERSHIP FEES – VALUE FOR MONEY

We have reached that time of the year when association membership fees are again due to be paid. The fee for the 2016-2017 financial year is $55 (reduced to $45 on presentation of a valid Centrelink-issued health care or pension card), which represents an increase of $5 on the 2015-16 fee. This increase is consistent with the decision by the Department of Health to approve an increase of $15 in the compulsory Stoma Appliance Scheme service fee to be phased in over a three-year period that began on 1 June 2015. The final phase of the approved increase will apply to membership fees for 2017-18.

During my 16 years of working in an association environment I have often heard members question why a fee needs to be paid to access the Stoma Appliance Scheme (SAS). *“I didn’t choose to have a stoma so why should I have to pay for it?”*, or *“The Stoma Appliance Scheme is an Australian Government program and should be free!”* are both statements that I—and, I am sure, many other association workers—hear time and time again, particularly at this time of the year. It’s appropriate then that we occasionally revisit the subject of association membership fees to see just how they fit into the bigger picture of the scheme, and to remind ourselves just how lucky we are in Australia to have access to such wonderful government support in the shape of our Stoma Appliance Scheme.

According to the Department of Health’s website, during the 2014-15 financial year the SAS cost Australian taxpayers $87,135,682. This figure was an increase of approximately 1.5 per cent on the 2013-2014 cost of the scheme ($85,818,352) and approximately 4.5 per cent on the cost of the scheme in 2012-2013 ($83,342,054). Based on scheme user numbers for those years of 41,866, 41,461 and 40,497 respectively, it can be said that the scheme provides an average of more than $2,000 of ostomy appliance support to every Australian ostomate every year.

To access scheme-funded appliances, an ostomate must submit an order to the Australian stoma association with whom the ostomate is a registered and financial member. In simple terms, the association purchases the appliances from the ostomy appliance supplier, distributes the purchased goods to the member who ordered them and then, either monthly or bi-monthly, submits a consolidated claim to the Department of Health for reimbursement for the cost of those goods plus a 2.75 per cent SAS handling fee. The purpose of the handling fee is to help the association with the cost of administering SAS products on behalf of the Commonwealth government. During the 2015-2015 financial year the combined handling fee paid to our 22 member associations was $2.325 million. The actual combined costs of operating the 22 associations was in excess of $5.2 million.

So how do association membership fees fit into the picture? Well, in 2007 the Department of Health, which is responsible for developing scheme-related policy, recognised that the SAS handling fee paid to associations was not commensurate with the true cost of administering the scheme on the government’s behalf. Therefore, to assist associations with the cost of administering scheme supplies not covered by the 2.75 per cent SAS handling fee, the department introduced a national uniform SAS service fee and stated that this was to be paid to the association from which a member normally obtained their ostomy appliances. The department further stated that the SAS service fee would be compulsory but that financial members of stoma associations would not be required to pay the fee if the association to which they belonged charged the uniform national stoma association membership fee as determined from time to time by a meeting of the ACSA Council. As the national uniform membership fee has aligned with the SAS Service fee since 2007, an increase in the SAS service increases means an increase of the same amount in the national uniform association membership fee.

While this explanation may be confusing to some, the matter of association membership fees really does come down to two key points: First, Australia’s stoma associations rely on the prompt payment of annual membership fees so that they can continue to administer stoma appliances through the Stoma Appliance Scheme on the government’s behalf; and secondly, that paying a nominal membership fee of a maximum of $55 to be able to access more than $2,000 in ostomy appliance support each year really does represent exceptional value for money! ●

Please send your ”Ask Kylie” questions via email to feedback@australianstoma.com.au Alternatively, hard copy submissions may be sent to The Editor, *Ostomy* AUSTRALIA, C/- ACT & Districts Stoma Association GPO Box 1260 Canberra City ACT 2601

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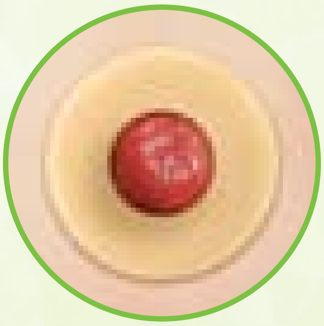

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Ask Carmen

OUR Stomal Therapy Nurse

Dear Carmen,

This is for Carmen as a helpful hint to Tony Lanning and others who may suffer this condition [Ask Carmen, *Ostomy* AUSTRALIA, April 2016].

I have had my stoma for almost ten years now and suffer from the condition described. Over time I get more and more of these yellow lumps that look like pus blisters and my bleeding becomes heavier when I do a clean up. All this happens gradually. After about a year of this I took myself off to the stomal therapy nurse. She cauterised the blisters with silver nitrate. They disappeared and the bleeding ceased.

Since then I have had to go every 12 months to her for this treatment as gradually the yellow lumps reappear and the bleeding gets heavier. For a few months I am free of the problem but it always returns. Silver nitrate is the best treatment I know of.

Good luck to Tony as these things are unsightly and worrying.

Regards, Margaret Weise

Thank you Margaret for sharing your experience.

Usually silver nitrate is reserved for the treating of granulomas, i.e. small red bumps on the stoma or on the skin immediately around the stoma and hypergranulation tissue/proud flesh in a wound.

However, one of the amazing features of silver is that it is a very strong anti-microbial—in other words it kills a variety of bacteria instantly.

I suspect the yellow pustules are not hypergranulation tissue but tiny foci of infection possibly around hair follicles and the treatment with the silver kills the bacteria and dries up the individual spots.

I suggest you try and work out with your stomal therapy nurse if there is something you can do to prevent the little pustules so that you don't need to resort to treatment.

Sincerely, Carmen

Dear Carmen,

I have an ileostomy, which is permanent, and have had so since I was 17. I am now only 23. From day one I've been told to consume salty foods or add salt to foods for all the various reasons, which I've been doing.

However, I actually haven't even thought of it until now—but are there any implications in doing this for the rest of my life? Obviously ostomates can lose salt/fluids more easily, but will replacing it have implications for my arteries, heart or cholesterol? Being young I have a lot to think about when it comes to maintaining my health, not only for the short term but the long term too. I thought writing to you instead of calling my usual gastro doc might provide an answer to this question for others as well.

I have also heard a story that cholesterol is linked to the large bowel so people with ileostomies need not worry. Is there any truth behind this?

Regards, Sarah, South Australia

Dear Sarah

I suggest you have your blood electrolytes checked regularly to see what your sodium and potassium levels are. This will be a good indicator of whether you are having enough sodium in your diet. Certainly I would think with your established ileostomy your stoma output would be consistent and hopefully not high volumes, and you would be able to modify your sodium intake to a more reasonable level without compromising your health.

As for the cholesterol issue, I am afraid I have not left myself enough time to research this more. I think we should ask Margaret Allen from Nutrition for Ostomates to write a bit about both these concerns.

I do know that research is showing more and more benefits of a healthy large bowel and that the function of the large bowel is far more than re-absorption of water, as is sometimes the simplified explanation. I know you don't have a large bowel but I am sure it is still wise for your long-term overall health to keep a check on your cholesterol and not over-indulge in fatty, salty foods.

Sincerely, Carmen

Dear Carmen,

I am an 84-year-old with the following chronic conditions: severe tinnitus since childhood (headaches, etc), asthma which turns into pneumonia if I get the slightest chill or cold, two ulcers (gastric and

Continued page 34

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Continued from page 32

duodenum), small hiatus hernia, diverticulitis, a spot on the left lung (TB as a child), a spot on the right lung (could be the start of a tumour, being monitored by a thoracic surgeon), nodes on thyroid and cysts on the kidney (both recently diagnosed).

After a car accident in 1974 I had both shoulders operated on (rotator cuff), a right hip replacement and right knee replacement. My spine is damaged in three places. The hip and knee are now causing pain and are being checked. I have also had operations on feet, bunnion removal and hammer toes, resulting in pins, screws etc in both feet.

Six months ago I entered hospital for a routine colonoscopy. The surgeon caused a small tear in the bowel and I ended up with a colostomy bag (a four-hour operation, diverticulitis clearing of the bowel), which was a bit of a shock.

Now finally I have settled all my chronic complaints which were not connected to this operation. The specialist is now offering to reverse the colostomy.

The chronic conditions (plus other ops) take constant treatment and care but are disturbed badly when not handled while other medical procedures (i.e. reversal of the colostomy) are in progress.

I would rather have a shorter life than procedures that prolong life but at a high cost.

I have always managed an extremely active and productive life and have eased my activities to cater for my needs. I live with my husband in a retirement village and enjoy walking, movies, reading, short shopping trips, and family.

My question—is there anything more I can personally do (I think I am handling my colostomy) or do I need continued attention from the expert people who know so much more than I about this condition? I change my bag from three to four days and apart from dark pink skin round the stoma, am extremely careful about cleanliness and care.

I have always had a reasonable diet because of my chronic conditions (confirmed with a dietician) and controlled any diahorrea and other irritations.

Do I need to see "the person" who can guide me along the way?

Regards, Betty Watkins NSW

Dear Betty,

Thank you for your letter. From my understanding you are managing your stoma pretty well in spite of receiving it as a surprise. You describe a full and active life in spite of this and your other "conditions".

However, you describe redness around the stoma but not whether this is skin erosion. Sometimes there is a discolouration around a stoma from scarring or from being constantly exposed to faecal matter or from being occluded with the adhesive backing of the bag.

I really recommend that you have a review by your local stomal therapy nurse. He/she may recommend re-sizing of your stoma appliance or some other form of skin barrier.

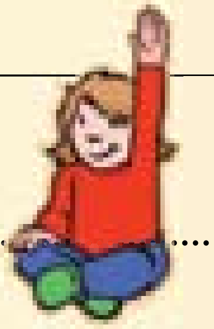
Your concerns regarding deterioration of your other medical conditions when you have the stoma reversed are valid. Reversal of what I assume was a Hartmann's procedure (i.e. you still have your anus and rectum with the stoma made from the end of the large bowel) may actually involve having another temporary stoma and if not, if your stoma is an end colostomy, then there will be a surgical join (anastomosis) to re-establish the route.

Just because reversal of the stoma is offered it does not mean you have to do this.

If you are having a full life experience not restricted by your stoma you can consider keeping it for life.

All the best with your decision-making Betty and please make that appointment for a review of your stoma.

Sincerely, Carmen



NEED MORE HELP?

Please send any questions or concerns you might have to Carmen, our journal's Stomal Therapy Nurse.

Nutrition for Ostomates

Submitted by: ***Margaret Allan**, VIC*

Margaret Allan is a qualified Nutritionist. She advises both ostomates and the general public on diet and health-related matters.

In this article Margaret discusses the importance of gastrointestinal health and her recently launched Nutrition for Ostomates Outreach Program.

Stomal surgery can be a large and life-changing operation with many possible pitfalls, and can affect people differently depending on the nature of the surgery. Some people can have stomal surgery and hardly miss a step, whilst others experience significant repercussions that are chronic and deeply entrenched.

The nutritional implications of this on the individual can therefore also vary significantly, so that some people need little change to their dietary intake whilst others need a much greater degree of nutritional education and support.

Through my work with ostomates over the years, I have come across a common and frequent dilemma—a lack of specific nutritional support that is tailored to the varying needs of the ostomate. In my opinion, in order to provide adequate nutritional support to an ostomate after stomal surgery, many factors need to be taken into consideration. These include the age of the patient, specifics of the surgery, current medications and other illnesses. I also believe there are two tiers to the nutritional treatment plan: ensuring dietary intake is adequate and appropriate, as well as ensuring the gastrointestinal tract is healthy and functioning optimally.

All Australians are advised to adhere to the Australian Dietary Guidelines, which provide advice about the types and quantities of food that need to be consumed regularly for health and wellbeing.

For some ostomates, however, it may not be possible to consume adequate quantities of many of the recommended foods due to issues with increased output or a potential blockage, with the result being that general dietary intake becomes inadequate and nutrient status is compromised.

On top of that, for those ostomates who are struggling with their health after stomal surgery, the need for certain nutrients can be greater than the general recommendations. Therefore particular strategies need to be put in place to ensure there is the greatest possible diversity in the diet to meet nutrient requirements without added issues.

In addition to achieving optimal nutrient intake, however, is the added requirement of ensuring the gastrointestinal (GI) tract is healthy to support optimal nutrient absorption. The small intestine in particular is the major site where nutrients pass from the GI tract across the bowel wall into the bloodstream, so any disease or surgery that reduces function in this tissue has the potential to reduce absorption of nutrients. This can lead to compromised nutrient status despite adequate dietary intake, because many of the nutrients consumed in food are not absorbed and are consequently lost down the toilet. I believe it is therefore imperative to consider the health of the GI tract in addition to dietary intake to fully support the wellbeing of ostomates.

This is an important factor for urostomates as well as ileostomates and colostomates, as the majority of the immune system is located in the gastrointestinal tract. Urinary tract infections are one of the key concerns for this group, and therefore maintaining a strong and healthy immune system to fight infection is vital. This cannot be achieved if the gastrointestinal tract itself is not healthy and functioning at an optimum level.

I have spent the best part of the past 10 years attending lectures, seminars, conferences and now webinars on the requirements for health and wellbeing, always with an ear out as to how the information is relevant to or different for ostomates.

Many general dietary recommendations or strategies are not applicable to ostomates—for example to achieve weight loss or to address diabetes or cardiovascular disease. At these events, I have been your representative in the field of nutrition, always on the lookout for ways to adapt information in order to support the health and wellbeing of ostomates.

It is this knowledge that I bring forward when consulting with an ostomate individually or speaking to a group. Common problems such as:

- dietary challenges
- output issues
- fatigue

Continued page 36

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- low mood
- poor sleep
- weight concerns

and many more are addressed with the aim of creating greater health and freedom.

Nutritional support is then provided via:

- appropriate dietary recommendations and recipes
- education and mentoring around individual circumstances
- tailored supplement support that addresses nutrient deficiencies that cannot be fully addressed via dietary measures alone
- overall lifestyle and wellbeing strategies aimed at generating progress towards a more healthy and fulfilling life.

For many years now I have been consulting with ostomates in Melbourne, but have been frustrated at not being able to support ostomates further afield.

I have also travelled to many parts of this country to deliver nutritional presentations to groups of ostomates, which is always my great honour and pleasure. I really enjoy answering questions in person on these occasions. However, again I have experienced the same frustration at not being able to provide a greater level of support to the wonderful people I have just met.

To this end, I have recently launched my Nutrition for Ostomates Outreach Program, which is aimed at providing specialised nutritional support for ostomates across all parts of Australia. I am making use of the amazing technology we currently have available to us, and am conducting nutritional consultations over the internet.

The consultations are professional and private, and take into consideration individual issues and circumstances. The greatest advantage is that they can be conducted from the comfort of your own home!

Nutritional consulting is my profession and what I do for a living, with my focus being to provide the missing nutritional links for ostomates in order to support overall vitality and wellbeing. I am aiming to provide a greater level of nutritional support to a wider group of ostomates than previously available, and therefore enhance general feelings of freedom and fulfilment.

Wishing you good health and happy days, **Margaret**

Key points:

- **There is a lack of specific nutritional support that is tailored to the varying needs of the ostomate.**
- **It may not be possible for ostomates to consume adequate quantities of many recommended foods, leading to reduced nutrient status.**
- **The need for certain nutrients after stomal surgery may be greater than dietary intake can provide.**
- **The gastrointestinal tract must be healthy to support optimal nutrient absorption and immune functioning.**
- **Many general dietary recommendations or strategies are not relevant or applicable to ostomates.**
- **Tailored nutritional support that provides the missing links to support health and wellbeing in ostomates is essential.**

For more information on the Nutrition for Ostomates Outreach Program or to contact Margaret for nutritional support, please contact **www.nutritionforostomates.com.au**

Further information about the Nutrition for Ostomates Outreach Program appears in the advertisement below.

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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 fourth 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 Olver 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: rexmarn@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) 5563 1446

WESTERN AUSTRALIA

ALBANY
Meets in the Albany District Hospital Conference Room at 9.30 -11.00am on the third Friday every three months.
For details: Terry: (08) 98474701

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 Bvd. Mount Warren Park QLD.
Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107.

BRISBANE
Operated in the Greater Brisbane Area by Qld Stoma Association and Qld Ostomy Association.
Phone: (07) 3359 6500
Website:
qldstoma.asn.au/bosvs.htm
Operating hours: 7 days, 8am to 8pm

GOLD COAST
Supporting Ostomates Needs Group.
Meet every three months at various venues.
Private and Confidential,
C/- PO Box 703, Labrador, QLD 4215
Phone: 0429 126 163
Email: gcsong@live.com.au
Facebook: www.facebook.com/goldcoastostomysupport

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

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
Evon Fuller (07) 5447 7158 or eful@bigpond.com
Laurie Grimwade (07) 54459008 or 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 10.00 am on the first Monday of Mar - Jun - Sep - Dec at the Cancer Support Centre, 69 Howick Street, Launceston.
North-West: Meets 10.00 am 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
Email: 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
Web: www.bgk.org.au

PARENTERAL NUTRITION DOWN UNDER
Secretary on (02) 9987 1978
Email: contactpndu@gmail.com
Web: www.parenteral-nutrition-down-under.webs.com

MITROFANOFF SUPPORT AUSTRALIA
PO Box 256, South Melbourne, Victoria 3205
Email: info@mitrofanoffaustralia.org.au
Web: 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
Website: www.ainscorp.com.au

Dansac
PO Box 575, Port Melbourne, Victoria 3207
Phone: 1800 331 766
Email: customerservice@dansac.com.au
Website: www.dansac.com.au

Coloplast
PO Box 240 Mt Waverley Vic 3149
Freecall: 1800 653 317
Email: au.care@coloplast.com
Website: www.coloplast.com.au

ConvaTec
PO Box 63, Mulgrave, Victoria 3170
Freecall: 1800 335 276
Email: connection.au@convatec.com
Website: www.convatec.com.au

Future Environmental Services
PO Box 319, Blairgowrie, Victoria 3942
Phone: +61 3 5985 2828
Email: health@futenv.com.au
Website: www.futenv.com.au

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PO Box 599, Port Melbourne, Victoria 3207
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Phone: 136 136
Website: www.3m.com.au

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Toll Free Number: 1300 365 404
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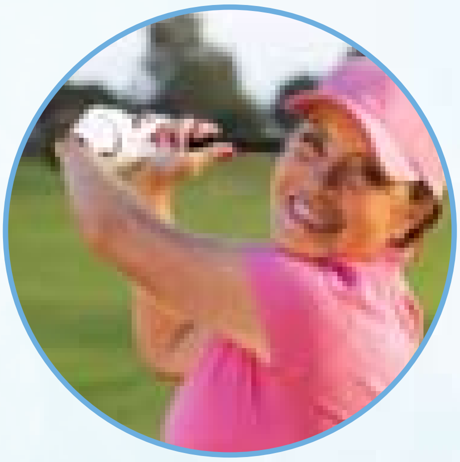

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