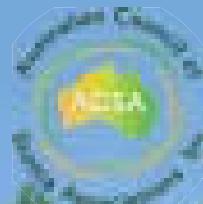


Ostomy

A U S T R A L I A

Volume 24
Number 1
April 2015

Print Post Approved
PP 100008088
ISSN 1329-959X



National Directory of Ostomy Associations

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

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Telephone/Fax: (02) 6205 1055
Website: www.actstoma.org.au
Operating hours:
1st & 2nd week of each month Mon,
Tues, Wed. 10.00am - 1.00pm
Office Manager: Lindsay Foster
Email: actstoma@alphalink.com.au
Secretary: Tanya Harber

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Unit 2 Casi House
25 Vanderlin Drive, Casuarina
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Web: <http://nt.cancer.org.au/>

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Enquiries email:
waostomy@waostomy.asn.au
Orders Email:
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Operating hours and appliance
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Secretary: Jess Whitehouse

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Kirrawee NSW 2232
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Kirrawee NSW 2232
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Website: www.ostomynsw.org.au

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Operating hours:
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Hyde Park, Castletown 4812
Operating hours:
Monday 9.00am - 4.00pm
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Fax: (07) 4636 9702
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88a Crofton Street, Bundaberg
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OSTOMY ASSN OF SA

(formerly Colostomy Assn of SA)
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Website: www.colostomysa.org.au
Distribution of supplies: Mon - Fri
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Secretary: Ruth Horne

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to 2pm 1st & 3rd Tuesday evenings
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OSTOMY TASMANIA INC

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Fax: (03) 6228 0744
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Tues 9.00am - 1.00pm
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VICTORIA

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Golden Square, VIC 3555

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Melbourne 3000
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Fax: (03) 9650 4123
Email: colostomy@mail2me.com.au
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GEELONG OSTOMY INC.

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Fax: (03) 5243 6335
Email: goinc@geelongostomy.com.au
Website: www.geelongostomy.com.au
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Wednesday, Friday 9.30am to 2.30pm
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Website: www.oam.org.au
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ACSA wishes to acknowledge the valuable
contributions of the previous Editors of our
Ostomy AUSTRALIA journal; Barbara Callcott,
Judy Lopez and Noel Dillon.

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Phone: (02) 8011 3535
Email: Journal@AustralianStoma.com.au
These contact details apply only to matters
directly associated with *Ostomy AUSTRALIA*
Only Email, Word or PDF documents, and hard
copy submissions accepted.

Published by:

Australian Council of Stoma Associations Inc.
Website: www.australianstoma.com.au
Email: feedback@australianstoma.com.au

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Printed by:

Graphic Print Group
Graphic House, 10 - 14 Kingston Avenue,
Richmond, SA 5033
Phone: (08) 8443 8011 Fax: (08) 8234 0226

Graphic Design by:

Joe Kraus Design
Phone: 0437 582 167

Advertising Enquiries to: The Editor

The Editor Advertising & Copy Deadlines:

<i>Issue</i>	<i>Copy and Advertising</i>
April	1st February
August	1st June
December	1st October

Cover Picture:

Hunter Valley Gardens, Pokolbin, NSW
Photo by Kim Lyell

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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.

All contributions must include your name and address for publication. If you do not wish your name published, please say so in your letter, and only your initials will be printed. Please also note that an electronic copy of this journal is available to non-Ostomates on our and other internet websites. The editor and publisher take no responsibility for any information contained in 'Letters to the Editor' and 'Your Say / In Your Own Write' and specifically disclaim all liability. Concerning any medical information contained in this publication, the reader is strongly advised to first obtain appropriate medical advice before implementation.

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The Australian Council of Stoma Associations Inc. advises that it has no control over the use of personal particulars supplied by Ostomates to companies in response to advertisements contained in *Ostomy AUSTRALIA*. Unless the advertiser states otherwise, your name and address information may be used by the company to let you know about its products in the future.

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 thought it might be appropriate to start my second President's Message by providing a little information about my background, which I hope will provide context for one of the issues I will raise in this article.

December 2014 saw me celebrating fifty-five years as an Ostomate. I was nine when I became an Ostomate and I have been fortunate that it gave me the opportunity to live the full and I think interesting life I have. Growing up and moving into adulthood provided some challenges (Carol, my wife of forty years sometimes questions whether I have, in fact, reached adulthood). This was done with the support of a wonderful family, a bevy of friends and the fantastic support of the members of the Association that is now Ostomy NSW Limited (ONL). One thing that I didn't have in those teenage and early adult years was ready access to Ostomates of my own age. I suspect if I had, it would have made the journey a little easier.

In November, Peter McQueen (past President), Kylie McGrory (Administration Officer) and I attended the meeting of the Asia and South Pacific Ostomy Association (ASPOA) in Ho Chi Minh City, Vietnam. The meeting provided an insight into the conditions Ostomates face in neighbouring countries. Talking with delegates from the region reinforced how fortunate we are in Australia to have such a generous and well managed government Scheme to support Ostomates. The support provided to Ostomates in neighbouring countries through the Australia Fund is also greatly appreciated.

One of the other topics discussed at the meeting was support for young Ostomates. The ASPOA sponsors the 20/40 Focus Group Movement which is co-ordinated by the ASPOA's Secretary, Ronaldo Lora. Ronaldo requested that all ASPOA members support the 20/40 Focus Group through local activities. ACSA has in the past made efforts to establish and support a national youth group but unfortunately these efforts have not met with success.

As a former young Ostomate (albeit a long time ago) I would welcome the formation of a national youth forum, under ACSA sponsorship, that focusses on the issues that young Ostomates face. I am therefore calling for volunteers from within Associations to establish a national youth forum. The breadth and capability of social media provides the opportunity to establish a national mutual support network for young Ostomates. As President of ACSA I would relish the opportunity to act as sponsor and mentor. I look forward to being overwhelmed with volunteers.

The Stoma Appliance Scheme is under constant review by both government and The Department of Health. In

2014 the Department commenced a review of the products listed under Group 9 of the Stoma Appliance Scheme Schedule. Quoting from the Department's website:

"The objective of the Group 9 Review is to assess the clinical appropriateness of Group 9 products, their appropriateness to the SAS and the appropriateness of how they are used by people with stomas."

The review will:

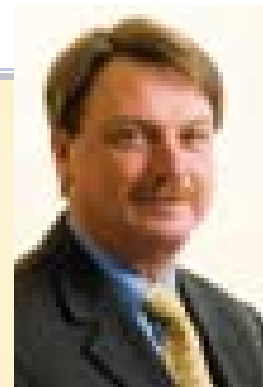
- *examine the products listed under SAS Group 9 and assess their clinical benefits and relevance to people with stomas;*
- *investigate the comparative differences between like products – evaluating effectiveness and cost;*
- *consider current guidelines/criteria for listing accessory products under SAS Group 9; and*
- *review the products in relation to supply, pricing, eligibility and maximum monthly quantities."*

The Department has also released an Economic Analysis and Literature Review and in November 2014 called for submissions in response to a Public Discussion Document. A number of Associations submitted responses and ACSA made a detailed and considered response which is available on the ACSA website: www.AustralianStoma.com.au

The Review is being conducted by the Stoma Product Assessment Panel within The Department of Health and ACSA has a nominated consumer representative on the panel as well as myself as ACSA's representative. As Group 9 products accounted for around twenty-four percent of the total cost of the Scheme in 2012/2013, it is important to ensure that products in this Group deliver effective support to Ostomates and can be shown to justify the significant government expenditure. The ACSA Executive will keep Associations informed of developments in the Review as they occur.

As I write this at the beginning of February 2015, work on establishing a National Stoma Appliance Scheme Management System continues, but regrettably not at the pace I had hoped. ONL, due to the ill health of their Treasurer, has not been able to provide the financial information required to finalise the cost of acquiring the TOMAS application by ACSA. I would hope that by the time this article is published, the sale has been finalised and we are well on the way to installing the National System in the first Association.

Geoff Rhodes PRESIDENT



Letters to the Editor

Dear Editor

It was with much interest I read the articles in the August 2014 edition of the *Ostomy AUSTRALIA* journal. Having just celebrated my fiftieth anniversary of pain-free health, I am so very thankful for the skill of the Scottish surgeon who performed my ileostomy operation on 7th July 1964.

Fifty years ago in Scotland, we were not given all the information patients have today. Anyway, I was so sick I doubt it would have registered. After my operation I well remember the joy of eating a fried egg for the first time in years and not having any ill effects. Yes, we had a tough time trying to find ostomy supplies and were pleased to have double-sided plasters, which pulled skin off from around your stoma each time you changed, normally at least twice daily. Later, skin bond cement was helpful and Gamgee tissue was my best friend to absorb leakage. After eight years I was introduced to karaya gum rings (similar to small Eakin seals) which were absolute heaven. Nowadays, with the selection of modern supplies, it is a breeze plus having all the assistance from the Stomal Therapy Nurses.

Congratulation to Ileostomy Association (Vic) Inc. who have commenced including the cost of my month's supplies at the bottom of their packing advice. I was absolutely flabbergasted when I saw the figure for just one month's supplies. This brings it home how much each item costs and how much we are being subsidised each year.

I note from the newsletter I recently received from Ileostomy Association (Vic) Inc. that our annual administration/access fee is to rise by \$5 each year for three years, commencing from 1st July 2015. This increase is well overdue for the excellent service we receive from our various Associations. We are just so fortunate having so many willing volunteers.

Thank you for an excellent publication.

Margaret, ACT

Dear Editor

I recently purchased a set of "airport friendly" braces (made in USA) from Executive Accessories in South Australia. Having used other types purchased locally with disappointing results, I find these braces are well made with very strong clips made with all composite materials. The transaction was done online, with excellent service.

Raymund Credlin, VIC

Dear Editor

After reading Megan's story "Love at First Sight" in the August 2014 issue, it occurred that like me, most readers would not know what a J-Pouch is.

While there are plenty of web sites on the issue, for those without internet access a J-Pouch can best be described as an internal reservoir created from a part of the small intestine.

John Geeves, QLD

Help!

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

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

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

**The Editor, *Ostomy AUSTRALIA*
PO Box 195 Frenchs Forest NSW 1640**

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.

An electronic copy of this journal is also available to Ostomates and non-Ostomates via the ACSA and other internet websites.



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 an article 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 for the front cover.

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

Ostomy AUSTRALIA does not endorse the contents of readers' letters nor do we vouch for the accuracy of any claims made in those letters. Readers should not rely on any such claims in the absence of medical advice and should consult with their treating doctors prior to embarking on any course of treatment.

Those Wonderful Stomal Therapy Nurses

Submitted by B.H., QLD

I wish to put on record my appreciation of the work done by Stomal Therapy Nurses (STN).

My ileostomy story started in October 2011, following years of treatment for Crohn's Disease and bowel cancer. I left hospital armed with a supply of two-piece drainable appliances, feeling sure that this was the most suitable thing for me and confident that I would soon master the procedures involved.

Over the next three years as my general health and muscle tone declined, the abdomen became flabby and saggy and the frequency of leaks increased. Housework, lifting, reaching up or down, and even travelling in a car, were all likely to cause leaks, smells and messes.

During this time in an attempt to overcome the problem, I consulted people, books and articles and studied advertisements for the dozens of available appliances. The only changes made were of a masking nature, attempting to treat the problems I was experiencing and not the cause.

By the time that I was about to turn eighty I was aware that my whole life was being ruled by my stoma, restricting options and making me miserable.

In desperation I contacted the STN who had been so helpful three years ago and with her experience and expertise she knew which of the many available appliances would suit me. So I tried a very flexible one-piece drainable pouch with a thin seal applied to the pouch before gently pressing it onto the skin. Much easier for an old lady!

In the two months since then, not a drop of output, runny or thicker, has ended up anywhere but in the bag. The skin remains smooth, pink and pain free.

Thank you to all those wonderful Stomal Therapy Nurses.

Some Creative Thinking

Submitted by E.L., SA

Prior to my ostomy operation I had been in hospital with a very bad illness which almost cost me my life. I was not home long after recovering from that episode before I was rushed to a private hospital for surgery to remove part of my bowel and fitting of an ostomy bag. I was in hospital for three weeks, but altogether with both illnesses I was in hospital for seven weeks and also lost a fair bit of weight.

It is now almost two years since I had that surgery. I feel good and have no trouble using the bags although I have had a few major leakage episodes. I just have to watch what I eat.

However, I did have a problem with the delivery of my ostomy supplies, which I always receive around the first of each month. One month I didn't receive my order and ran out of ostomy bags.

I did not know what to do. I rang everywhere I could think of to see what had gone wrong. I also rang my local hospital to see whether they had any spare ostomy bags but without success. I then rang the Stomal Therapy Nurse but had to leave her a message as she is only in her office on Tuesdays.

So, I thought, what am I going to do?

Where there is a will, there is a way! I cut down some plastic bags (the bags that my ostomy supplies come in) so that they would fit the size of my stoma and then taped these all around so that they would not leak. I was very stressed, and hoped that they would not leak and I would not get an infection. Thankfully, this solution worked well but I did get a rash from the tape. My order eventually arrived.

That is why I applied to the government to get an extra box of ostomy bags, which they allowed me to have.

My January 2015 order didn't arrive until 12th January but luckily I still had an extra bag left from December. I am ninety-two years old, am managing pretty well and hope that I never run out of ostomy bags again!

Just a Spoonful of Sugar?

Submitted by Rodney Stevenson, NSW

I am a 61 year old male, have been a double Ostomate for the last five years and read with great interest, Margaret Allan's article discussing "Dietary Solutions to Prevent Urinary Tract Infections" in the December 2014 journal [page 38].

Due to Stage IV bladder cancer, in 2010 my bladder was removed and an ileal conduit created, using part of my small intestine to facilitate urine drainage through a stoma. As Margaret's article indicates, bacteria resides naturally in the intestine and does not usually cause concern in this native environment. However, when part of the intestinal tissue is used for the urinary system, complications can arise with bacterial overgrowth causing Urinary Tract Infections (UTIs). I was plagued on many occasions with this painful condition.

I have been reluctant to take too many antibiotics due to antibiotic resistance. I try to keep antibiotics as a means of last resort, especially the "big guns" such as gentamicin for pseudomonas aeruginosa, a particularly nasty form of gram-negative bacteria. I have tried all kinds of dietary modifications to prevent/treat UTIs, including those mentioned in Margaret's article, but the biggest breakthrough of all for me was including the dietary supplement D-Mannose (available via the web) in my dietary and nutritional regime.

D-Mannose is a monosaccharide sugar found naturally in some fruits and berries such as cranberry. It may sound counter intuitive to treat UTIs with a 'sugar' but the theory is that D-Mannose attaches to bacteria better than bacteria attaches to human cells in the urinary system and when an adequate quantity of D-Mannose is taken it spills into the urinary system coating any bacteria present and is then washed away with



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normal urination. This natural supplement has been a 'God-send' for me. I take one capsule (500mg) first thing in the morning with a glass of water and another capsule with a glass of water last thing at night before I go to bed and I have not had any UTIs since I adopted this regime.

I hope that this information is useful to other people with ileal conduits as, with the prevalence of antibiotic resistance, I believe that D-Mannose can be a real life-saver.

Instant Relief

Submitted by **Marie Kelly, NSW**

After sixteen great years with an ileostomy it is good to find that there are still some things I can learn.

Due to perspiration under the end of the bag I had been having a problem with skin irritation on my lower abdomen in summer. I had considered making some bag covers, but then had the idea of wearing a pair of cotton hi-cut briefs pulled up under my bag, as well as my usual undies over the bag. Result? Instant relief! Maybe this may also help someone else.

I would also love to hear if anyone has a simple solution to keeping a bag dry when showering.

My Helpful Tips

Submitted by **Wendi Gill, SA**

I have enjoyed reading the Journal since becoming an Ostomate in 2007 and after reading the December 2014 issue, have now decided to impart some knowledge which may help other Ostomates.

- For Isobel Davie (and any other Ostomates having difficulties with getting additional supplies): Contact your Stomal Therapy Nurse and ask for what you need, and if the Nurse agrees she can fill out an Application for Additional Stoma Supplies form and send it straight through to your ostomy association. Be sure of what you want as the Application can only be done once a year. If in doubt ask your Stomal Therapy Nurse. I also use a one-piece drainable appliance and use Windless tablets to alleviate any odours.
- For those travelling overseas: I take a written and signed letter from my doctor explaining what I have and where it is situated. This alleviates any embarrassing questions when I wish to take a backpack containing my medical supplies and a change of clothes, along with an overnight bag containing the same to put in the overhead storage on the plane. Unfortunately there have been occasions when I have had to use both after having breakouts on long overseas flights, the results of all that good eating in Canada and Hawaii. I also had plastic shopping bags for any soiled clothing. Speaking from experience, I find changing in an aeroplane toilet is really the pits and very claustrophobic.
- For Nancye Turner: I purchase 250 of Kimberly Clark's WypAll branded Single Sheet Handi Wipers (part number KC 4202). It takes a bit of time to cut them in half, fold and cut again before refolding. This gives me 1,000 towels which will last

me a year, even with the occasional large output. They are strong and absorbent.

- To John Samphier and Peter Fitzsimmons: I also follow a similar procedure to you both. I have a handy supply of the small towels mentioned above, adhesive remover wipes, and skin lotion tissues in a Glad Sandwich Bag which accompanies me to the bathroom along with a perfumed "Nappy Sack". All soiled product goes straight in the "Nappy Sack" while unused product is re-sealed in the lunch bag and restocked if needed for the next session.

Hope this information helps someone.

Ups and Downs but I am Still Here!

Submitted by **Neil McGregor, VIC**

After reading in the Journal of all the ostomy dramas others have experienced, I thought I would also write something about my own dramas. The following is from a journal I have written about my health problems and cures.

Back in April 2009 I had a very sore bottom, internally, so I went to my doctor in Walkerston, Queensland, who sent me to Mackay Base Hospital where they examined me and said I would have to go to Townsville Hospital. There they examined me, took x-rays and then told me I would need an operation to repair an anal fistula. They also told me I would have to be fitted with a colostomy bag, which I knew nothing about, but that was about to change. They also told me the bag would be removed at a later date.

After the operation, I was given a demonstration on how and what to do with the colostomy bag and how to order my supplies. I did not enjoy wearing this thingy but I am an up-and-go type of guy so it was back to work I went.

I had one really bad accident with my ostomy gear and that was when hitching my work pants up. It caught under my fingers and pulled away making a stinky mess. Luckily I had a change of clothes with me and the service station owner let me use his bathroom to clean up.

When I went back for my check-up (much later and sadly too late for my rectal muscles), they informed me they could not do the stoma reversal and I would own it for ever more. Grrrr! I can tell you I was not a happy chappie. NOT what I was expecting!

I also had a problem with my bottom leaking mucus which just got worse, so they operated and completely sealed up my bottom. They also did some repairs to my stoma and removed part of my bowel and tube. This was done in Melbourne.

Well this all happened over six years ago and I haven't had any problems with the fittings or leakage since.

I have also had a lot of dealings with Stomal Therapy Nurses throughout Australia, initially at those hospitals in northern Queensland, then it was down to Melbourne. I must say that all the Stomal Therapy Nurses were excellent and very helpful. I am also very thankful for my lovely wife who had a horrid time looking after me.

Nearly five years ago I was diagnosed with lung cancer which resulted in the removal of my left lung. Unfortunately, I had a

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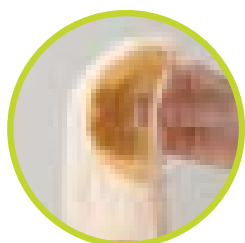
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References: 1. Szewczyk MT, Majewska GM, Cabral MV, Hölzel-Piontek K. Osmose Study: Multinational Evaluation of the Peristomal Condition in Ostomates Using Mouldable Skin Barriers. Poster presented at ECET, Paris, France, June 2013.
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major infection after being sent home which resulted in me being placed in a coma for seven days. The repairs were then redone, followed by chemotherapy which was not that flash and I failed to have the last course.

I was ready for work again but then the x-rays showed that I had a brain cancer so it was off to Townsville again for radiation treatment, which took three weeks. After all this treatment I was told to retire as I would be unable to work or drive.

So here we are back in Melbourne, close to family and with the Peter MacCallum Cancer Centre looking after me.

Anyway, it has been six years of ups and downs but I am still here.

Hope you enjoy this and see there is still life after all this.

My "Drip Tray"

Submitted by **Alex Kara, VIC**

I use drainable bags exclusively and I like to let the skin around the stoma "breathe" for as long as possible between changes. To permit this I shower without the bag, dry off and as soon as possible attach my "drip tray" after I pat dry the stoma. I use clean, dry face flannels to pat dry the stoma (this permits me to keep the towel "clean"). Folded in quarters, I can get eight clean surfaces (a batch of eight costs around \$5 in the supermarket). With the "drip tray" attached, I can move freely, within reason, around the house without the fear of causing major catastrophes. At least I have the confidence to make it to safe ground (off carpet/absorbent material) before any major hard to clean messes erupt.

My "drip tray" was designed using Sketchup, which is a free 3D drawing tool available for both PC and Mac and can be downloaded off the Internet. I then used my design to print on a 3D printer. While not everyone has a 3D printer they are getting relatively cheaper (around \$1,500) or can be built, much cheaper, using free plans off the Internet. However, with the incredibly growing popularity of these machines a little bit of networking could probably land most individuals with access/contact. Alternatively there are companies that may print from your design.

The "drip tray" is mounted on a contoured plate that was designed to fit my belly and the contour imported into Sketchup. The tray incorporates the same contour for easy attachment, which satisfies my immediate requirements. However, anyone could probably design a simpler attachment. The mounting clips are printed, again using the 3D printer, from a Sketchup design and will fit standard sized elastic available from shops such as Spotlight.

I line the "drip tray" with tissues (or moist wipes) as the 3D printed plastic is not perfectly smooth and may not wipe cleanly (if unlined I use disinfectant to soak the tray to remove any trace of faeces, hence I have a couple of trays).

I have provided a few photos of my "drip tray" and also a picture of my first design, which was prettier and more streamlined but not as functional. However, this is not a beauty contest.

If you like this idea, have access to a 3D printer and would like

the challenge of designing/customising one yourself, give it a go (a SketchUp file is available via email: onlyalexkara@aussiebb.com.au). Otherwise, you could canvass the ostomy supply organisations to see if any are willing to create a commercial tray as I could not find any existing ones.

3D printed item. The contour was designed using a flexible contour bar available from large hardware shops, traced on paper, scanned and imported into Sketchup to use as a template for shaping.



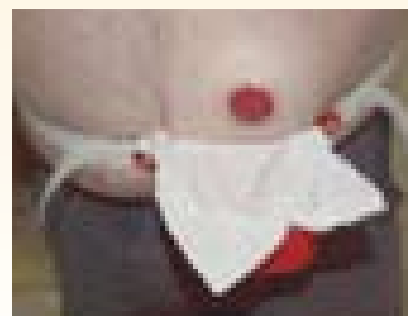
Contoured plate fitted using some printed clips and elastic. The plate is oversized to enable tissue packing (underneath) to enable levelling of the catch tray more evenly.



Tray fitted to plate. It has a lip on the back that has the same contour as the plate and simply slips over the plate. It can be moved sideways for better positioning. The width of the tray accommodated "squirts" better.



The tray is lined with tissue for ease of cleaning. Lining is recommended as the printed plastic is not smooth and therefore not easily wiped clean as soiling may get imbedded between "printed layers".



My first attempt. It looked neater but the receptacle was too small to permit indiscreet droppings and the entire unit needed to be removed if soiled. I also found it more difficult to line with tissues.



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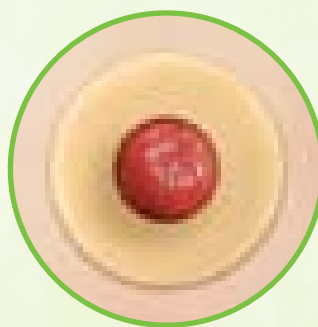
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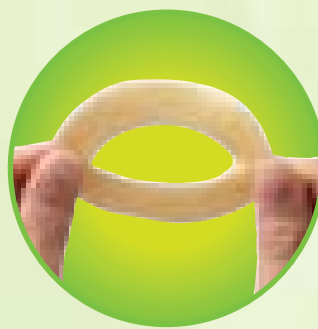


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Thank You from Papua New Guinea

Submitted by: **Janet Yaki**, Founder and Interim President
Papua New Guinea Stoma Association

I recently gave a brief presentation at the ACSA 2014 Annual Conference, explaining how Papua New Guinea (PNG) ostomy patients must resort to other things to do the job of ostomy bags as these surgical appliances are not readily available in Papua New Guinea.

We have over eighty Ostomates, of which sixty-three are children and the rest are adults. The majority are from poor communities in rural areas and shanty settlements within urban centres.

Life is quite difficult for Ostomates in PNG, where chemists typically sell a single ostomy bag with base for \$17 to \$20. An average worker can't afford to have a constant daily supply and it is much more difficult for people living in rural areas as they have no income. To make matters worse, they live in huts without a power supply, indoor running taps, flush toilets or showers.

It is now five years since my colostomy surgery at Chang-Hua Christian Hospital in Taiwan and as an ostomy patient, I also experienced the discomforts of not having an ostomy bag.

To witness the sufferings of my fellow citizens is unbearable. Their sufferings are mine now.

I am so thankful to Mr David Eagle from Salts Healthcare in England who fortunately came to my rescue and supplied me with a two year's supply of ostomy bags. Having the comfort of these precious bags, I am now able to move around freely and help other Ostomates here.

The surgeons who perform these surgeries are saving a lot of lives. They work under duress and I commend them for that. We also have one Stomal Therapy Nurse in the whole country which is insufficient to cope. Unfortunately, post-surgery we are left to fend for ourselves after being discharged from the ward.

Three years ago I founded the Papua New Guinea Stoma Association when I discovered that there were others suffering much worse than I. It was so heartbreaking for me to see my own people going through so much discomfort and worse still, patients dying because of inadequate facilities and lack of surgical appliances to cover their stoma.

I therefore took it upon myself to assist other Ostomates through my own experiences of living



with a stoma. I do not have a medical background but I couldn't sit back knowing that PNG's Ostomates were out there, suffering silently.

Papua New Guinea Stoma Association is slowly creating awareness but it is so difficult penetrating a society where superstition is rife. Our communities believe in sorcery, magic, poisoning and most times blame such sicknesses on other people's doing. They take the law into their own hands which makes matters worse.

My vision is to see that all of PNG's Ostomates will have a constant supply but as we don't yet have a distribution centre or office, I store the supplies in my bedroom. I package the supplies and send these to other parts of the country through our "Wantok Network System" (relatives or anyone travelling to that destination).

I greatly believe that all school-aged children have the right to a good education. However, stigma is a major issue and they are unable to attend classes in our public education system due to the scarcity of ostomy bags. Several school-aged children I assisted wished they were able to attend classes. A couple of girls and their mothers cried, saying that having a stoma had stopped them from going to school and the mothers wished their daughters were in school.

A major obstacle faced by the Association in appealing for funds and donations is the fact that we operate from within a country rated very poorly by Transparency International on their corruption index. It is no secret that potential donors are wary of assisting because of the fear that any help will be defrauded. This is a major reason for my setting up the PNG Stoma Association; to operate as a separate, independent entity standing apart from our broken public system and serving the people in areas where our government's policies and systems have failed.

Australia's Gold Coast Ostomy Association has been generously donating ostomy supplies to the Papua New Guinea Stoma Association. We are also so grateful to Amanda Hill who had been sending us her surplus before connecting us with Gold Coast Ostomy Association through Jon MacPhail, now their Overseas Co-ordinator.

Thank you Gold Coast Ostomy Association:- Warren Rayment (President), Norm Kelly (Manager), Sharleen



Increases to Association Membership Fees

Have you been notified by your ostomy Association that their Membership Fees will be increasing for the 2015/16 financial year because the Department of Health has increased the Stoma Appliance Scheme Service Fee?

During 2014, The Department of Health approved an increase in the Stoma Appliance Scheme Service Fee of \$15, to be phased in over three years at \$5 per financial year, commencing 2015/16.

As the current Stoma Appliance Scheme Service Fee* is \$45, the following future Service Fee* will apply to all Scheme registrants:

Financial Year	Full	Concession [^]
2015/16	\$50	\$40
2016/17	\$55	\$45
2017/18	\$60	\$50

* excluding GST (Membership fees do not currently attract GST)
[^] registrants who present a current Centrelink issued pension or healthcare card

In terms of **clause 4.2** of the **Stoma Appliance Scheme Operational Guidelines for Stoma Associations;**

"... a Service Fee shall be payable by members of the SAS in respect of the costs of operating the SAS that are not met by the 2.75% handling fee (Clause 7.4). The Service Fee shall be a national uniform annual amount as determined from time to time by the Department, in consultation with ACSA, and shall be payable to the Association where the member usually obtains their stoma related products. The fee shall be compulsory but Associations shall make provision for the fee to be paid by instalments in the case of financial hardship."

However, in terms of **clause 4.3** of these Guidelines:

"Associations may charge an Association Membership Fee in respect of the services they provide to their members. Financial members of Stoma Associations shall not be required to pay the SAS Service Fee provided the Association

of which they are a member charges a uniform national membership fee and uses part of its membership fees to meet the costs of operating the SAS that are not met by the 2.75% handling fee (Clause 7.4).

Associations may also charge an additional Membership Fee in respect of the services they provide other than to the supply of stoma related products under the SAS. A member who is not able to pay the additional Membership Fee because of financial hardship may apply to the Association in writing to have the additional Fee waived. If the additional Membership Fee is waived, the Association shall also make provision for remainder of the Membership Fee to be paid by instalments."

As the uniform national Membership Fee is set at the same rate as the Stoma Appliance Scheme Service Fee, Association Membership Fees will also increase in step with any Stoma Appliance Scheme Service Fee increase.

Continued from page 12

Condon (Appliance Officer), Jon MacPhail (Overseas Co-ordinator) and all the staff for taking us on as your project. You are making a difference in our lives and we appreciate all that you are doing for us.

With the increase in the number of patients, we still need more assistance with surgical appliances. Our health service deprives us our right to special health care. Papua New Guinea Stoma Association is creating awareness to educate the community on the bladder cancer and IBD (inflammatory bowel diseases). I am getting calls from patients and relatives for supplies after the hospital's surgeons refer them to me for supplies. That is how bad the health services are at our public hospitals.

After returning from the ACSA Conference, I have been kept very busy as patients had nowhere to get their next supplies during my absence and it is difficult to get others to assist patients when I am away.

There have been five more patients who recently had surgery and others who came to seek assistance after suffering silently for so long. There was one with a hernia and a prolapsed stoma who had it covered with the largest plastic shopping bag. I couldn't assist him with colostomy bags as there isn't any size that would fit him. He needs surgery to correct his condition.

I am thankful to have attended a Stoma Care Session presented by Elaine Lambie, Gold Coast Ostomy

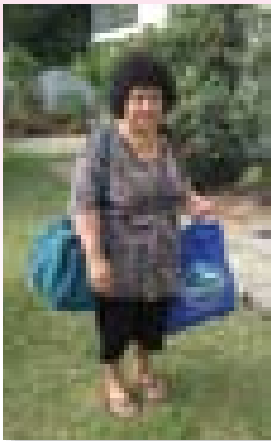
Association's Stomal Therapy Nurse, who gave a talk on how to treat a prolapsed stoma. I advised the patient to do what I had learnt in that session.

A lot of the members who attended the 2014 ACSA Conference and staff from ConvaTec indicated they would give me support in the coming year and I am so thankful for their assistance. It was truly a pleasure meeting you all.

Many may stand by and think that as individuals we are too insignificant to make a difference, to make an impact in the world, but I am living testimony which proves that individuals do make a difference. My victory over cancer was due to an accumulation of many individuals in my life who were willing to make a sacrifice for me. Therefore, I do what I do today as an individual, knowing that individuals like yourselves also do the same, and in the greater scheme of things our individual efforts add up to make a world of difference in the lives of those that need it most.

From an individual mustard seed grows a great tree, from a single rain drop comes forth a raging river.

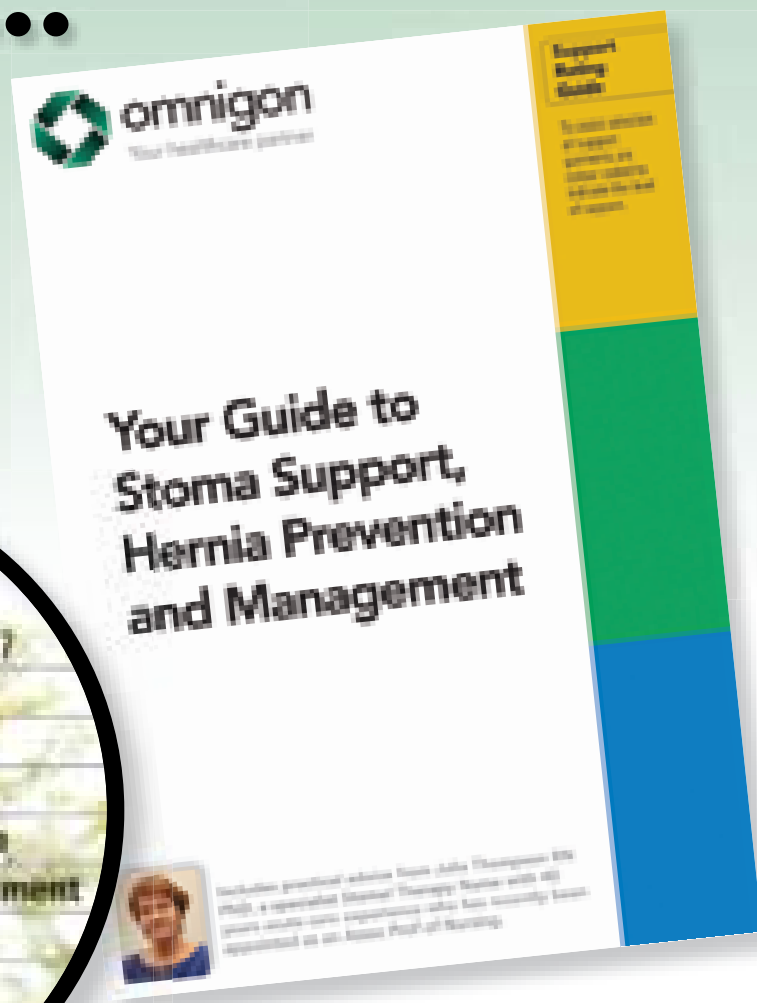
Thank you, Janet.



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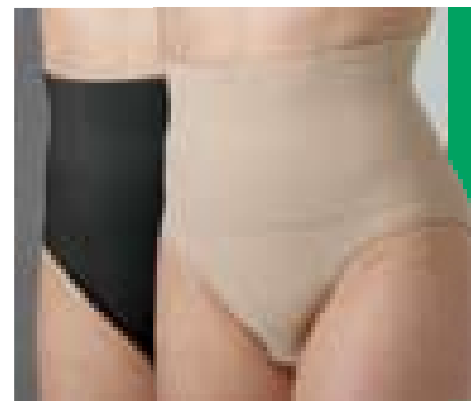
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- ▶ Available in standard and high waist



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- ▶ Discreet and comfortable support

Support Rating **4** INTERMEDIATE



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If you have developed a hernia, consultation with a Health Care Practitioner is recommended.

¹: Data on file Omnigon 2012 ²: A review of 16,470 on the American United Ostomy Association Register revealed 30% incidence over all types of stomas. (Gray et al, 2005)

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The human body is an amazing machine. It is resilient, it can withstand the toughest of obstacles and goes as far as the mind can push it. For me, this is all too true.

At the age of sixteen I had a very bad Salmonella food poisoning infection that was left untreated for a week due to my stool sample having gone missing. It was during this short period that the Salmonella had permanently damaged my entire gastrointestinal system.

I was perpetually constipated, constantly losing weight and unable to eat most foods as they simply caused too much stomach cramping and pain. It took twelve months to find a colorectal surgeon who believed that I was not an attention seeking teenager like some other specialists and doctors believed. Prior to my diagnosis of permanent damage from the Salmonella food poisoning, or sheer bad luck as I like to call it, I was told that I had everything from an eating disorder, cancer, IBD/IBS, Crohn's disease through to even making it all up.

I was seventeen when I was left with no option but to have a permanent Chait Caecostomy to try and get my bowel moving as it had by then completely stopped working. As you can imagine, it was difficult to come to terms and accept my new post-surgery body. I now had a tube that protruded from my stomach, and which would be there for life. After twelve months of feeling uneasy and unsure, lacking in body confidence and not wanting to look at myself in the mirror, I got over it and started living again.

I found my love for fitness and being active when I met my best friend and partner. I had a gym membership but had no idea about weights, so spent my time doing cardio workouts. My partner introduced me to BodyBuilding.com and from then on I was hooked. I printed workouts from the site and constantly gained motivation and inspiration from the many success stories and the amazing athletes.

It was in June 2014 that I took my fitness journey more seriously, when I found Maria Andriano, a coach at Creative Fitness and Nutrition. The primary goal at the time was to try and resolve my digestion issues as I was still unable to eat anything high in fibre as it caused too much discomfort. Amazingly, under her guidance and outlook on

nutrition and training, I was able to re-introduce foods I hadn't eaten in over five years. Never had I been so excited to eat green beans, cucumbers and kale! Come July, I was in amazing shape and loving my new found love of fitness, but most importantly I had also learnt how to love myself.

I had just returned from a work trip to Shanghai China when Maria suggested that I should compete. It had always been a dream of mine to get on stage but I never thought I would have a worthy physique.

I had a great competition preparation, which was intense but worth every minute. I was constantly eating, was never malnourished and my strength had increased. In October 2014, I competed in the Bikini Novice division at the INBA NSW Muscle and Fitness Model Show. Unfortunately I did not place, but I gained so much from stepping onto that stage and wearing my ostomy appliance with pride. I felt like a million dollars up there, and it felt like a reward for everything my body had been through over the past five years since falling ill.

There is something about being up on stage and competing; it's an experience that nobody can take away from you and you can't put a price on it. Never had I experienced such self-empowerment, pride and honour as

I did on that day. I really did have something that made me stand out from the crowd and the other competitors on the stage that day. It was a really proud moment for me.

I am currently having a good off-season where I can gain more muscle and change my physique with my coach, Maria, who has done absolute wonders for me.

This is only the beginning of my competition journey and I am so thankful to have such a supportive coach and good friend by my side who believes in me.

I hope that my journey inspires others to accomplish their goals and to not feel defeated by any obstacle thrown at them. If you believe in yourself enough, you can achieve absolutely anything, and I think I am a good example of this. Never had I let my ostomy hold me back. Rather it has motivated me to push myself beyond my own perceived limits to accomplish things that I never thought were once possible. ●

I Learnt How to Love Myself Again

Submitted by: **Kaitland Burrows, NSW**



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MAL'S STORY

Submitted by: **Mal Davis**, Qld

My journey really began on 15th March 2010 when the results of my Bowel Screening Kit returned positive.

My GP rang and asked me to see him as soon as possible and he arranged for me to have a colonoscopy. This was done on 22nd April and located a polyp in the lower rectal region. From this result my GP arranged for me to see a colorectal surgeon. CT-scans were then performed, which determined that surgery was necessary and that I might require a permanent colostomy bag.

Mentally I did not cope very well with this news and my darling wife and I were advised to go away and decide what direction to go in. I made contact with two naturopaths that we both knew and made appointments to see them both. They began to treat my cancer the natural way and I looked into all types of natural therapies.

All was going well until February 2012 when I contracted a golden staph infection (*staphylococcus aureus* bacteria) to seventy percent of my skin. My immune system was not able to cope so the cancer began to slowly grow and by the end of July 2012, I could feel a small haemorrhoid lump at my anus. I went to see my new GP and she felt inside my anus and could feel a thickening in the lining.

She again referred me to a colorectal surgeon and an appointment was made for the end of August. Upon examination the surgeon immediately arranged a CT-scan for me on 6th September and following this, a colonoscopy and rectal ultrasound in day-surgery on 20th September.

After recovery he led my wife and I into a private room and advised that I had two choices. The first was to do nothing and I would die a very painful death within twelve to fifteen months, at the most eighteen months. The second choice was to have major surgery with the removal of a large section of my colon and anus and having a permanent colostomy bag.

My wife and I arranged for a family get-together to discuss the results. It was a very emotional time and they all spoke of their love for me and did not want to see me die, so it was agreed I would have the surgery. I phoned the surgeon and he advised I would have five sessions of radiation treatment to be followed one week later by my surgery. Following this would be three sessions of chemotherapy.

I had my first appointment with the radiologist on 10th October, followed by my permanent tattoos (something I never thought I would have) two weeks later. My radiation treatment occurred from 5th to 12th November.

I was placed on the operating table on 19th November at 3:45pm 2012. After nearly three hours in the operating theatre and over two hours in recovery, I was wheeled up to the ward where my darling wife and family were waiting. I could not speak as I still had the oxygen mask over my face, but I put up my thumb to let them know that I was OK. They each gave me a kiss on the forehead and went home, leaving me to hopefully try and get some sleep.

During the night the nurses removed the oxygen mask, a unit resting on my chest and the electrodes stuck on my chest. Next morning, three nurses wheeled me into the shower/toilet area, removed my surgical gown and gave me a lovely wash. I could now see what was connected to me from the mobile trolley. To the left of my belly button was my new pouch, a small plastic tube was across my tummy and another one along my right side. These, I was told, were connected to a small bag which held black things that looked like miniature hand grenades. These were pain busters that would gradually get smaller over the next five days as their pain killing drugs slowly pumped into the surgery areas. Down my front, from belly button to crutch area, was a large dressing. Under my crutch to the top of my bottom was a large dressing and inserted into my penis was a catheter tube which went into my bladder and drained to a large bag hanging off my trolley.

It was so nice to have a clean gown put on. I was also feeling very hungry, but was told that I could only have clear soup and water until my stoma began to work, which at first would give lots of wind. Well they were not wrong!

There was many a tune coming from my pouch for several hours. Finally this messy stuff came through, which pleased the nurses and they then permitted me to fill out the meal menus. I ticked nearly every box and through the night asked the nurses if they could find me something to eat.

The next day a physiotherapist visited and asked me to suck into a device until all three balls were at the top of the tubes.

NATIONAL BOWELCANCER SCREENING PROGRAM

Hotline: 1800 118 868

Australia's National Bowel Cancer Screening Program (NBCSP) aims to reduce illness and death from bowel cancer through regular screening to support early detection.

The NBCSP is currently inviting men and women turning 50, 55, 60 or 65 to screen for bowel cancer. Participants are sent a free, easy to use screening kit that can be completed at home.

To invite you to take part in the program, your name has been drawn from either the Medicare or Department of Veterans' Affairs enrolment records.

In the 2014 Budget, the Australian Government announced a further \$95.9 million over four years to introduce two-yearly screening for all Australians aged 50 to 74.

Between 2015 and 2020, more age groups will be added to the screening program:

2015 – 70 and 74 year olds

2016 – 72 and 64 year olds

2017 – 68, 58 and 54 year olds.

People aged 52, 56, 62 and 66 will be included from 2018 to 2020.

By 2020, around four million Australians will be invited to screen each year, which could save up to 500 lives annually and significantly reduce the burden of bowel cancer on Australians and their families.

About Bowel Cancer

Bowel cancer is one of Australia's most common cancers, especially for people aged over 50.

In Australia, the lifetime risk of developing bowel cancer before the age of 75 is around one in 19 for men and one in 28 for women, which is one of the highest rates of bowel cancer in the world.

Around 80 Australians die each week from bowel cancer, but if found early it is one of the most curable types of cancer.

Bowel cancer develops when cells in the bowel lining grow too quickly, forming a clump known as a polyp or an adenoma.

Polyps are usually benign, but most bowel cancers develop from these tiny growths. Polyps can grow for several years before undergoing additional changes and becoming cancerous and spreading to other parts of the body.

Bowel Cancer Risk Factors

There are many different risk factors for bowel cancer. The risk is greater for people who:

- are 50 and over
- have a significant family history of bowel cancer or polyps
- have had an inflammatory bowel disease such as Crohn's disease or ulcerative colitis
- have previously had adenomas, a type of polyp, in the bowel.

You are considered to have a significant family history of bowel cancer if a close relative (parent, brother, sister or child) developed bowel cancer at a young age (under 55 years) or if more than one relative on the same side of your family has had bowel cancer. Your doctor can work out your risk and the best screening or other testing for you based on your individual circumstances.

More than 75 per cent of people who develop bowel cancer do not have a family history of bowel cancer.

You can lower your risk of developing bowel cancer by having a healthy diet, exercising regularly, reducing your alcohol consumption and quitting smoking.

Symptoms of Bowel Cancer

Bowel cancer can develop with few, if any, early warning symptoms.

Symptoms of bowel cancer include:

- bleeding from the rectum (back passage), or any sign of blood after a bowel motion
- a recent and persistent change in bowel habit, for example looser bowel motions, severe constipation and/or needing to go to the toilet more than usual
- unexplained tiredness (a symptom of anaemia)
- abdominal pain.

If you have symptoms you should see your doctor.

Treating Bowel Cancer

You will usually require surgery if bowel cancer is found. If the cancer is found at an early stage, the chance of a full recovery is high. Most people will be able to return to their current lifestyle and activities.

Source: Department of Health web site: www.cancerscreening.gov.au

Too easy I thought! Well, when the first ball was less than one third up the tube a pain went right thru my chest area. I had a lot to learn and recover from, but she did take me for a small walk down the corridor with all my packages hooked onto my trolley. Shopping would be so easy in future. After five days I managed to get all three balls to the top of their tubes. First challenge completed!

The Stomal Therapy Nurse visited that afternoon and advised me that the following morning she would take me through the procedure for changing my skin barrier {wafer}, pouch and cleaning around the stoma area. This was what I had not been waiting for. How would I cope?

Next morning, the Nurse first set up everything on my bed. I was propped up in bed and could see all that she was doing as she began removing the skin barrier, which allowed me to see my stoma for the first time. Well, when I saw him all my fears disappeared, he was so ruddy looking. As she began to clean around him I thought I must give him a name, so I chose to call him "Taffy". That was my nickname at school in the north of England, with my surname being Davis. So "Taffy" was cleaned, a new skin barrier and pouch attached and I thought we are going to be the best of friends for the rest of our lives. We never leave each other's side and we have no problem sleeping together. We are the best of mates as long as I keep away from corn off the cob!

The surgeon visited on the first day and advised that the operation went well and that all the tumour had been

removed. However, on the second day he visited again and his facial expression looked glum. They had a look at the pathology again and found the tumour to be of the aggressive type. He was not 100% sure if some cancer cells may be left in my system, so recommended that I have twelve sessions of chemotherapy and he would advise the oncologist of their findings.

The following day the oncologist came whilst my wife was visiting and advised that my treatment would be four to five hours at the Cancer Centre having a cocktail of chemo drugs administered and then be connected to a CADD unit which would pump the final chemo drug at a controlled rate over forty-six hours. As there were to be twelve chemo sessions he also suggested that I have a portacath inserted in my chest to give me more freedom of movement, especially through the night. He also advised that there would be very minimal side effects; no hair loss, just a slight tingling in the finger ends when I touched something cold and possible tiredness for a few days. I agreed to this treatment and on 17th December (my wife's birthday), I had the portacath fitted during day-surgery performed by the same surgeon who had done my major operation. The chemo would commence at a later date.

After five days the surgeon advised that my recovery was proceeding far quicker than expected, so that same evening I was disconnected from all the items connected to my trolley. It was so wonderful to go outside in the fresh air for a walk in the sun.

Continued page 22

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After seven days in hospital the surgeon advised me that I could go home and be cared for by an outside registered nursing organisation. These visits were to be twice each week to check my wounds, change my dressings and ensure that I was able to handle the changing and cleaning of my stoma. So with this in place I left hospital on 26th November.

The first session of chemo on 8th January went well, with no side effects. My second session started two weeks later and finished on Thursday when the pump was empty. However, diarrhoea started later that afternoon (around 5:30pm), so I took two Gastro-Stop as advised. Through the night the diarrhoea returned so I took more Gastro-Stop. This continued throughout Friday so on Saturday I phoned the Cancer Ward for advice. They suggested that I continue taking two Gastro-Stop each time I had diarrhoea.

By Monday morning I had taken twenty Gastro-Stop, so I again rang the Cancer Centre and they advised me to come in immediately. Upon arrival I was put on a drip, all my vitals checked and blood tests taken. The blood tests were OK and after ten hours I left to go home.

On Tuesday morning my hair began to fall out during my shower and the nails on my feet and hands turned purple. By Friday all my body hair had gone except for my moustache. The skin was peeling off the soles of my feet and palms of my hands. Ulcers formed in my throat and mouth along with tingling sensations like electric shocks in my mouth and on my fingers and toes. I could not eat anything so went out and got some baby formula and whey protein powder.

I began to lose weight rapidly and lost over ten kilograms in six days. I was feeling really weak, the diarrhoea was still there and "Taffy", my stoma friend, was really letting me know how uncomfortable he felt. By Monday morning my urine began to turn the colour of pomegranate juice, so I rang the Cancer Centre again and they advised me to get there immediately. Once there I was put on a drip, put into an isolation room and had all the tests done again. I really was a mess!

When my oncologist arrived and saw my condition he immediately instructed that I be admitted to the Ward. There, nurses took blood, urine and diarrhoea samples over the next eight days. My oncologist visited me every day, even as late as 11:00pm. I could see the concern on everyone's faces but nothing was showing up in my pathology results. My name must have covered all the cubicles in the pathology lab. A variety of drugs were tried until finally, on the morning of the fifteenth day, the diarrhoea began to slow, my waste began to slowly form and "Taffy" was beginning to feel himself again. I was finally discharged from hospital after sixteen days of continuous diarrhoea! My oncologist instructed that I take a complete rest and to phone him when I felt strong enough and advise if I would continue with the chemo.

Seven weeks later I rang him and told him I would continue although my darling wife and family did not want me to have any more chemo.

These decisions however, for all of you going through

or are about to go through chemo, are very personal. They are life and death decisions that we were making and if the chemo would prolong my life and kill any cancer cells in my body then I could not say "No".

On 2nd April I was to start three sessions of chemo at 25% strength. If anything went wrong, then I was to stop immediately and would cease having any more chemo. Fortunately they all went well.

I had another long break to go to a wedding in Adelaide. The oncologist thought this would do both my wife and I the world of good. It did! We had a great time, eating at many RSLs on the trip.

I continued my chemo again on 26th June, with seven sessions to go. The oncologist resumed me on 33% strength, and would increase it until the last session when it would be 100%. Praise the Lord, all went well, with only very minimal side effects.

I had more CT-scans at the end of October and these looked OK though there was one area the radiologist, oncologist and surgeon were not sure about. So they arranged for more CT-scans to be done at the end of January 2014. The suspicious area was smaller so it could not be a tumour. They believed it to be scar tissue or possible radiation damage. This was an exciting result for my oncologist and a few moist eyes were present in the room. No more scans or blood tests until August 2014!

I am now fully recovered. My body hair began to slowly return after three months and I now have a full head of hair again, darker colour than previously and curly, which I have not had for over twenty years. My blood counts are back in the normal range. New nails grew on my toes and fingers, which are almost as strong as before.

What a journey! I am so pleased that I made the decisions I did. It is now over eighteen months since the surgeon told my wife and me that if I did nothing then I would die a very painful death. We take one day at a time and rejoice each morning when I wake up and thank the Good Lord.

I cannot thank my darling wife enough for the unbelievable support that she has given me through this period and for my GP to send me to a very good and understanding surgeon, who in turn brought into our life a very learned and compassionate specialist oncologist. These along with a group of nurses whose commitment and dedication was way beyond all my expectations in a wonderful hospital environment.

Previously, I didn't travel by bus or train as there aren't any toilets on local transport, but now I can enjoy both without stress. I love the freedom of walking and driving anywhere for long periods of time without wondering if there is a toilet close by. My wife and I can now go out together and really enjoy ourselves.

To anyone who reads my journey, and is wondering how they will cope, I would say do not hesitate.

PS. One of my favourite foods is baked beans. Each time I have them "Taffy" sounds like an orchestra, even in the best of company. ●

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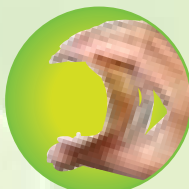
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Dementia: How did we get it so wrong?

Article by: **Dr Jane Tolman**,
Associate Professor of Aged Care

BA Dip Ed (Tas); M Ed (Ottawa); BSc(ANU);
MBBS(Tas); FRACP

Director of Aged Care,
Royal Hobart Hospital, TAS

I recently had the privilege of participating in the second running of the Massive Open Online Course (MOOC) on **Understanding Dementia** run by the Wicking Dementia Research and Education Centre at the University of Tasmania. This has provided a forum for learning and discussion about dementia for fifteen thousand carers, health professionals and interested persons from all around the world. More than that, the participants are able to seek answers to their questions, and to tell us their concerns about their "journey" and about their expectations.

I think there is much room for improvement in the way health professionals have dealt with dementia.

We handle the diagnosis of dementia very badly. Families complain that doctors are unwilling to make the diagnosis, defer the diagnosis, or deny the diagnosis (just getting old). Statistics tell us that only about forty percent of people with dementia ever get a diagnosis. There are established sets of criteria for diagnosis; but many of us still use a cut-off score on a basic cognitive test to make a diagnosis, maintain that a diagnosis can only be made post-mortem with a biopsy, or tell our patients that it is a diagnosis "of exclusion". While evidence suggests that the personal story ("history" in doctors' language) offers considerably more weight to a diagnosis than any examination finding or test, families still find it hard to put their case, present their information and are sometimes dismissed due to privacy issues.

Notoriously, people with dementia develop a lack of understanding of their situation. Doctors call this "lack of insight". People with dementia also lack skills required to make good decisions, to reason and to solve problems. These features of dementia are poorly recognised by many health professionals. And yet they can expose the person with dementia to extreme danger. Assessing cognitive capacity for decision-making can be challenging. Many clinicians are hesitant about providing an assessment, and many who do so, provide an inadequate assessment. It is essential that doctors embrace this role, and develop their competence in such assessments.



What families most want to know about dementia is what will happen as the condition progresses. When we do make a diagnosis, we rarely address this. Current staging systems of dementia tend to focus on what people can do rather than what their needs are, are often designed for research, and rarely address the real need: **how to provide dignity to very vulnerable people**. At the time of diagnosis, or soon after, loved ones (and the person with dementia where relevant) should be given information about the stages ahead and what they mean. There should be a "road map" to help people navigate the path.

Dementia is often described as a memory problem and clinics for its diagnosis and management are still sometimes labelled as Memory Clinics. It's time that we acknowledged that dementia is about a range of domains, including:

Cognitive - *memory, language, insight, judgement, planning, reasoning;*

Function - *inability to perform household and other tasks and ultimately personal care;*

Psychiatric - *commonly delusions, hallucinations and depression;*

Behavioural - *aggression, screaming, following, calling out; and*

Physical - *swallowing, continence, mobility and eating.*

Families and carers have the right to know the facts. When these symptoms of dementia arise, families should not be surprised and need to be able to recognise these as manifestations of the disease.

Dementia is a relentlessly progressive terminal illness. As a profession we have failed to identify dementia as a disease which has much more in common with

cancer than with forgetfulness. At the time of diagnosis of other neurodegenerative conditions such as Motor Neuron Disease, a palliative approach is often instituted from the start, and early decisions are made about future feeding and assisted breathing. But in the case of dementia, we often offer families few choices, because we have failed to recognise that quality of life will be compromised, or to identify the role quality of life plays in decisions about management.

The behavioural and psychological symptoms of dementia are common, and yet they are poorly understood by many of us. Many clinicians offer treatments which have little (or sometimes no) demonstrated usefulness and which have well documented adverse effects. We continue to offer medications which sometimes only work by virtue of their sedating effects, and we fail to communicate the facts to families. The best evidence from international data is that at best twenty percent of those with dementia who receive antipsychotic medication for the treatment of behavioural and psychological symptoms derive benefit. Despite this evidence, up to eighty percent of the residents of aged care facilities who have dementia are regularly taking antipsychotic medication.

Despite the rhetoric, we rarely practise holistic, person-centred medicine when it comes to dementia. This would mean the following: acknowledging that every person with dementia is a unique case; providing the knowledge which is essential in making wise decisions about management, and being aware of the evidence; ensuring that there is a decision-maker who can make informed decisions (in collaboration with the clinician); offering choices, and perhaps above all ensuring that this, of all conditions, requires a very clear focus on dignity for the person with dementia, and careful consideration of the best way of providing it. Management of dementia should always be a collaboration between the person with dementia, their loved ones, the medical team and paid carers.

The MOOC has taught me that we need to listen more to those who live with dementia; that is, to the carers, loved ones and professionals. We can provide good care for those with dementia but in many ways we need to go back to the basics. We also need to make sure that we listen to carers, engage them in management and acknowledge the critical role of education. ●

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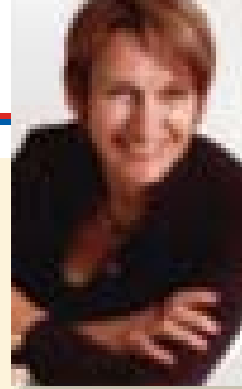
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**Dear Carmen**

I have had an ileostomy for eight years and prior to that a colostomy for twenty-five years. Over the last three years I have been troubled with kidney stones three times and possibly a fourth. Two of these stones were blasted by laser and the others I passed naturally.

I have been having ultra-sound scans and CT scans to monitor for further development of stones. These scans were ordered by my urologist and now seem to be ongoing. At my last visit my urologist pointed to my ileostomy whilst he was examining me and said *"That is a common cause of you developing stones"*, which was the first time I have been made aware of this.

When I Googled *"The relationship between Kidney Stones and Ileostomies"*, I found it to be a very common problem for people with an ileostomy and I discovered a considerable amount of information about the subject.

What I wish to find out is how I can minimise the incidence of forming more stones. I was able to capture one of the stones I passed and it was analysed as a Calcium Oxalate stone. Early on I asked my urologist how I can dissolve these and he replied that he could prescribe a drug which could be expensive over time, but that in his experience I would be better off eating two oranges per day, which he does himself. I have been doing this but am still producing stones.

On reading the blogs on various Web sites, it became evident to me that as an Ileostomate, it is very important that I keep myself well hydrated because not all of the water I drink passes through my kidneys. Instead, most of it passes from my body via my ileostomy. It seems to be very important to be well hydrated (i.e. don't drink water just to quench your thirst but drink water regularly to prevent being thirsty) and to consume oranges or drink lemon juice. Is this the best thing to do?

On looking through past *Ostomy AUSTRALIA* issues I found several articles about hydration and a small mention about stones in one issue.

Would you please explain the relationship between kidney stones and Ileostomates, and do you have any tips on how to minimise stone formation.

Any information would be appreciated. I am sure other Ileostomates would also be interested.

Regards, Neil Watson, QLD

Dear Neil

As you say, there is quite a lot of information on the internet about the relationship between kidney stones and ileostomies. I found a very old study (1981) that looked at over four-hundred people who had their ileostomies created in the 1950s to the 1970s. This survey identified about ten percent having kidney stones. I could not find any recent

studies to show what the current statistics would be.

Nowadays there are far fewer permanent ileostomies created. For most people with ileostomies these are temporary and they will have them for a period of three to twelve months. I know a lot of emphasis is placed on educating patients about maintaining adequate levels of hydration so that there is a normal urine output.

Maintaining hydration is not just about fluid intake, it is about fluid intake and electrolyte balance. So drinking fluid that also contains electrolytes is important. There are commercially available fluids such as Gatorade and Powerade or you can make up a solution called "St Mark's Electrolyte Mix" yourself.

Back to the kidney stones: you are right in saying it is because of less fluid making the journey through the glomerulus of the kidney to be filtrated and excreted as urine. The fluid that does arrive is higher in all the 'salts'

that can crystallise and form stones. There are many types of kidney stones not just calcium; there are uric acid and struvite or brushite stones. Who has ever heard of those?

In my reading in preparation for answering your question I found the answer more and more complex depending on how much and which part of the bowel has been removed and on what type of crystals/stones are likely to be formed.

When searching the internet for answers it is always prudent to check any advice with your renal specialist or gastroenterologist as not everyone is the same and there are different considerations.

Whether drinks that are high in Vitamin C (such as cranberry) or eating two oranges a day do anything is debatable depending on what type of stone one is forming.

Basically the effect of an ileostomy with a large bowel resection or an ileocaecal resection does put one in a higher risk category for urinary calculi (i.e. urine supersaturated with salt and minerals) and the best way for avoiding these is to maintain a good level of hydration so that one regularly passes pale coloured urine. Also be aware that kidney stones are a possibility if you start experiencing painful symptoms.

Sincerely, Carmen

**NEED MORE HELP?**

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

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1. Where can I obtain a catalogue of products which are available through the Stoma Appliance Scheme?

While there is no comprehensive “product catalogue” as such, the Stoma Appliance Scheme Schedule does contain details of products available to registrants of the Stoma Appliance Scheme (SAS). Details contained within the Schedule include a listed product’s SAS code, supplier code, description and maximum monthly allowance. The current Schedule can be found at the Department of Health’s website: **www.health.gov.au/stoma**

If using the Schedule to assist with product ordering, please be aware that there are restrictions in place for ordering multiple products with a similar purpose. To avoid confusion or disappointment, it is best to contact your Association for guidance when placing an order for more than one product with a similar purpose to ensure that your order does not exceed maximum Scheme allowances.

Before introducing a new product into your stoma care regime, it is essential that the advice of an appropriately qualified health practitioner such as your Stomal Therapy Nurse be sought to assess the suitability of the product for your individual circumstance.

2. I am planning my first overseas trip later this year. Do you have any tips for travelling with a stoma?

While having a stoma should not stop you from travelling, there are always risks associated with any travel including delays, lost luggage and unexpected illness. Taking a few precautionary “stoma related” measures may help to make your travel more enjoyable and reduce the impact of unexpected nasties along the way:

- Pack plenty of ostomy supplies (pouches, etc); at least one-and-a-half times more than you would normally use. Removing appliances from boxes and repackaging them in clean plastic bags will help to make carriage much easier;
- Keep a good supply of appliances in your hand luggage, just in case your luggage goes astray. If using a “cut to fit” appliance, remember to pre-cut the appliances and to stow scissors or sharp

objects with your checked luggage;

- When travelling by aircraft, try to book an aisle seat so that you don’t have to climb over other passengers for trips to the toilet;
- If you normally use closed bags, pack a few drainable bags in case of changes in bowel habits;
- Take steps to prevent or cope with an onset of diarrhoea. If carrying medication, remember to check if the medication is legal in your destination country/s and to carry a Doctor’s letter explaining that the medication is for your personal use;
- Stay well hydrated (bottled water!) and be extra careful with your choice of foods, especially those that may have been washed, such as salad vegetables;
- Obtain a “Travel Certificate” from your Association. The Certificate explains your condition in a number of languages and may come in handy if you experience problems at any country entry/exit points;
- Ensure that you have adequate travel insurance! Check your policy thoroughly to ensure that any pre-existing medical conditions and your stoma are not excluded;
- Obtain a list of medical professionals and ostomy associations local to your destination. Information about international associations may be available on the International Ostomy Associations Inc website: **www.ostomyinternational.org**;
- Find out if the country/s you are travelling to have a Reciprocal Health Care Agreement (RHCA) with Australia. Information about RHCA’s can be found at: **www.humanservices.gov.au/customer/services/medicare/reciprocal-health-care-agreements**;
- Check the **Travel Secure** website (**<http://travelsecure.infrastructure.gov.au/>**) and familiarise yourself with your right to privacy if your ostomy is detected by a body scanner in an Australian international airport. ●

Please send your “Ask Kylie” questions via email to **feedback@australianstoma.com.au**

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A Mathematical Explanation of Success Something more to think about...

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There is a strictly a mathematical explanation that might help you answer these questions, and it goes like this:

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A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

is represented as:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26

Then:

H - A - R - D - W - O - R - K

$8 + 1 + 18 + 4 + 23 + 15 + 18 + 11 = 98\%$

and

K - N - O - W - L - E - D - G - E

$11 + 14 + 15 + 23 + 12 + 5 + 4 + 7 + 5 = 96\%$

but

A - T - T - I - T - U - D - E

$1 + 20 + 20 + 9 + 20 + 21 + 4 + 5 = 100\%$

So, one can conclude with mathematical certainty that hard work and knowledge will get you close but it is attitude that will get you there.

It has an indisputable mathematical logic and now you know why some people are where they are!

100%



Bulletin Board

OSTOMY ASSOCIATION OF MELBOURNE INC.

We have moved!

Our new address is:
Burwood Industrial Park
Unit 14, 25-37 Huntingdale Rd
Burwood, VIC 3125

Telephone: (03) 9888 8523

Fax: (03) 9888 8094

Email: enquiries@oam.org.au

CHANGE OF MEETING VENUE

Benalla/Wangaratta Ostomates Group

We have obtained the use of the Masonic Centre in Benalla, situated on the corner of Benalla Street and Walker Street, for our meetings in February, June and October.

Enquires: Contact Rex Nankervis on 0417 318 834

NEW OSTOMY SUPPORT GROUP

Tweed Stoma Support Group

Meets: 12 to 2pm on the third Tuesday of March, June, September and December.

Venue: South Tweed Sports Club.

Enquires: Contact Jane Bright on 0409 671 162

ANNUAL GENERAL MEETING

Young Ostomates United Inc

Please join us at our Annual General Meeting and listen to our Guest Speaker, Melanie McGrice. Melanie is a Dietician from "Nutrition Plus" who specialises in Inflammatory Bowel Disease (IBD) and food intolerances, etc.

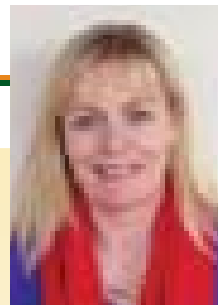
Where: Nurse's Memorial Centre, Slater Street (off St Kilda Road), Melbourne

When: Saturday, March 28th starting at 10:30am

Please contact Helen Ebzery via email (helshae@hotmail.com) if you would like to attend the AGM so you can get a better idea of numbers for catering purposes, etc.

AASTN President's Report

Submitted by **Kirsti Dixon** - AASTN National President (Australian Association of Stomal Therapy Nurses)



Welcome to 2015. What a summer we have had so far. I hope that everyone had a lovely Christmas and you are looking forward to a brand new year. To all our colleagues in South Australia who have been affected by the bush fires, you are in our thoughts and prayers.

What a year this will be with our 40th AASTN National Conference being hosted by Victoria in October. This will be held in conjunction with the Asia Pacific Federation of Coloproctology Congress and the Spring CME meeting. Of course it is in a fabulous area and spring is a beautiful time of year in Victoria. It is a great time for colleagues to get together within this great nation of ours, to share ideas and catch-up.

The AASTN Executive are continuing to meet monthly during the year via Skype. We have had January off, but will be in to the full swing of things come late January or early February.

Don't forget that the AASTN has a fantastic website that is open to the public. It has some great leaflets and links to other sites. Go to **www.stomaltherapy.com** or just Google "AASTN"!

Till next time, Kirsti.

If You Think You Can't 😊

If you think you are beaten, you are.

If you think you dare not, you don't.

If you'd like to win but you think you can't, it's almost a cinch you won't.

For out in the world you'll find success begins with a person's will.

It's all in the state of mind.

Think big, and your deeds will grow;

Think small and you fall behind.

Think that you can, and you will.

It's all in your state of mind.

If you think you are outclassed, you are.

You've got to think high to rise.

You've got to be sure of yourself before you can ever win a prize.

Life's battle doesn't always go to the stronger or faster one;

But sooner or later, the one who wins is the person who thinks they can.

AUTHOR UNKNOWN

Corsinel®

The strong upper part of Corsinel underwear supports the hernia

Designed as regular underwear

Comfortable to wear and supportive fit

Easy to put on

Available in low and high waist

Re-establishes a normal body profile

Latex free

Lace Briefs and Boxers - now available on the Stoma Appliance Scheme! 3 FREE pairs per year

Optimal balance between compression and comfort

Corsinel has been developed especially to support a parastomal bulge which has appeared in connection with a stoma.

The upper part of Corsinel underwear supports the hernia and makes the user look good. The lower part is made from a softer material making the garment easier to apply and take off. The combination of the two kinds of material makes Corsinel more comfortable and makes it stay in place.

www.corsinel.com.au

Regular Briefs also available on the SAS or for purchase online at www.statina.com.au

It was early 2013 and I was a healthy twenty-year-old, working a full time job and living an active life. I also knew that I had Crohn's Disease but did not fully understand it until everything changed one night while I was on holidays visiting my parents. I suddenly felt a shot of agonising pain in my right side and couldn't move until about an hour after the pain had settled. My parents took me to the local GP the next day but as I was returning home there wasn't a great deal he could do except put me on antibiotics for a week.

After finishing the antibiotics I still had pain and that was when I definitely knew something was wrong. That night I took myself to the closest hospital thinking it was just a flare-up and they would give me something then send me on my way, but this wasn't the case. I was not aware that my life was about to dramatically change.

Doctors came and went, taking me for an MRI, CT-scans and ultra-sounds until I was finally told I would need surgery as my bowel had perforated and a large abscess had formed on the outside of my intestines. The doctors were also concerned for my ovaries as the scans indicated they had suffered as well but we wouldn't know exactly until they did a procedure.

Being a young girl with no family nearby I was terrified, panicking and thinking of all the "what ifs" and "why". Luckily my family were on the next flight and at my side by the next morning. That day I was transferred to another hospital and scheduled to have surgery two days later.

On 14th March 2013 a surgeon came to explain what would be done. He told me how badly damaged my bowel had become and spoke to me about the possibility of waking with an ileostomy. The thought of this instantly overwhelmed me and I was devastated.

I was just two weeks from turning twenty-one and I might have an ostomy bag after the operation! How would I cope with this? I had endless thoughts running through my mind but my family told me to stay positive. It might not even happen and they are just preparing you for the worst, they said. I went to bed that night knowing the next day was going to be hard and things would change.

On 15th March I awoke early as I was to be the first procedure that morning. I said goodbye to my family and before I knew it I was awake. It was all over, but I felt like I had been hit by a truck. I couldn't move or do anything and the pain was horrible. I was in and out of sleep for the next day, dosed up on strong medications to help with the pain, but with my family right beside me the whole time.

The surgeons explained that my bowel was one of the worst they had seen and that a planned four hour procedure had turned into an eight and a half hour operation. They had managed to save my ovaries which would be fine but they had no choice but to give me an ileostomy as my bowel

was badly ulcerated. At first I wasn't too worried as I was so focused on the pain and wanting to feel better.

After a week in hospital I should have been getting better but wasn't. I couldn't hold food down and constantly felt sick. So once again the doctors did more scans and found that I had developed haematomas so it was back to theatre again.

That night I awoke feeling much better and could now eat and drink. Things were finally looking up. Five days later and having been in hospital for fourteen days, I now weighed thirty-nine kilograms but I was going home!

This is when everything hit me! I broke down about possibly having an ileostomy for the rest of my life. I thought it would change my life dramatically and people would look at me differently. I was just devastated!

I spent the next eight weeks at home with my family, recovering and rebuilding my strength, getting my appetite back. It was then that I realised I needed to look at the positives. I told myself this has happened and crying won't change a thing but just might make me feel worse. So I

decided to make the best of a bad situation. I told myself that other people go through worse things every single day and this ileostomy operation had saved my life. Without this bag I probably wouldn't be here.

This rethink really changed my outlook on life and made me appreciate every little thing. There is a saying that "it is the little things in life". Well it really is.

I was scheduled to have my reversal done in June 2013. I was so excited but received a phone call two days before advising that my surgeon was sick and they didn't know when I would have my surgery. I was disheartened but luckily it was rescheduled to two weeks later.

I had my ileostomy bag for four months before it was successfully reversed. It was a very long hard journey but I got there in the end. This experience would have been a lot harder if not for the ongoing support from my wonderful family.

I am now healthy and happy, weigh sixty kilograms and am really loving and appreciating life. I know that having tackled this I am now ready for anything. This nasty disease can come back at any time but I am determined not to let it rule my life.

Everything in life happens for a reason. Although I wasn't grateful at the time, I am now so thankful for my bag, not only because it saved my life but because it has helped to shape me into the person I am today.

I'm hoping that my story can help other young people going through the same thing. There is always a positive in your negative - you just have to find it. ●



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Simplicity® stoma support wear is made from a lightweight breathable fabric which contains no cotton. Soft and comfortable, the two-way stretch fabric allows you to move around freely, while ribbing on the front provides a flush finish, making your pouch virtually invisible. And now, our ladies' briefs and unisex boxers are available in a discreet, neutral colour – perfect under any clothes.



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It was a bright sunny day when Young Ostomates United (YOU) celebrated its 25th Birthday at the Nurses Memorial Centre on 29th November 2014. The weather depicted the mood of the day; it was a wonderful get-together of friends, old and new. With eight trade displays, we were grateful for all the company support.

It wouldn't be a party without music, so we had Dave Sutton on guitar, Andy on drums and Sarah playing and singing. Many thanks to Dave and his special friends! This was followed by our own Bek who sang three beautiful songs that had us all clapping and cheering. A special moment and it was also fitting that Kerrie (Bek's mum) won the Christmas Hamper.

What a wonderful venue the Nurses Memorial Centre is with so much room and its first class facilities, though it was a pity that the parking was a nightmare! The food was delicious and varied, thanks to Helen's two lovely girls who worked in the kitchen. A highlight was the Birthday cake, which Anne organised. The photo on the cake was taken at YOU's first country visit to Rutherglen, where all members wore "I belong to YOU" T-shirts.

Jane chaired the day's proceedings, making sure we kept to time, particularly when Anne, Jane and I presented the "Story of YOU over 25 years". This will be edited and made available to members in the New Year and on our webpage. It was also a pleasure to present Ros Mulholland and Dave Sutton with their Life Membership certificates.

Thank you to all who joined our celebrations. One of Helen's favourite expressions is "There is no 'I' in team" and so much work goes into these events behind the scenes thanks particularly to Helen, Anne and Jane.

YOU would not be viable today if it had not embraced social media. A special thankyou to Mike Petrescu (who manages the regular updates to our webpage) and to the YOU Facebook family which is growing daily. Following are a few YOU web statistics:

Website Visitors since 3/10/03 – **12,000**

Major website visitor sources since Jan 2013 – **33.6% Australia, 30.9% USA, 12.5% Brazil**

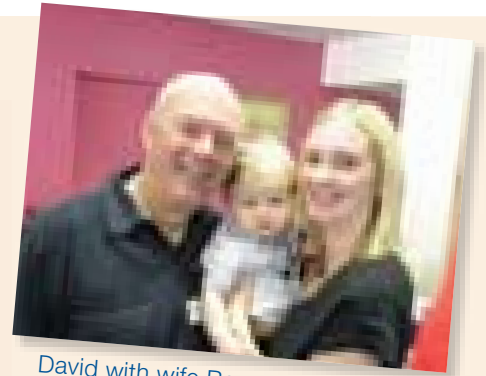
Countries of Website visitors since Jan 2013 – **71**

Twitter – **86 followers/18 tweets**

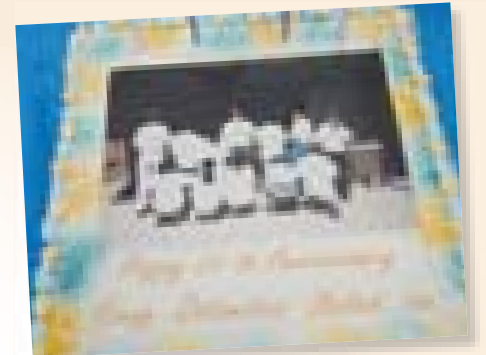
Facebook – **48 likes**

To commemorate YOU's Birthday all members were given a magnet showing the YOU logo and web address.

As the founder of YOU I feel justifiably proud of our achievements over the years, and that YOU is still giving help and support to younger Ostomates and their families in their time of need.



David with wife Bec and son Timmy



Helen, Anne and Paul



Jane, Anne, Lilian, Helen and Susan



Jane and Susan

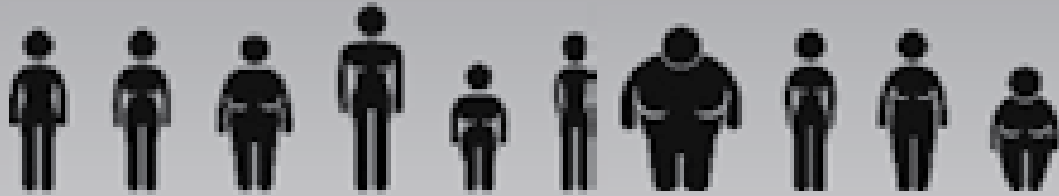


Bek



Genevieve and Lilian

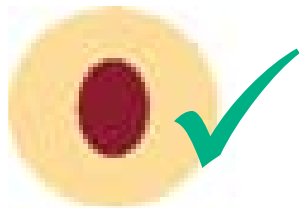
People come in different shapes and sizes and so do stomas!



Do you want to give the skin around your stoma the BEST PROTECTION there is?

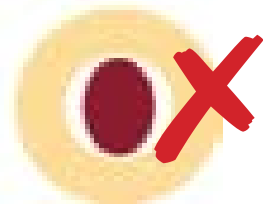
Then use the world's top selling seal, Eakin® Cohesive, and experience the difference.

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Cohesive
Seal

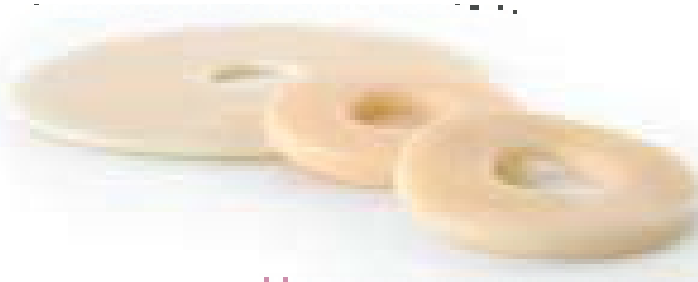


An Eakin® Seal hugs your stoma's exact shape & gives you the best skin protection possible.

A Pre Cut
Seal



A Pre Cut seal leaves gaps and can result in sore, red irritated skin.



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* Effect of a long life ostomy seal on faecal enzyme activity by " Grace McGroggen, TG Eakin & Dr Lorraine Martin, Queens University Belfast

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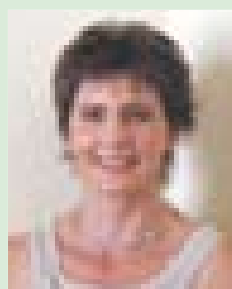
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Nutrition for Ostomates

Submitted by: **Margaret Allan**, VIC



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

Margaret is based in Melbourne and is available for clinical or Skype consultations by

appointment. She can be contacted via email on: margaret@foodfirst.com.au

In this article Margaret discusses dietary solutions to manage Lactose Intolerance.

Lactose is the sugar molecule found in milk. It is digested by the enzyme lactase that is secreted by intestinal cells. Lactase activity is highest immediately after birth so infants can digest milk appropriately, but in the majority of people lactase activity declines dramatically during childhood and adolescence to about five to ten percent of the activity at birth.

Only a small percentage of people (approximately thirty percent) retain enough lactase to digest and absorb lactose efficiently throughout adulthood.

Lactase deficiency may also develop when intestinal cells are damaged by disease (e.g. coeliac disease), surgery, prolonged diarrhoea or malnutrition.

A decline in lactase activity can lead to poor digestion of lactose, otherwise called lactose intolerance.

When more lactose is consumed than the available lactase can digest, the lactose molecules remain in the digestive system undigested and attract water. *This causes bloating, abdominal discomfort and diarrhoea that may or may not be frothy.* The undigested lactose also becomes food for intestinal bacteria, which multiply and produce gas which leads to flatulence. These symptoms usually begin between thirty minutes and two hours after consumption of dairy foods, and the severity of symptoms depends on the quantity of lactose that was ingested, and how much lactase activity remains within the digestive system of the individual.

I have put together the following table, which illustrates the different amounts of lactose in a range of dairy products from lowest to highest per 100 grams or 100 millilitres of food:

From this table we can see that some cheeses (Parmesan, blue vein, cheddar, camembert, brie and feta) and dark chocolate have no or very low levels of lactose, whereas buttermilk, cow's milk, dips made from cream cheese and both white and milk chocolate contain a much greater quantity of lactose.

Generally speaking, people who are lactose intolerant can still tolerate some lactose, usually up to twelve grams of lactose per day or up to four grams per meal. More than this may lead



Food		Lactose (grams)
Parmesan cheese	100 g	0
Blue vein cheese	100 g	0
Cheddar cheese	100 g	0.1
Camembert cheese	100 g	0.1
Brie cheese	100 g	0.1
Feta cheese	100 g	0.2
Chocolate (dark)	100 g	0.4
Cream cheese spread	100 g	0.4
Cream	100 ml	1.8
Haloumi cheese	100 g	1.8
Cottage cheese	100 g	1.9
Ricotta cheese	100 g	2.0
Sour cream	100 ml	2.5
Cream cheese	100 g	2.5
Ice cream	100 ml	3.3
Cheese cake	100 g	3.4
Goat milk	100 ml	3.7
Cheddar cheese spread	100 g	3.8
Custard	100 ml	4.1
White sauce	100 ml	4.7
Yoghurt	100 ml	5.0
Buttermilk	100 ml	5.6
Cow's milk	100 ml	6.3
Cream cheese dip	100 g	6.4
Chocolate (white)	100 g	10.2
Chocolate (milk)	100 g	11.6

Reference: Food Standards Australia and New Zealand NUTTAB
2010 Online Database

to the abdominal symptoms outlined previously. However, please note that lactose intolerance is not a serious threat to health, and can be managed via dietary modification.

We don't always consume 100 grams or 100 millilitres of a food, so the following table shows the lactose content of everyday serving sizes of common dairy foods:

Food

		Lactose (grams)
Butter	1 tbs	0.1
Cheese (Cheddar, Blue Vein, Brie, Feta, Edam, Gouda, Swiss)	30 g (size of a matchbox)	0.1
Cream	1 tbs	1.0
Sour cream	1 tbs	1.0
White sauce	2 tbs	1.0
Chocolate (Milk, White)	50 g (approx. 2 rows)	5.0
Ice cream	2 scoops	6.0
Custard	½ cup	6.0
Goat's milk	1 cup	9.0
Yoghurt	200 g tub	9 - 10
Cow's milk	1 cup	12 - 14

Please note that the above figures are provided as a guide only, as the amount of lactose can differ within a product range according to fat content and added substances such as fruit, chocolate, nuts etc.

Therefore, if you are lactose intolerant, it is advisable to avoid large quantities of:

- milk and all milk-based products (unless they are lactose free)
- cream, sour cream, crème fraîche
- most kinds of yoghurt (some very acidic yoghurts tend to contain less lactose because the bacteria in the yoghurt help to digest the lactose)
- cottage cheese and cheese spreads (hard, aged forms of cheese, such as parmesan and cheddar, contain very low levels of lactose so they may be tolerated)
- sauces made from milk or cream, such as white sauce, cheese sauce, etc
- quiche, frittata, flans, pancakes, custard, batter and other products containing milk
- rice and other forms of pudding made from milk products
- most home-made cakes, as they tend to contain milk (products made from butter but not milk such as biscuits, cookies and pastry are usually better tolerated)
- sheep and goat's milk (these contain less lactose than cow's milk but are not lactose free)
- ice cream, as this can be particularly difficult for people with lactose intolerance to digest (not only is the ice cream made from milk, but extra lactose is often added to improve the texture)
- packaged dessert mixes, as these tend to contain lactose
- chocolate made from milk products
- any food containing the words 'milk solids' or 'non-fat milk solids' on the product label (lactose is added to many processed foods, including breads, canned and powdered soups, cookies, pancakes mixes, powdered drink mixes such as flavoured coffee, Milo, Ovaltine,

drinking chocolate, processed breakfast cereals, processed meats and salad dressings)

- lactose in medicines (lactose powder is used in many tablets and capsules to bulk up the drug)
- lactose-based foods on an empty stomach

Milk and dairy products often provide the main source of calcium in the diet, and there is a high need for calcium in the body to keep bones strong and healthy, especially in older individuals. There can therefore be a concern about calcium intake when dairy products are removed from the diet.

Some alternatives to milk and dairy products to consider are:

- lactose-reduced cow's milk (e.g. Zymil or long-life milk that is labelled as 'lactose free')
- soy, rice, oat or almond milk
- soy cheese such as Mini Chol
- soy yoghurt
- soy ice cream
- gelati
- very acidic/tart yoghurt
- chocolate made from carob
- food labelled 'suitable for vegans'



However, there are other food sources of calcium, such as:

- almonds (which I would recommend in small amounts in the form of almond spread as found in the health food section of most supermarkets)
- firm tofu
- apricots
- calcium-fortified orange juice (in small amounts at a time so as not to loosen output)
- tinned salmon containing softbones
- sardines with soft bones
- spinach (in small amounts and chewed well to avoid the risk of a blockage)
- broccoli (cooked and eaten in small amounts or as a soup to avoid the risk of a blockage)
- dark green leafy vegetables (in small amounts and chewed very well to avoid a blockage)
- sesame seeds (which I recommend in the form of tahini for Ostomates)
- calcium fortified soy, oat, almond or rice milk



As always, my recommendations when extending the diet and incorporating new foods into the menu are to try a small amount at a time, eat slowly, chew food really well and wait a few days to determine the response.

Wishing you good health and happy days, Margaret.

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: Tandra (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
12 Feb - 9 Apr - 11 Jun - 13 Aug - 8 Oct - 10 Dec
Venue: Club Coffs, West High Street, Coffs Harbour.
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 in Room 4 at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries: Jennifer (02) 6586 0270

ILLAWARRA

Meet: 10.00am to 12 noon on Wednesdays 18 Feb – 19 Aug – 22 Apr – 21 Oct – 10 Jun – 16 Dec in the Education Room, Figtree Private Hospital,
1 Suttor Place, Figtree 2525.
For further information, contact Helen Richards STN on
(02) 4225 5046 (Monday only)

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 last Saturday in Feb - May - Aug (AGM) - Nov.
Venue: Hamilton Wesley Fellowship Hall,
150 Beaumont St. Hamilton.
Enquiries: Geoff 02 4981 1799 or Eleanor (02) 4997 5141 or Maree (02) 4971 4351

ORANGE & DISTRICT

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

SHOALHAVEN

Meet: 2.00pm on 2 Feb - 11 May -17 Aug - 16 Nov
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).
2015 meeting dates to be advised.
For further information, please contact: Diane or Lu (STNs) on
(02) 8738 4308

SYDNEY - PENRITH AREA

Meets: 27 Feb - 24 Apr - 26 Jun - 8 Sep - 6 Nov commencing 2.00pm.
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 - SOUTH-WEST AREA

Meet: Saturdays 3pm-5pm on 2 May – 22 Aug in the Macarthur Room and 6:00pm on 21 Nov in the club's Bistro Restaurant for our Christmas Dinner.

Venue: Revesby Workers Club, 2b Brett St. Revesby (closest parking at front of Club).
Contact: Ann-Maree McDonald STN
Phone: (02) 9722 7196

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

SYDNEY - ST. GEORGE / SOUTH EAST AREA

Meet: 11.00am first Wed. each month Feb through to Dec
Community Centre, Premier Street. Kogarah
Contacts: June: (02) 9311 0201
Allan: (02) 9556 3268

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

Meetings on first Monday of the month from 10am to 12 noon.
Venue: Horizon Club, Yathong St, Wagga Wagga (located rear of Yathong Lodge, Wagga Wagga Base Hospital)
Enquiries: David (02) 6971 3346 or 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: rexmar@bigpond.com

OSTWEST

Meetings held third Monday of the month in February, May, August and November.
7-9 pm at Melton Health,
195 - 209 Barries Rd, Melton VIC 3337
Contacts: Jenny Brown
(03) 9746 9121
Tricia Young (03) 9743 5868 or 0416 128 069
Cheryl Prendergast (STN):
9747 7600 (Tuesday and Fridays, every second Wednesday).

MILDURA

Meet: Every third month
Venue: Mildura Base Hospital Conference Room
Contact: Tandra (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

NORTHERN

A Melbourne based Support Group with a welcome to all with a stoma.
Venue: Darebin RSL Function Room, Preston.
Contacts: Peter: (03) 9460 1125 and Krys: (03) 9431 2779
STN Email enquiry:
genevieve.cahir@nh.org.au

SOUTH GIPPSLAND

Meetings 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

WESTERN AUSTRALIA

ALBANY

Meet at Albany District Hospital Conference Room
At 9.30 -11.00am. third Friday every three months
For details: Terry: (08) 98474701

BUNBURY

Meets:1.00pm second Monday of every second month. Feb - April - June - Aug - Oct - Dec
Venue: Cancer Council Meeting Room, Plaza Street, Bunbury.
Contacts:
Kevin Jones: (08) 97959229
Fiona: (08) 97216797

GERALDTON

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

MANDURAH / ROCKINGHAM

Meet third Friday of each second month from Jan.
Meetings are held at different locations each time normally over a barbecue lunch.
Visitors welcome.
Contact: Bethwyn: 0439 927 491

QUEENSLAND

BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre,
10 -18 Mt. Warren Blvd. Mount Warren Park QLD.
Contact: Pat Miers (07) 3827 9811

LOGAN

Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre Corner Wembly & Ewing Roads
Contact: Pat Miers (07) 3827 9811

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

BRISBANE

Operated in the Greater Brisbane Area by QLD Colostomy Assn and QLD Stoma 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

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 Headland Bowls Club, Syd Lingard Drive, Buderim
Meetings commence at 10am on the third Monday of even numbered months. Enquiries:
Winifred Preston: (07) 5476 6313
presto1849@hotmail.com
Evon Fuller: (07) 5447 7158
eful@bigpond.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 3.00 pm to 4.15 pm.

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

2015 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

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



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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

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Phone: +61 3 9569 2329
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Website: www.futenv.com.au



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