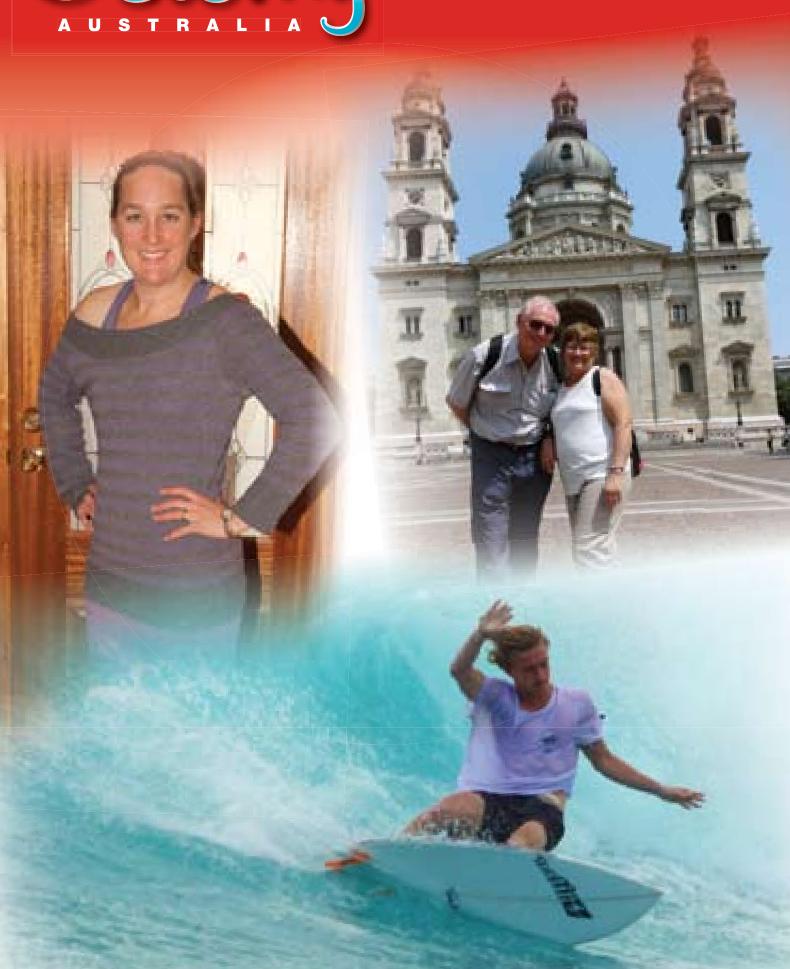


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National Directory of Stoma Associations

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

AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSN INC.

Second Floor, ACT City Health Centre, 1 Moore St, Canberra City, ACT 2600 Postal Address: GPO Box 1260, Canberra City, ACT 2601 Telephone/Fax: (02) 6205 1055 Website: www.actstoma.org.au 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: Carole Forsyth

NORTHERN TERRITORY

CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House 25 Vanderlin Drive, Casuarina Phone: 08 8927 4888 Fax: 08 8927 4990

Email: ostomy@cancernt.org.au Web: www.cancercouncilnt.com.au

WESTERN AUSTRALIA

WA OSTOMY ASSN INC.

15 Guildford Rd, Mount Lawley 6050 Telephone: (08) 9272 1833 Fax: (08) 9271 4605 Enquiries email: waostomy@waostomy.asn.au Orders Email: orders@waostomy.asn.au

Operating hours and appliance pickup: Mon, Tues, Thurs 9.00am -

Secretary: Jess Whitehouse

NEW SOUTH WALES

COLOSTOMY ASSN OF NSW INC.

5/7 - 29 Bridge Road, Stanmore 2048 Telephone: (02) 9565 4315 Fax: (02) 9565 4317 Operating hours: Mon to Thurs 9.00am - 4.00pm Friday 9.00am - 2.00pm Office Manager: Mrs Jenny Kemp Secretary: Norma Toohey Telephone: (02) 9565 4315 Email: ostomy@iinet.net.au Website: www.ColostomyNSW.com.au

OSTOMY NSW LTD

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

QUEENSLAND

GOLD COAST OSTOMY ASSN INC.

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

NTH QLD OSTOMY ASSN INC.

Shop 4, 52 French Street, Pimlico Telephone/Fax: (07) 4775 2303 Fax only Mondays & Thursdays All correspondence & orders to: PO Box 1017 Hyde Park, Castletown 4812 Operating hours: Monday 9.00am - 4.00pm Thursday 9.00am to 3.00pm Secretary: Barbara Myles A/H (07) 4775 2303

QLD COLOSTOMY ASSN INC.

22 Beaudesert Rd, Moorooka 4105 P.O. Box 198 Moorooka 4105 Operating hours: Tues & Thurs 9.00am - 3.30pm Secretary: 07 3848 0138 Fax: 07 3848 0561 Email: admin@qldcolostomy.org Web: www.qldcolostomy.org

QLD STOMA ASSN INC.

4/10 Valente Close, Chermside 4032 Telephone: (07) 3359 7570 Fax: (07) 3350 1882 Website: gldstoma.asn.au Operating hours: Mon, Tues & Thurs 8.30am - 2.30pm Emergency No: (07) 3359 7570 PO Box 370, Chermside 4032 Email: admin@qldstoma.asn.au

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

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

WIDE BAY OSTOMATES ASSN INC.

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

SOUTH AUSTRALIA

COLOSTOMY ASSN OF SA INC. (C.A.S.A.)

160 South Road, Torrensville 5031 Telephone: (08) 8354 2618

Fax: (08) 8354 2621

Email: colosa@colostomysa.org.au Operating Hours

Mon - Fri 10.30am - 2.30pm Secretary: Ruth Horne

ILEOSTOMY ASSN OF SA INC.

73 Roebuck St. Mile End. SA 5031 Telephone: (08) 8234 2678 Fax: (08) 8234 2985 Office hours: Mon-Fri 10am to 2pm Distribution times: Tuesdays 10am to 2pm 1st & 3rd Tuesday evenings 7pm to 8pm.

Secretary: Dawn Osborne Telephone: (08) 8268 3645 Email: ileosto@bigpond.net.au

TASMANIA

OSTOMY TASMANIA INC

Amenities Building, St. Johns Park St. Johns Avenue, Newtown 7008 P.O. Box 280, Moonah 7009 Telephone: (03) 6228 0799 Fax: (03) 6228 0744 Operating hours: Mon 9.00am - 3.00pm Tues 9.00am - 1.00pm Sec/Treas: Sue Hoyle

Email: admin@ostomytas.com.au

VICTORIA

BENDIGO & DISTRICT OSTOMY ASSN INC.

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

COLOSTOMY ASSN OF VIC.

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

GEELONG OSTOMY INC.

Geelong Ostomy Inc. 6 Lewalan St. Grovedale VIC 3216 Postal Address: PO Box 1069, Grovedale VIC 3216 Telephone: (03) 5243 3664 Fax: (03) 5243 6335 Email: goinc@geelongostomy.com.au

Website: www.geelongostomy.com.au

Operating hours: Monday,

Wednesday, Friday 9.30am to 2.30pm Administrator: Joanne Holmes

ILEOSTOMY ASSN (VIC) INC.

Suite 322, 3rd Floor, The Block, 98 -100 Elizabeth Street, Melbourne VIC 3000 PO Box 32, Flinders Lane. VIC 8009 Telephone: (03) 9650 9040 Fax: (03) 9650 1723 Email: ileovic@three.com.au Web Site: www.ileostomyvic.org.au Operating hours: Appliances Mon to Thurs 9.30am - 2.00pm Emergency Contact: (03) 9311 5658 Contact: Terry Carver

OSTOMY ASSN OF MELBOURNE INC.

Axxess Business Park. 71/170 Forster Road, Mount Waverley VIC 3149 Telephone: (03) 9543 1224 Fax: (03) 9543 1994 Email: enquiries@oam.org.au and orders@oam.org.au Manager: Sue Read Operating hours: Mon to Fri 9.00am - 4.00pm STN by appointment only - Tuesday only: 9.30am - 2.30pm

PENINSULA OSTOMY ASSN INC.

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

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Equipment Distribution Centre, Royal Children's Hospital. Flemington Road, Parkville 3052 Telephone: (03) 9345 5522 Fax: (03) 9347 5046 Operating hours: Mon to Fri 8.30am - 4.30pm Orders: 24-hours notice Coordinator: Mrs Jacque Harrison

WARRNAMBOOL & DISTRICT OSTOMY ASSN INC.

279 Koroit St. Warrnambool 3280 Telephone/Fax: (03) 5563 1446 warrnamboolostomy@swh.net.au

Operating hours: Friday 12 noon - 4.00pm Secretary: Lois Thwaites

Website: www.ostomynsw.org.au



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Ostomates Dana Kroenert, Tom Klein and Mitch Hayes (clockwise from top left).



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

From The Editorial Desk

What a great response to our August issue, with many more letters and emails received than normal. It is certainly the most I have seen in my short stint as journal Editor and a great sign for the future of our journal. Hopefully it wasn't just the winter weather which allowed you more time to put pen to paper (or fingers to keyboard), and that you will send in many more over the summer months.

In particular, the article written by Sarah Larcombe ("Sarah's Story - Appreciate the Life You Have") for our last issue prompted quite a few letters complimenting her on her positive outlook and courage. Several of these letters are from other young ostomates, all with a similar positive approach to life and the unexpected independence they gained after their operations.

Thank you to all those who responded to our "Like to be on the front cover of this journal" appeal by sending in their photograph and story. Unfortunately we could not use them all on the front cover of this issue and also felt that it was unfair to select just one, so we settled on a selection of three photos and created a montage. Keep sending them in please.

Another one of the letters and emails received also raised an interesting question -"When I first started getting the magazine it always contained the email addresses of others with the same problem. I contacted some and had some emails sent back and forth without any problems. Why was this changed if people had no objections to having their email addresses shown?". I agree it would be great if we could continue this past practice but privacy and protection from spam emails and letters is now a much more critical issue than it used to be. We have all heard of (and many will have received) those scam emails saying you have won or inherited millions.

While hard-copies of the *Ostomy* AUSTRALIA journal are only distributed to ostomates or people with a clearly defined interest in ostomates or related areas, the journal has also been available on the internet for the past few years. This makes it available globally to anyone interested in reading it. Likewise, we are able to freely read the journals and articles published online by many overseas ostomy groups. Unfortunately, this information is also available to some mischievous and devious people who are quite willing to misuse any personal contact details published in our journal.

If you have a computer with internet access, or someone who can help you, another great way to exchange helpful hints and suggestions with other ostomates, or simply just to learn more, is to have a look at some of the internet-based ostomy forums (or blogs as they are also known). Many of these forums allow you to freely exchange information with other ostomates, both locally and overseas, and without revealing very much of your personal information to the rest of the world. The Ostomates.com.au web-site (bottom of page 47) is one such forum and there is nothing to stop you joining any of the many overseas-based forums as well. However, please remember that you should not rely on any hints and suggestions in the absence of medical advice.

You should always consult with your doctor or Stomal Therapy Nurse prior to any change of treatment.

Please keep sending in your stories and helpful suggestions for our upcoming Journals.

Wishing you all a happy and safe Christmas and New Year. Take care and stay healthy.

Kim Lyell EDITOR

Help!

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



Please send your submissions via Email, Word or PDF documents 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. Just 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 a narrative relating to the photo subject.

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

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

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

There is

no DIS

in my

President's Message

2012 IN REVIEW

In this December issue of *Ostomy* AUSTRALIA, I take pleasure in having the opportunity to extend to all of our readers, best wishes for the upcoming festive season and best wishes for a peaceful and enjoyable New Year.

Christmas is an exciting time of the year in Australia and, while it is a festival of our Christian heritage, many of those who do not share a Christian background still enjoy and actively participate in the celebrations and holidays that mark this very important time of the year. As a result the whole country relaxes and enjoys the goodwill that is the essence of the season. It is remarkable to see how most people make that special effort to extend goodwill to those they meet socially and in business. Although life does not always provide the joys we hope for, we should always make every effort to make our world and the world around us the best it can be for a few days at least.

As it is nearing the end of another busy year I would like to share with you some of the significant aspects of the year's activities.

The Stoma Appliance Scheme

Management of the Stoma Appliance Scheme (SAS) in conjunction with the Department of Health and Ageing continues to be the most important aspect of our national activities. We enjoy an excellent working relationship with the Department and, as a major stakeholder in the SAS, continue to be consulted in all significant decisions regarding the scheme's management.

The ACSA Journal "Ostomy AUSTRALIA"

The quality of our Journal "Ostomy AUSTRALIA" has continued to improve over the years and has been enhanced by the fresh energy and vision brought to its development by successive editors who have all provided their own personal touch to help make it bigger and better. Whilst the Journal continues to be self-funding in its operation, this was not a principal criterion in creating the Journal. Providing a service to ostomates was and always has been the most compelling reason motivating the production of the Journal and the revenue it generated was secondary but most welcome.

I take this opportunity to congratulate Kim Lyell on the completion of his first full year as *Ostomy* AUSTRALIA Editor. As with all previous Editors, Kim has maintained the quality of the Journal through his own individual flavour which continues to enhance its production.

WCET World Congress Adelaide

In April I had the good fortune to attend the World Congress for EnteroStomal Therapy Nurses held at the Adelaide Convention Centre. As an Ostomate it was reassuring to observe the professional manner in which the congress was conducted. While all aspects of the congress were enjoyable, the guest speakers who presented papers on a diverse range of topics were particularly interesting. I think I speak for all attendees when I say that the congress presented an excellent opportunity to establish contacts with health care professionals from different parts of the world.

Asia South Pacific Ostomy Association (ASPOA)

During October 2011 the first regional conference of ASPOA was held in the Middle Eastern city of Tehran, Iran. The Iran Ostomy Society (IOS) is the sole member of ASPOA from the countries of central Asia and had originally been chosen to host the meeting in 2008.

As part of the conference a comprehensive scientific program was included and well attended by many nurses who were given professional credit for attendance. A diverse range of subjects were covered by the program including the role of IOA in the Ostomy World, the present status of Asian Ostomates, Nutrition and Ostomy, Sexual complications of



Ostomates, side effects of chemotherapy, continent Ostomy, Irrigation and many more. It is widely recognised that the best way to improve the wellbeing of Ostomates in Iran is to have better qualified health professionals looking after their needs. The IOS has, and continues to be, the main catalyst for the education of nurses in Ostomy care in Iran. As yet there is not a WCET recognised Stomal Therapy course in Iran, but there is widespread support amongst health professionals that this issue be addressed.

The ASPOA regional meeting was held on the second day of the conference after the Educational program was concluded (I could not help but feel that the main reason the Iran Ostomy Society wanted to host the ASPOA conference was to increase the credibility of the education program and to lift the profile of Ostomates and their need in their country).

ACSA Executive Meeting in Darwin

In March 2012 the ACSA Executive met in Darwin for the first time as decided at the Annual Meeting in 2011. The meeting was held in Darwin to show support for our Northern territory Ostomates and to ascertain if Darwin was an option to hold our Annual Conference. Representatives from the Cancer Council NT and the NT Ostomy Association presented an overview of their operation and we found that many of their problems were not dissimilar to those experienced by other Associations.

The Australia Fund

The Australia Fund is the principal overseas aid project undertaken by ACSA. It is managed by an independent subcommittee in obtaining or affording basic ostomy supplies. The fund continues to maintain a very high level of assistance to Indonesia, as well as two areas in the Philippines: Manila and Davao. Requests from Iran, Zambia, Kenya and Ethiopia have also been dealt with.

The reports that the Australia Fund receives back from our overseas destinations speak of the immense difference that our donated appliances make to the lives of ostomates who have very little support with medical issues in addition to the lack of appliances. As a result of the work of the Australia Fund they are able, many for the first time, to have some hope of receiving limited access to the reliable standard of ostomy appliances which we in Australia take for granted.

Finally in looking over the year's activities, I feel confident that, through the promotion of the wellbeing of our members, by supporting Ostomates less fortunate than ourselves, and through the continuation of our international commitments through the Asia South Pacific Ostomy Association, we are continuing to meet our objectives.

Once again, I wish all of our readers a joyous festive season and a happy and safe new year.

Peter McQueen PRESIDENT

Letters to the Editor

Dear Editor

Thank you for publishing Sarah's inspirational story (Sarah's Story – *Ostomy* AUSTRALIA August 2012) which has left a lasting impression on me. A wonderful young woman. I wish her the very best life has to offer.

Living with a stoma has happened recently and unexpectedly to me. Residing in rural NSW, I have been largely left to work things out for myself as I go along. So far, so good. There are no local resources and I live alone, but I am now cancer free so I have a lot to be thankful for.

I look forward to the next issue of the Journal and all the helpful information that comes with it.

R.S. NSW

Dear Editor

In the August issue of *Ostomy* AUSTRALIA you published an article written by a young lady named Sarah Larcombe.

I too had the exact same circumstances as her two years ago when I was 21, except I was diagnosed with Ulcerative Colitis. I also cannot have the reversal operation and will have to have another operation to remove my rectum.

Like Sarah, I nearly died as my large intestine perforated the night before my operation. I was sick for six months and spent nine weeks of them in hospital due to complications and weight loss. But just like her I hold no resentment towards my bag, as it saved my life.

If you could please tell Sarah thank you for reaffirming for me that I am not the only young female in the world to go through this, that would be great.

And she is right, it is not the end of the world, it's the start of a new one.

Carly Smyth

Dear Editor

I had the same trouble as Mary Ellis (Your Say, In Your Own Write - *Ostomy* AUSTRALIA August 2012). My operation was on 6th October 2010 at the Mater in Brisbane and I now have a stoma. At home after the operation, my daughter was marvellous as I had numerous leaks and problems.

I contacted the stoma nurse at the hospital and went in to see her. She changed the bag over as it was the wrong one for me. However, it could have been more of a problem if I needed to go in on the weekend as stoma nurses are not on duty then.

I also had to go to a psychologist in the end which I found very useful. I understand that they have stoma nurses and a psychologist available at Sydney hospitals but they do not employ psychologists here.

There should be some form of follow-up to see how you are going after the operation and you can only contact your local GP at the weekend.

Cheers

Margaret Shaw, QLD

Dear Editor

I was diagnosed with stage three bowel cancer in 2006. The dust finally settled in 2008 after multiple operations, chemo and radiation but my prognosis and quality of life was not good at all.

I was living in south-east Queensland while my two sons had settled in Melbourne. So I sold up and relocated closer to my family to spend time with them before I "fell off the perch".

I was being monitored but my quality of life was deteriorating, living with diarrhoea, pain and acid, moving from one loo to the other. Leaving the house became a challenge, but I never gave in. The local council could have employed me to write a book on the locations of loos, both public and not so public.

I was referred to a gastro clinic, but the new pills and potions they provided gave me little or no improvement. Finally after heaps of "oh my gosh" tests I was placed on the semi-urgent surgery list. After six hours of surgery In March 2012, I lost my large bowel together with one-and-a-half metres of my small bowel. And I was introduced to....THE BAG....

Well what an adventure! I refused to call it "the bag" and instead preferred to call it "the device". I initially named it "Fred" which I thought was appropriate as I have had a few guys pass through my life that were "full of it" so to speak. Now I call it "Petal", because it is something that peels away (or drops off) from your body.

When I left hospital "the device" would not stay on, and I walked around with my hand on my side to hold it in place. I then spent time with the stoma nurse at the Colostomy Association in the city. She was an angel. She spent time with me and ordered many samples for me to try.

I left her office with a different "device" and the biggest smile together with a small tear in my eye. I had total



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freedom for the first time in six years.

However, I wasn't going to go home straight away as I had lots of living to catch up. I didn't consider that it was still only three weeks since major surgery and I soon ran out of steam. I literally had to crawl onto the tram and fortunately it was downhill from the tramstop to my home. I only just made it to the couch and slept for the rest of the day.

I had my "L-plates" on big time (with lots of funny stories). I also went through "the gas" stage where I even considered putting weights in my shoes to stop me from floating away.

Well, Petal and I have been together for seven months now and I have now learnt what to do and what not to do, which allows us to live in harmony. We get on very well and are inseparable, go everywhere together, and yes, we even sleep together (blush, blush). Sometimes Petal plays up but it is now easy to get her back on track.

We are so fortunate to live in this beautiful country of ours, where for just a few dollars, we can join an Ostomy Association and access every imaginable device, lotion and potion to make our life easier.

Having your body waste disposable outlet relocated is such a very small price to pay for your life.

Delviene Chesterton, VIC

Dear Editor

At the age of 58 years I was diagnosed with Ulcerative Colitis. I had never heard of this disease, but soon found out about it. I was sent to a gastroenterologist and was told "we will soon get this under control" and was started on cortisone and enemas.

Five years later he referred me to another specialist. This specialist was into the research side of the illness and along with traditional treatments, also conducted trials to develop new ideas, for which I was a willing participant to try and find the answer for me.

I will not go into the debilitating symptoms except to say my condition had deteriorated to the point where I was scared to go out in fear of having "an accident". I knew where all the toilets were and I would not eat for hours beforehand if I had to go anywhere I wasn't sure about.

After another seven years trying to find an answer, surgery was suggested as an option.

During my illness I lost my dear husband to Leukaemia. He was my rock and main support. I wasn't sure I could face major surgery without him. After six months of agonising whether to go ahead and with the support of my family, I decided to proceed as my quality of life was not good. I had a Proctocolectomy via a Laparoscope performed by a wonderful surgeon. He has given my life back to me and I will be forever grateful.

That was six years ago and at the age of 75 years I have never looked back. I am writing my story to let you know how my life has changed for the better. I am back playing tennis and have been on many holidays, including a three week trip to New Zealand.

I have not had any major issues. I am very comfortable being an Ostomate and am managing my situation very well. I would like to thank my Ostomy Association for the wonderful service they provide. I am very grateful to them. I place my order for supplies one day and like magic it turns up at my door in no time.

Shirley Walker, VIC

Dear Editor

You may care to publish the following story about an incident which occurred to me in China recently.

I wear a colostomy appliance with a belt and as I passed through security the officer detected a bulge on my abdomen. She asked me "Money bag?" to which I replied "No – medical – hospital – doctor" but it wasn't understood. I then showed my multilingual traveller's information paper which also didn't help.

The officer demanded to examine me so I insisted on privacy. She told me to remove my appliance but I refused. She then called for assistance, including a person to test me for explosives. I was cleared and released. Not a suicide bomber after all!

I was very shaken by the officer's aggression.

Katherine Kingsbury, VIC

Dear Editor

I would like to thank Brian Hunter for his very detailed article on "Managing your Ostomy Stocks" in the April edition of the journal. I found it very helpful and as a result have benefited from reading it.

I did not know that you could have more than one size of colostomy bags, so I have now remedied that. Sometimes there is quite a distance between towns when travelling interstate and in the past that is usually when you get caught out. Now that I have the maxi size, it should make a difference.

Annette F, VIC



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Beau Reilly, QLD

I was browsing the August issue of *Ostomy* AUSTRALIA and came across Sarah Larcombe's Story. All I can say is what a courageous young lady and it was inspiring to read about her experience.

I was diagnosed with Crohn's Disease as a young boy, about three years-of-age. I'm now a 30 year-old male, and had a colostomy fashioned when I was nine years old as a result of severe Crohn's Disease. Within a year, the rest of my large bowel was removed and I ended up with an Ileostomy. I have lived with an Ileostomy since then and will have it for the rest of my life. All I remember is my health being in a terrible state all of the time until the operation was performed. Having the surgery back then gave me the opportunity to live.

It was interesting to read Sarah's Story and realise that I went (go) through many of the same challenges, but that you learn to better appreciate many of life's offerings, and your health when it's in a good state.

Like Sarah, I've always been determined to do what I want and to REALLY enjoy the good times. Despite having a bag, I learnt to surf when I was fourteen and continue to do so whenever I get a chance (one of my passions). I lived for two years in Ireland and travelled extensively during this period. I've had successful relationships with girls, been to university (which involved field work in remote North Queensland) and recently returned from a snowboarding trip overseas.

Anyway, Sarah's story inspired me to write a few words, and just highlight that becoming an Ostomate can significantly improve one's life (though I'm sure many readers already know this).

Cheers for a great read.

Tom Klein

I was given my lleostomy after bladder cancer and then had my bladder removed back in 2010.

My wife and I celebrated "being alive" after all the medical dramas and chemo by taking a ten-day "European Vacation" with Globus tours. We were the only Aussies in a bus full of Americans. How interesting that turned out to be.

We also had our iPhones loaded with essential applications (or "apps" as they a better known).

- We kept in touch with all our friends and family for no cost using the "Viber" app.
- We sent images back home, and also received some.
- My emails were dealt with each morning and night.
- Our children tracked us day and night using the "Find my friends" app.
- For translation with some hard to understand Europeans we used the "itranslate" app.
- And the "Toilet Finder" app turned out to be a very useful tool to find that elusive "WC".

I work as a freelance Video producer in the regional Victorian city of Mildura.



My jobs are more interesting now as my medical situation dictates what can and can't be done.

Mitch Hayes, VIC

I went to Indonesia with my girlfriend and a few mates a couple of months ago and this photo was taken of me surfing on an island near Bali.



I live in Victoria and usually surf in a wetsuit because I find this keeps my colostomy bag drier and holds it in place when I'm surfing (also because the water is freezing).

At first I was a bit worried about how my bag would go in Bali, especially all the different foods over there. I also had to pack light and efficient because we were constantly moving and following the surf. This became quite a hassle carrying and trying to fit all my bag supplies and wipes into my back pack and board covers. Luckily I didn't have any problems, and everything was easy and okay.

I was born with an Imperforate Anus and I've had my bag since I was four. I'm now nineteen and find that it doesn't really stop me doing anything. Sometimes I even forget that I've got one.

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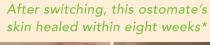
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Your Say, In Your Own Write

How Times Change

Submitted by **Paul Martin**, Vice President, Queensland Colostomy Association

I often hear some ostomates complaining about their appliances, whether it be size colour or shape, and think to myself they don't know how lucky they are given what ostomates in the early to mid-60's like myself had to wear.

I first became an Ostomate in 1968 at the age of three. Unlike today, there wasn't a choice between appliances back then, one size fitted all, so to speak.

The pouches, or bags as they were called back then, were made of thick rubber, similar in shape and size to a hot water bottle and just as thick. You were issued with two bags every six months and four flanges (or wafers as they are called today).

The pouches were reused over and over on alternate days - one was placed in a bowl of disinfectant overnight and the other worn. We had no self-adhesive flanges. We brushed a cement onto the rubber flange and around the skin of the stoma, then pressed it against the skin until it adhered to the body. Micropore tape would then be placed around the flange for added protection.

The next process was to place a metal butterfly ring on top of the flange. This was used to support the belt that had to be worn tightly around the waist because of the weight of the Urostomy bag.

There were no such things as seals, so leaking was a common occurrence. What takes minutes today (to change a leaking flange) took a whole lot longer. The flange had to be removed as well as the cement used to adhere it to the body. Both the flange and skin had to be cleaned before the flange could be re-applied.

When I look back over the last 44 years, life for Ostomates has changed for the better. It is pretty amazing stuff given the different choices of appliances available to us today when you compare what was or wasn't available in years gone by.

Are You a "Gutless" Wonder?

Submitted by Maxine Wade

From recent letters to Carmen it appears to me that many new ostomates need to understand how their new shortened intestine will work and how to manage their bags.



As a Crohn's Disease Ileostomate since 1998, it took me a while to make sense of how my body was coping without my large bowel following the removal of my remaining eight-inches of large bowel in 2006.

To be really simplistic - you eat food that passes into the cement mixer of your stomach where bile etc is added to break down all that yummy food and drink. This then passes into your small intestine (almost 21 feet or 7 metres long) where most of the nutrients are absorbed back into your system to help your body function. The large bowel is responsible for removing most of the fluid and recycling it back into your body. The remaining waste is stored in the large bowel until you need to have a bowel motion.

Without a large bowel (which is approximately 5 feet or 1.5 metres in length) the more fluid unwanted waste from your small intestine now passes a lot more quickly into your bag. Many lleostomates have mentioned that they have to empty their bag more often. Well of course, you no longer have that five-foot large bowel reservoir for poo so where do you think all that waste is going to go?

I have learned to eat low residue food (meaning less waste for the bag and therefore less emptying) especially if I am going on busy shopping trips, or on long walks, flights etc.

I am very envious of people who can continue to eat exactly the same food that they ate before they became an Ileostomate. Some foods and drink gave me the runs or blockages but knowing that my "output" is about the width of a pencil, I make sure I have plenty of liquids during the day, chew my food well and avoid those fibrous foods that might give me issues.

I don't like eliminating some foods or drink from my diet but if it means I don't have bowel blockages or bag blowouts then that's what I have to do. Now and then I try and re-introduce the food or drink that caused me problems years ago. Sometimes they are acceptable, sometimes not.

I can survive without champagne or white wine and can drink some fruit juices in moderation. Freshly squeezed vegetable juices are well tolerated which is a bonus.

Now and then I will still eat something I shouldn't when I go out – like rhubarb and berry crumble with nuts and muesli on top – but worry about the consequence when I get home. I am also not one of those diners who looks at a menu and says "Oh I can't eat that or that, I have Crohn's Disease" (how boring is that to your fellow guests). I just look at the menu, choose what I want and if necessary ask for something unsuitable to be substituted with something more digestible - such as swapping hot chips for mashed potatoes, or fibrous vegetables for a salad. Restaurants are quite used to people wanting to change accompaniments in meals.

So, learn to understand your "abbreviated" intestine, and your life and bag emptying management and routine will become much easier.

There are also options on bag sizes and you may find managing and emptying your bag less if you use a slightly larger size, but this all depends on you, your lifestyle and your personal preferences. There are bags to suit us all and the appliance companies are more than happy to send you samples.

Another thing to remember is that enteric coated drugs are not broken down in your intestine so always mention this to your medical practitioner if getting a repeat of a prescription you took before your operation, or even when getting a new medication.



More Tips for Flying High

Submitted by Max Major, NSW

After receiving my August 2012 Ostomy AUSTRALIA magazine I read the experience of Brian Hunter from Queensland (changing of bags during a flight) something I will have to go through on my flight to the USA in January 2013.

One of my tricks to hold my shirt out of the way was to get a lanyard put onto my mobile phone. I put the lanyard around my neck then loop it up and under my shirt / singlet and out the front. This holds my clothing away from my stoma which allows me to use both hands to do all the rest.

I had my operation in November 2008 and after lots of learning, I wish I had the benefit of the Cancer therapy group to which I now belong. Diet is a major problem for me and I try to steer clear of fatty foods. I am an active 74-year-old, do line dancing with my wife 3 times a week and love it. Love the magazine, keep up the good work.

Let's Hear it for the Bathroom Heat Lamp

Submitted by Brian Hunter, QLD

So you've done the removal, the clean-up, the skin preparation; and now you reach for the new bag or the new flange-ring. Now what's the last thing you (should) do before mounting an adhesive flange?

Why, it's the temperature thing of course: you must raise the flange temperature.

I know sometimes we are running late, or we are just dog tired. For whatever the reason, sometimes we cut corners and we skip this step. But we should all know better.

There is no doubt that warm flanges result in better 'grab' and better performance – longer and more secure adhesion. All your careful preparation can be wasted just by skipping this one last step. But just how do we do this?

We read a lot of good tips. Tips like - hold it against your thigh; sit on it; stick it under your arm; blow on it; use a hair dryer; etc. But there is a better way; an easier simple solution.

Most bathrooms today have ceiling fans. Better still, most bathrooms today have heat lamps - heat lamps mounted in the ceiling. So to save precious time AND to heat up that flange, all you have to do is hold the flange under the heat lamp. Five or six seconds is probably all it takes and it's done. It's easy and the flange is ready to install (at the right temp). If it's warm enough, it will last and should not fail.

Of course this depends on your height: if you're a shortie, you might have to count to ten.

Continued page 14

An Effective Solution for Erectile Dysfunction (ED)

Submitted by **Paul Martin** - Vice President, Queensland Colostomy Association

Having been born in 1965 with Spina Bifida and becoming an Ostomate in 1968, I have experienced the same problem as W.G. from NSW (Letters to the Editor - *Ostomy* AUSTRALIA August 2012).

All the operations that I have undergone over the years has caused nerve damage. This coupled with being born with Spina Bifida took its toll on me and erectile dysfunction was a result. So I can understand W.G.'s frustration and feel a great deal of empathy for him.

My urologist once told me Erectile Dysfunction (ED) is the male equivalent of a woman having her breast removed - you lose a part of yourself that defines your gender and being.

I too went down the same road as W.G. trying different types of medication without any great success. Viagra, Cialis and Levitra - I tried them all.

After exhausting all avenues my doctor suggested a penile implant, so a few years ago I had a device implanted.

It was a relatively easy procedure. I booked into the hospital and the operation took ninety minutes. I spent more time in the recovery room than I did in the operating theatre. My stay in hospital was short and I was released the next day with the instruction not to lift anything or exert myself for four weeks.

The implant was made up of three parts - a reservoir which holds sterile fluid and sits next to the bladder. This is attached by tubing to a pump, which sits in the lower scrotum, which is then attached by tubing to the two cylinders that are in the penis. To operate the implant, the pump located in the scrotum is squeezed several times and fluid flows into the two cylinders, giving a completely natural appearing erection! The complete device is put in place via a very small incision in the scrotum.

As for the cost, my private health insurance paid the bulk of the costs and I was only left to pay a small gap to my surgeon. There are several types of implants on the market and my advice would be to visit a urologist and have a talk about what is available beyond medication.

ED is a delicate subject to talk about at any time and I must admit I did have some sec-

Write in to have... YOUR SAY!

ond thoughts about putting my name to this letter but with World Ostomy Day approaching and the public awareness campaign surrounding the day it is time to come out of the shadows and start discussing what it is to be an Ostomate.

What gave me the courage to do just that was reading the life story of Sarah Larcombe from South Australia and her positive outlook on life at such a young age, and thinking what a great Ostomate Spokesperson/Ambassador she would make.

Modifications to my Base Plate

Submitted by David Gardiner, WA

The August edition of our wonderful journal prompted me to write regarding the appliances I use. Having been an Ostomate for five years (I am 67 years of age), I still use the same brand I left hospital with, and am generally very happy indeed with the product.

The one issue I do have I solved by making a few simple one-centimetre long cuts around the perimeter of the baseplate, as my abdomen is quite rounded where my stoma is. I find especially in summer or while exercising and doing sport, the baseplate can buckle and tends to lift away from my skin.

I make about nine or ten "slots or wedges" with a very small pair of nail cutting scissors. Each baseplate takes less than a minute to alter.

I have written to the manufacturer asking if they could make them like this and they were kind enough to actually phone me, acknowledging it was a good idea and they could "take it on board".

There is a brand of baseplate that comes already made with slots (they advertise in our journal) but wonder if it might be patented?

It works for me and I will continue to alter the baseplates of this very good product.

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Life as an Ostomate in 1938 (Mabel's Story)

Submitted by Ruth Horne

Paul Riome is a Canadian Ostomate who recently posted this article on his blog. It has been published in the American Ostomy magazine but given the reaction from the fold at CASA, I thought our Aussie ostomates might like to read it as well.

My Grandma Mabel had ostomy surgery in 1938, and was sent home with no ostomy equipment. How did she cope? How did she live with her ostomy?

I have tried to recreate her experience.

Let us try to imagine 1938, and imagine living with an ostomy in 1938. This was before



Pictured above - Grandma Mabel, 2 years after ostomy surgery.

the internet, before cell-phones, before microwaves, before TV, before plastics. The stock market had crashed in 1929, followed by a decade named the Great Depression. In parallel, there was a decade of drought and crop-failure in the entire Mid-West of North America, aptly named the Dirty 30s. This was before the second World War!

It was a challenging time to live. This was also before Flanges and Pouches and any other Ostomy gear was invented. Ostomy patients were sent home after surgery, with no collection device.

No collection device !?!!

How did Mabel live with an ostomy without ostomy equipment?

Mabel lived on the prairies in Western Canada, where summer temperatures rose to +40 degrees Celsius and winter temperatures dropped to -40 degrees Celsius. The only heat in the house was the stove, which burned coal when they had money, wood when they could scrounge, and buffalo-chips (dried cow manure) when there was nothing else.

There was no cold running water. Water was pumped from a well - winter and summer. There was no hot running water. They heated water in a large pot on the stove. There was no shower. There was no bath-tub.

There was no bathroom in the house.

There was just an outhouse — a seat perched over a pit in a small building fifty yards from the house. This outhouse experience, in winter when it was minus 40 degrees, was the origination of the expression "so cold it would freeze your backside off!".

With no collection device supplied, available, or even invented yet, Mabel made do with rags and towels (try

to imagine her angst). Mabel's husband Walter was a practical and inventive man, and soon devised a tin-can with a belt-strap, to contain the stool. This was leaky and stinky, but a big improvement over the very messy rags.

Personal ostomy clean-up was in the outhouse, probably with a pail of cold water - summer and winter.

The tin-can had to be strapped tightly around her waist to reduce the leakage (not prevent leakage - just reduce leakage). The edge of the tin-can bit harshly into Mabel's skin and left a nasty red compression ring on her skin. Walter was a horseman who made his own horse-harnesses, so he built a leather collar to cover the tin-can edging. This was certainly more comfortable and leaked less. But it was difficult to clean the leather collar and the device was still stinky.

Mabel considered a glass container which would be easier to clean than the tin-can. But adding a leather collar and attaching a belt would be difficult and the risk of glass breakage and serious cuts to her stoma would be a big concern. The tin-can with leather-collar, strapped around her waist, was Mabel's best-and-only ostomy equipment.

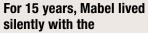
The four-inch circle around her stoma was constantly covered with stool, and I expect she had many rashes, breakdowns, infections, and damages to her skin. The salves used for harness-burns on horses would have been Mabel's only relief from these skin problems.

There was no real ostomy equipment for Mabel.

There was no 'support group' for Mabel.

Mabel never talked about her ostomy. My father, who lived at home for the first six

years of Mabel's ostomy, was never told about her ostomy, never saw anything that would indicate an ostomy, never saw a bulge on her dress. While her husband designed and built her ostomy-gear, that would be the last time he participated and the last time they would talk about it. It just wasn't ever discussed.



inconveniences of an ostomy without ostomy-gear and with no-one to talk to.

Mabel was the sole steward of a one-acre vegetable garden. She dug the entire garden with a shovel, planted seeds and hoed weeds. In the fall, she dug out the potatoes and carrots, harvested and preserved corn, peas and beans for each cold winter ahead. For fifteen years, from age 52 to age 67, she worked that garden, and she lived with an ostomy. And she lived without ostomy equipment as we know it today.

How did Mabel keep herself physically clean, mentally content, and spiritually thankful, with such crude ostomy equipment, and under such harsh conditions?

Mabel was British, Victorian, stoic, and content ... never complained. She was so thankful that her ostomy gifted her 15 years of good living.

There have been days I have complained about my colostomy. Imagining reliving Mabel's ostomy experience, I will not complain again. **Ever.**

Mabel's Timeline

1886 Born in England (126 years ago) 1904 Age 18 Married Walter (108 years ago) 1912 Age 26 Emigrated to Canada (100 years ago) 1938 Age 52 Ostomy Surgery (74 years ago) 1953 Age 67 Died (59 years ago)

Reproduced with the kind permission of Paul Riome who recently embarked on a climbing venture in Nepal - check out further stories on www.livingbiggerwithcolostomy.com





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Perhaps in one of his most insightful moments my dad bestowed upon me is the simple truth, "If you don't eat, you don't poo and if you don't poo you die." When he shared that bombshell with me I remember giggling with glee at the

use of profanity to my seemingly juvenile eight-year-old ears. Now, having lived that reality first hand, it is no longer a laughing matter and I fully comprehend that simple, unfettered truth.

Parents are always trying to protect their children – it is their mantra and you are their deepest pride and joy. How was I to know that years later that simple truth was going to be a life or death matter.

I only ever envisaged cooking as a means to an end. You cook to eat. Eat to live. Because of my brush with death, cooking is no longer rudimentary. Cooking has framed my life in bright hues. It has brought me love, hope and joy. Food has taken on a wondrous and therapeutic role — not only nourishing my sick body back to health but providing both

a gateway and outlet for love, friendship and growth. I have found a way back to the light of life from the deep dark hole of illness and near death.

When your life takes a turn for the worse you never expect to learn, much less live an even fuller life. Having had my entire large intestine removed and relying solely on intravenous feeding for six weeks I never imagined what it would feel like to have food disappear so completely. I no longer looked at food, much less thought about it. But, this was just the beginning. The past three and a half years have been filled with immense heartache, joy, fear, anxiety, love and the pure survival instinct I knew I had in me. As an Ostomate, consumption of food now relates to how much sustenance I can absorb in my small intestine. If I consume the wrong foods it is akin to having gastroenteritis – and we all know what that is like!! I will always have my stoma, but I am pain free and healthier than I have been in ten years. Food has led me on a magical journey and I am truly blessed that I had family and friends around to help me discover how beautiful my life now is.

In the beginning, when my rehabilitation was slow and gradual, I grew my very own vegetable patch. It was my patch of sunshine. I tended and loved that earth. Everything I planted grew and flourished. Whilst tending my crop I forged a lasting kinship with my neighbour. She helped me in ways that no money or surgery could. In particular, I smile reminiscing about her frequent "night time raids". Under the cloak of darkness, torch and scissors in hand, she would scurry over to my patch and snaffle that last ingredient, parsley, bok choy, rosemary, to add the finishing touches to her already stupendous dishes. She was my real life

"knight in shining armour" – but her tools of trade included a spatula, whisk and love. It was marvellous.

She was like health tonic. She got me outside. Little by little, I spent more and more time outside with her.

Cooking from the Heart - From Sickness to Health

By Dana Kroenert



July 2009 - After emergency surgery (my third of four surgeries) when I obstructed in hospital - I was a mere 58kg having just come off TPN.

With each passing day, our cups of tea overflowed as we tended my garden. The transformation, becoming stronger and stronger, was rapturous and freed me from my pain. Having been in hospital for so long I was scared of the world. She awakened in me a delight I never knew I had. Our mutual love of cooking and her remarkable friendship and care allowed me to begin healing.

Buoyed by the instant success of my vegetable garden, I thought that my once brown thumb, had in fact, turned green overnight. Branching out, I turned my talents to the two trees that had inhabited our backyard in a diminished capacity. A once spindly lemon "stick" and a weak, sagging fig-tree now stand tall and strong — much as I do. Fig, Ginger and Flaked Almond Jam is

my speciality — with my friends waiting for the next crop to savour this exquisite mixture. The recipe, from my mum-in-law, was handed down to her from her mum and is more than sixty years old. Looking back at those dark days, months and years I see that it was all a process. One that I am stronger for having survived. Cooking is now my road back and my way of giving back.

My darling husband knew that I wouldn't die. We have since had many tender moments together. Simply touching and holding hands, resting my legs on his as we snuggle on the couch cocooned in each other's love. This, to us, is bliss. He had to contemplate life alone, with the possibility of my death heavy on his heart. How would he tell our son, family and friends that I had died? I'm not sure if he has shares "Upstairs" but he knew that I had it in me to stay here and live. Through his enormous capacity for love, and the sort of quirky eccentricity, that makes me love him even more, he has strengthened my rehabilitation in the smallest and most loving of ways. He has bought me great cooking appliances — a whizzy, choppy thing, a slow cooker and a Mix Master.

Our first Christmas at home together he bought me the whizzy, choppy thing. To most this is just a normal, thoughtful, gift but to me it was much more. The extra significance lies in his understanding and desire to make me as well as I could be. As an Ostomate, the food I have to consume has less chance to be broken down in my body, therefore the opportunity to make food that has ingredients more finely processed has been wonderful.

For Mother's Day he gave me a slow cooker. Slow cookers help in more ways. Most notably for me they break food down so that



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it is more digestible and they cook by themselves. I had gone from being a full-time mum and wife, to almost invalid. By doing this, he offered me the chance to be those important people again.

His last gift, for Christmas 2011, was a Mix Master. I have long coveted this machine and it now takes pride of place in our kitchen whipping up wondrous delights to tantalise even the most discerning of taste buds. My new passion is baking. Creating and making foodie gifts for people who have given me my life back.

Giving back makes me smile. Not some silly Cheshire grin, just that warm, tingly feeling you get when you have done something wonderful. There is pleasure in the knowing. Knowing that somewhere there is someone enjoying what I have created with my own hands. My medical team have been benefactors over and over again — but to look at me now, after being so ill, can I ever really repay them fully? When my surgeon gave me the all clear, I returned with cake. His secretary, who was forever cancelling appointments and arranging hospital admissions, summed it up beautifully. In a text, she sent, "Cake unreal. Stay well".

Unfortunately I have ruined all other banana breads for those who consume mine. My physiotherapist was treated to weekly slices at our Pilates sessions. She has been my biggest fan through all this, and rains sparkly enthusiasm delighting all who meet her. To look at me, on the outside, you would not realise how ill I was. My face is full, my skin glowing, my hair shiny and my smile big. I do not wish to mask my pain. I try and show how far I have come with how well I am now.

Cooking has strengthened bonds. Family bonds. My son was 2½ when I started to get sick and for a long time was not sure if his mummy was ever coming home. Cooking is now our "thing". It allows us to be together without complications or sadness. Decked out in our aprons, we measure, mix and with little pinkies outstretched perform the all-important taste test. If we have dinner guests then we secretly arrange dessert so that it is a surprise. We may be right in front of our guests but somehow the cooking makes them magically evaporate from our world. Only when the dessert is ready do our guests magically reappear. Food creates harmony and we rejoice in the simple pleasures of time spent together enjoying sumptuous food.

Parents try to keep their children safe. My mum tried. In vain. She cooked and froze meals and visited hospital 1½ hours away to make sure I was okay. Every day, and every night she worried. When I was finally well enough to come home she and Dad moved their caravan to our front lawn and stayed for seven weeks. Without them our family would be in ruins. Cooking is now our way of starting a dialogue. They will always worry. Nearly losing your child is hard to reconcile. When my son and I go and stay with Grandma and Grandpa they cook — they love us with their cooking. I, in turn love them back, taking new dishes for them to sample. It is like a giant hug and we both find comfort knowing the other is healing.

My mother-in-law is the "Dessert Queen". She is the unwritten authority on all things cheesecake, pavlova and sponge. People travel from far and wide to share in her kitchen triumphs. At

our family gatherings there would always be a small sample of Dana-friendly desserts she had made, so that I could be included.

Love, in its most pure and simple form.

My life is now wondrously intertwined with cooking. Surviving this setback, I am able to live. Grappling with and succeeding in unlocking the code of food has entrenched in me a belief that food, love and health all go hand in hand. Not only has food given me sustenance it has awakened the desire to know more and understand fully the path before me. In our home, cooking is the currency of love. Not only is it the way to my man's heart, but the proof that I am here to stay. The only way I can give back is to keep cooking and getting better and better with each passing day. Food now takes on a central role in my life. Not only does it sustain me, it replenishes me mentally and spiritually. The most beautiful time is our evening meal. It is a time to sit together, relishing the miraculous splendour of our family – whole and safe. My son, in his five-and-a-half years on this earth has the most loving and generous soul. For a such a young person, his wisdom astounds me. His greatest love he stated one night, "Sharing my dinner with you and Daddy". With tears welling in my eyes I smiled at him and said thank you. Reflected back at me every day is the heartfelt thanks that I am still here.

Cooking can only come from my heart, all that I am and all that I give shines back on me when I look into the eyes of those who love me.



August 2012 Weighing in at a healthy 74kg!! One very happy girl.



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Report on the 2012 ACSA Annual Conference

Submitted by June Barns, Western Australian Ostomy Association

The 2012 Conference of the Australian Council of Stoma Associations (ACSA) was held recently in Fremantle, Western Australia. The purpose of the annual conference is to ensure that the rights of individual ostomates are maintained at the national level.

Proceedings began with the ACSA Executive Meeting on Wednesday September 19th, followed by Delegate Registration. On Thursday delegates met for the 12th Annual General Meeting of ACSA. Friday and Saturday saw the 43rd ACSA General Meeting take place.

These meetings were chaired by Mr Peter McQueen, President of ACSA. In his report on the activities of the Council and Executive, Mr McQueen provided the following interesting observations: ACSA maintains a good working relationship with the Department of Health and Ageing; the 'Ostomy AUSTRALIA' journal continues to be self-funded and of high quality; the World Congress of Enterostomal Therapists held in Adelaide provided useful networking for health professionals; the Asia South Pacific Ostomy Association (ASPOA) held the first regional conference of IOA in Tehran in October 2011; and the Australia Fund continues to provide assistance to developing countries. Mr McQueen also thanked Executive members and others who take on ACSA leadership roles.

The conference was officially opened by **Dr Ken Michael AC**. Dr Michael is a distinguished engineer, but is perhaps better known for his tireless and respected contribution to many aspects of government, business and community activity within Western Australia spanning more than 40 years. He has held many important positions including Commissioner of Main Roads, Chairman of the Board of Trustees of the Western Australian Museum, and Pro-Chancellor and Chancellor of the University of Western Australia. In 2006 Dr Michael was further recognised when he was sworn in as the 30th Governor of Western Australia. In his address Dr Michael paid tribute to the founder of the Western Australian Ostomy Association, Mr Peter McDonnell. He reflected on the work done by ACSA and told of his interest in the Stoma Appliance Scheme. He made particular reference to the Australia Fund as well as the information given to members through newsletters. It was clear to him that the work of the Stomal Therapy Nurses and the volunteers was very important for the well-being of ostomates. He felt that the theme of the conference, "Together as One" was most appropriate as it reflects all working together.

The Director of Product Schemes Section (Department of Health and Ageing), Ms Mary Ann Fisher, advised delegates that over 40,000 people now access Australia's Stomal Appliance Scheme (SAS), with 420 products and 2,000 variants of these products. The overall SAS expenditure for 2011/2012 was \$80 million. She

described ACSA as the scheme's shop-front and commended it to members. Ms Fisher acknowledged the vital role of associations and stressed that eligibility requirements must be adhered to. Further product reviews and periodic pricing reviews will be undertaken, but should not adversely impact any scheme participants. Forthcoming SAS operational guideline changes will include additional information on scheme administration. A review of accessories will also be done and Associations advised of the outcomes. A guideline for health professionals and scheme participants in relation to appropriate monthly usage of products under the SAS is available.

Reports to the meeting were then presented and contained many points of interest, including:

- The ACSA Website has been further developed and now includes a section specifically for children. Interest in our website has come from all over the world.
- Mr Gerry Barry, the Australia Fund/Relief Coordinator advised that \$230,000 worth of returned goods were sent overseas through the Australia Fund last financial year. Mr Bruce Harvey also reported on the success of the ACSA Australia Fund display at the AASTN Conference.
- The Appliance Officers' Meeting covered many important issues such as product expiry dates, posting of flammable items, legibility and size of codes on some products, and authority to receive irrigation kits or Conseal plugs. The Appliance Officer, Ms Sue Hoyle, urged members to ask questions as soon as a problem arises.
- Ms Kylie McGrory presented a comprehensive explanation of the *Not for Profit Reform Agenda* and how this will affect associations.

Friday's General Meeting discussed changing to two-day conferences. It was agreed that the Executive would assist with guidance but the running of the conferences remains with the associations.

The meeting continued with a variety of presentations:

- Mr Peter McQueen spoke on "Planning for the Future". He focussed on the need to foster new people and involve them in the management of associations. People with legal and administrative skills and knowledge are needed.
- Mr Warren Rayment, ACSA Awards Committee Coordinator, outlined the committee's recommendations and proposals for appraisal and constructive discussion by the meeting. Two awards to recognise outstanding contribution to the welfare of ostomates were suggested: the ACSA Distinguished Service Award and the ACSA Merit Award. The proposal was accepted by the meeting and will become ACSA Policy from 2013.









→ Together as One

- Ways of recognising *World Ostomy Day* (held on October 6th) were discussed, and associations encouraged to participate in the *Lilac for Life* campaign. The Queensland Colostomy Associations reported on their extensive promotion of *World Ostomy Day*, which included increasing public awareness through State Parliament, local media and a variety of activities such as a garage sale.
- A 'Plans and Procedural Document' should be made available for others to successfully take over the running of associations and valuable information should be passed on to new committee members.

The final day of the conference began with a presentation by Mr Geoff Rhodes, ACSA Vice President. Entitled "Cyber Security and Resilience", his presentation covered 'phishing' attacks, use of Smart Phones and associated risks to private information, and the use of public LANS and associated risks. This comprehensive presentation generated a lot of interest and many questions followed.

On Saturday afternoon we were treated to two speakers who were very well received:

• **Professor Barry lacopetta**, who has worked as a cancer researcher for the past 20 years, is the Head of the Translational Cancer Research Laboratory at the School of Surgery, University of WA. He has published over 150 papers, mostly in the field of colorectal cancer.

His current research interests include the establishment of a screening program in Western Australia to detect a familial form of bowel cancer. A second research project with the potential to improve current clinical practice aims to identify early stage bowel cancer patients who could benefit from chemotherapy. A third project involves the use of DNA markers to tailor chemotherapy to best suit individual patients.

Professor lacopetta explained how his research has identified families in WA who have a high risk of developing bowel cancer known as Lynch Syndrome. 1% to 2% of all bowel cancers are due to Lynch Syndrome with the average age at diagnosis being the early 40's. Work is being done in collaboration with geneticists, pathologists and surgeons. Prompt treatment can be given if families with this syndrome can be identified. Personalised cancer treatment is being provided with targeted therapies which only affect the cancer cells.

He foresees DNA sequencing becoming routine in the future with personalised cancer treatment being given. However, challenges include the fact that tumour cells can quickly develop resistance to drugs, as well as the cost of drugs and clinical trials.

• **Dr Kerlyn Carville**, Professor of Primary Health Care and Community Nursing and Silver Chain, presented our second talk, focussing on the Global Health Alliance Western Australia (**GHAWA**) Project in Tanzania.

Tanzania has a population of about 42 million people with 120 ethnic groups. The average age is 16 years and life expectancy is approximately 50 years. There is a high level of AIDS, many orphans, and a high level of albinism resulting in susceptibility to skin cancers. It is difficult for many people to earn a living, and there is no social welfare support.

GHAWA began from a meeting of Health Ministers of Tanzania and WA, and the Defence Minister. It aimed to provide Tanzania with trained nurses and midwives, and to foster education and clinical mentoring of their own nurses. In 2010 WA sent a team of nurse leaders to Tanzania.

Some of the needs encountered in Tanzanian hospitals were the lack of running water, more patients than beds, lack of modern wound dressing and ostomy equipment, prolific burns due to the use of open stoves in the homes, lack of pain management and insufficient nurses to cope. Since then, two-week intensive courses have been held to train their nurses in wound healing and management. They have also been taught how to assist ostomates by improvising with accessible materials. Seminars and forums for local doctors and nurses will be held with the aim to develop their ostomy management skills. The challenge is to teach good principles with limited resources and fifty nurses have already been trained.

As well as the serious side of the conference we had some enjoyable social occasions that allowed us to meet old friends, make new ones and to network for the benefit of our associations. A Cocktail Function was held in The Esplanade Hotel lounge on Wednesday night following Registration. Thursday night saw over seventy people board trams for a tour of Fremantle, which included an informative commentary on the history and sites of Fremantle with a meal and drinks included. Saturday night was a chance to dress up and over a hundred people enjoyed a beautiful three-course meal in the gracious Island Room in the heritage section of the hotel. Music was supplied by a duo and dancing was enjoyed by many. To complete the conference program Sunday's outing was more leisurely. Buses left Fremantle to wend their way through the river-side suburbs and Kings Park to the Barrack Street Jetty in Perth City. From there we boarded a boat for a two-and-a-half hour cruise on the Swan River while enjoying lunch and each others' company. The journey back to Fremantle took in the sights of Perth and finally a trip back along the beaches to Fremantle.

As in previous years, this conference helps to ensure that all Australian ostomates are being well-served by our national body and associations.

A wide range of topics was dealt with and a serious level of discussion underpinned decision-making. The Western Australian Ostomy Association committee was very pleased to welcome our visitors from other states and thanks them all for their contributions to ensuring the success of this conference.

The next ACSA conference will be held in Tasmania in 2013. •











longer-lasting version would give her greater freedom and peace of mind.

Marie has done everything she can Marie was worried that her to live a normal life after her stoma operation and accessories have played a big part in her progress. And she's not alone in that respect - over 70% of ostomates benefit from using accessories.

According to Marie, though, more could be done to make accessories even more effective. Marie explains: "I wish somebody would invent a more durable ring so I could worry less about leakage."

"A more durable ring would also give me the confidence to stay out longer as I wouldn't have to change my base plate so often."

baseplate was coming loose and therefore started to use the tape.

Ostomy issues

- 45% of all ostomates have skin issues
- 62% of this group don't even realise it
- 77% of skin issues are caused by leakage

"A more elastic tape would give me freedom of movement while giving me the confidence that my base plate is secured."

Coloplast has listened to the concerns of ostomates like Marie and is rethinking accessories.

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Reduce leakage

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Brava™ Mouldable Ring Durable for a long-lasting tight seal around the stoma



Care for skin

Brava[™] Adhesive Remover Soft, gentle and sting free spray

Brava[™] Skin Barrier Sting free and does not build up layers



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"Ask Kylie" A.C.S.A. Administration Officer

1. In a recent article I was interested to read that the uniform fees for membership of our associations was a top charge of \$45 per annum. As an Ostomate since 1993, I have been charged \$50 per annum. As a self-funded retiree of 86 years I have questioned this charge before but I have been informed that the extra amount is to subsidise the running or our branch. Could you please confirm your ruling on this matter?

The response to your question can be found by referring to The Stoma Appliance Scheme Operational Guidelines for Stoma Associations, (Department of Health and Ageing, May 2009), which states that:

4.2 SAS Service Fee

Subject to Clause 4.3 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 2.6% 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; and

4.3 Association Membership Fee

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 2.6% 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.

You have correctly identified that the current full SAS service fee is \$45, a fee which may be reduced to \$35 on presentation of a valid Centrelink issued concession or health-care card. Your association has also chosen to exercise its rights under clause 4.3 of the guidelines by charging an additional membership fee of \$5. In terms of this clause however, members who are not able to pay the additional membership fee because of financial hardship can apply in writing to the Association to have the fee waived.

2. I am a new Ostomate and am quite concerned about running out of stoma supplies but don't want to order too much as my stoma is only temporary and I am going to be reversed in the near future. Could you please suggest how much stock I should keep on hand?

While the needs of each Ostomate will differ from person to person, the general recommendation is that at least one

month of appliances should be kept on hand as reserve stock, in addition to your current month's stock, at all times. This will ensure that you have enough supply in the event that your product is placed into back order, misplaced en-route



or unavoidably held up for a short period of time. Because of the generous monthly allowances of product available through the Stoma Appliance Scheme, most ostomates will be able to accumulate a reserve supply from their standard entitlement. However, should this not be the case, your Stomal Therapy Nurse should be able to advise you on methods available to accumulate an emergency reserve supply. Remember though, while it is important that all ostomates have an adequate reserve of appliances, it is equally important that stock reserves are not kept in excessive quantities. Ostomy appliances do have an expiration date and so keeping an excessive amount on hand may result in wastage as products either reach their expiration date or are not required any more due to product change, reversal or natural attrition.

Australian Ostomates are very fortunate in that they have access to one of the most generous stoma appliance schemes in the world. However, expenditure on the Stoma Appliance Scheme over the past 10 years or so has grown at an unsustainable rate and so it is probably no coincidence that, in 2009, the scheme was identified by the Federal Government as an area for review. Consequently, recent changes have been made to the way in which products are considered for listing on the scheme and product pricing is now subject to an equitable and transparent framework. In May of this year, a 2012/13 Federal Government budget announcement identified further planned improvements to the management of the scheme with the objective of saving a further \$14.4 million over the next four years. It is no doubt therefore that the Australian Stoma Appliance Scheme is currently undergoing a period of transition never before experienced in its forty year history.

As users of the Stoma Appliance Scheme, every single Ostomate can also play a role in ensuring its continuing sustainability by following a few key strategies when ordering:

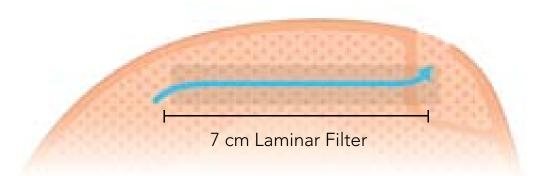
- a) Only order the products that you need in the quantities that you need them: Customise your order to your current requirements each and every time. Avoid submitting a request for a full entitlement unless it is required.
- b) Only order those products recommended to you by your Stomal Therapy Nurse or Health Care Professional:
 Consult your STN or Health Care Professional before changing your products or before adding additional products such as creams, pastes, hernia garments, seals etc. Remember, not every product suits every Ostomate!
- c) Consult a Stomal Therapy Nurse if possible when experiencing problems: Stomas can change, even after several years! If you do develop a stoma related problem (leakage, skin excoriation/irritation, poor adhesion) a Stomal Therapy Nurse will work with you to achieve a resolution.

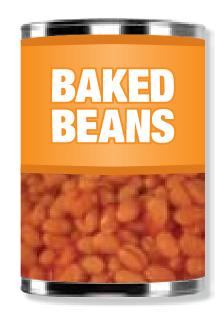
Please send your "Ask Kylie" questions via email to feedback@australianstoma.com.au

Alternatively, hard copy submissions may be sent to The Editor, Ostomy AUSTRALIA, PO Box 195, Frenchs Forest. NSW 1640

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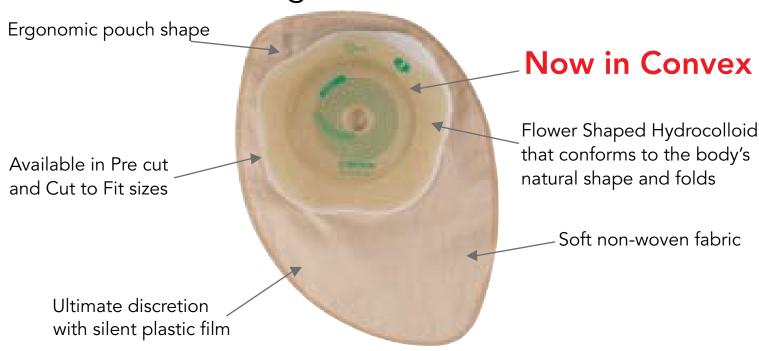




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OUR Stomal Therapy Nurse

Dear Carmen,

My story is no different to other Ostomates, but I have a problem which other people may have also experienced. In 2005 I had an Abdominoperineal Resection (APR) to remove a growth at the top of the rectum and now have a colostomy bag.

The bag has not been a problem, but after the operation I suffered bad burning pains in the area

where my anus used to be. This pain was so severe I had to visit a Pain Management hospital ward in Brisbane, where I had an epidural in the spine. This treatment helped a lot and all was well until 2009 when I had an operation to correct a Parastomal Hernia and rearrange the stoma.

Some sort of issue occurred during my 4-hour operation and after 3 days in intensive care I was taken for a further five hours of surgery. After this operation the intense burning pain returned.

I returned to Brisbane for pain relief but nothing was successful this time. I returned home with OxyContin as the only relief and managed to get off these pain tablets after 6 months, but still suffer pain especially after sitting for long periods.

My question is, have other people had this problem, and what treatment, if any, do you suggest.

My doctor prescribed Lyrica 75mg two times a day, which helps to control the pain, but the discomfort is always present except when I sleep. I am thankful that I sleep well.

I find your articles in the journal most helpful. In conclusion I wish to commend the people at the North Qld Ostomy Association for their courteous and prompt attention to our requests.

Thanks, D.D. Innisfail, QLD

Dear D.D.

Thank you for sharing your story with me and the readers. You have had a pretty torrid time of it and I am sorry that you continue to suffer. I guess at this stage if you are no longer willing to take the opiates then I am sure you will be modifying your life to accommodate and reduce the onset of pain.

I think your nerve damage needs to be addressed by the chronic pain team at your health institution as it is certainly outside my scope. I know this is no comfort to you but for other readers who have also had an APR this severe ongoing pain is rare, although many people do have more immediate postoperative pain and discomfort.

I wish you success in finding a solution to this very unpleasant and I imagine, exhausting situation.

Regards, Carmen

¥

Dear Carmen,

I have had an ileostomy since about the middle of 2010. Some 12 months ago the ileum began to prolapse, and this tendency has increased to the stage where, if the ileum is not restrained in some way, it will quickly protrude from the stoma up to perhaps 15cm in length. I understand that this condition is related to the presence of a couple of hernias, which make it virtually impossible to stabilise the ileum by surgical means without a major operation.

Given my age and physical condition, this is not recommended. Once the ileum has protruded more than two or three cm, the only way I have of retracting it is to lie flat on my back for anything from 10 minutes to an hour or more.

In order to control the ileum, I wear a support belt which must be tight enough to prevent the ileum prolapsing but not too tight. If it is not tight enough,

the ileum will push its way out under the belt. However, if the belt is too tight the ileum will be forced down until the end is level with the edge of the stoma, and some of the output from the ileum will inevitably be pushed into and under the seal, rather than above the seal and into the bag. This of course increases the likelihood of a "break out" of mess from around the bag, and reduces the time the bag can be left on before it has to be changed.

Under these conditions, none of the appliances (seals, bags) we have tried so far has been able to prevent at least some mess getting under the seal. It is also frustrating that we cannot explain the variation in effectiveness of bag changes (using the same appliance) in terms of any particular factor(s). Measured as the length of time before the next change is necessary, it varies from a few hours to occasionally two full days, and there are probably several factors involved, both physical and operational.

It seems to me that the type of appliance required is a special seal with a mesh "cage" attached, such that the ileum can protrude two or three cm, so that it pumps the output into the bag, but can prolapse no further. The mesh would have to be open enough to avoid any chance of blockage, but still able to restrain the ileum. Do you know of any such appliance? Is it a possibility?

Any comments or suggestions on my situation would be much appreciated.

J. Yates, TAS

Dear J. Yates

You have described the unfortunate dilemma of having to restrict a prolapse whilst still enabling the ileostomy to work. Lying flat will help reduce a prolapsed stoma as will gentle pressure exerted over the stoma whilst lying flat.

Applying your new bag whilst the stoma is reduced is important to ensure all the skin around the non-prolapsed stoma is protected.

I don't know of any appliance with a cage that could be used, however, there is a seal that incorporates a sleeve that snugly fits around the stoma ensuring that the output flows away from the body rather than pooling around the stoma. You may find this useful and it is worth trying. Check the Ostomy journal for an advert for this product and the company will happily supply you with some samples to try. It is important that the correct size is used so make sure you measure the size of the ileostomy when it is reduced.

Unfortunately, as you are unable to have the surgery that would repair the hernias and prevent the prolapsing, then finding a way to manage the ileostomy prolapse and prevent leakages is very important. Please do see your Stomal Therapy Nurse who may be able to offer some practical solutions.

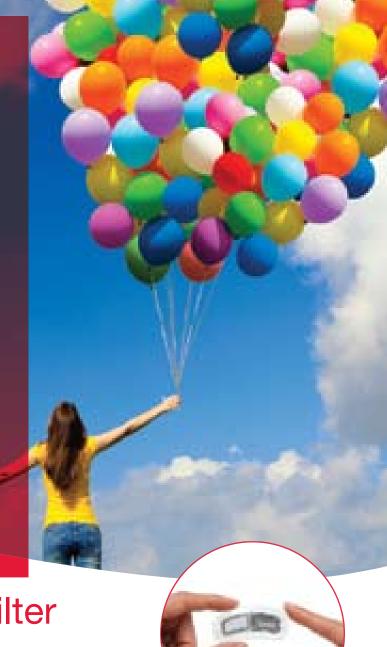
Regards, Carmen



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.

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Colostomy Association of South Australia Celebrates

Submitted by Ruth Horne

This year we, at the Colostomy Association of South Australia (CASA), celebrated our 50th Anniversary.

We had the joy of nearly eighty representatives joining together to celebrate both our 50th Anniversary and World Ostomy Day on Friday, 6th October 2012.

We were delighted to have representatives from the South Australia State Government, with Ms Lydia Dennett representing the Hon. John Hill, together with Councillor George Demetriou and Mrs Demetriou, representing the West Torrens Council.

Our delightful Master of Ceremony was CASA's good friend, Fiona Bolton, the STN at Calvary Hospital. Fiona did a fantastic job trying to keep our speakers to a strict time-frame: she mostly succeeded.

Mr Peter McQueen, President of Australia Council of Stoma Associations (ACSA), gave a presentation on the role of ACSA, CASA and the Australia Fund. Peter also provided CASA with a plague celebrating the event.

Councillor Demetriou and our CASA President, Mrs Rosemary Quick, presented letters of thanks and a small gift to each of our volunteers on behalf of the Council and CASA. Jackie Bone-George, a CASA member, then provided us with evidence that there is life after becoming an Ostomate, showing us some extraordinary photos of her very active hobby of scuba diving. She and her husband have been all over the world diving.

Our organising staff and volunteers did us proud. We dined in style at the TAFE Graduates Restaurant where hospitality trainees treated us to a fantastic three-course meal.

The Gastronaut hand-puppets were also guests of honour with our two "elderly" puppets: Ruth and Ron, "dolled up to the nines" and literally at the centre of each table. These were later raffled off together with a number of hampers donated by our supporters.

Proceeds from these raffles were distributed evenly between CASA and the Bowel Group for Kids. We were pleased to also donate three new puppets to the STN from Adelaide Women's and Children's Hospital.

CASA looks forward to providing assistance to South Australian Ostomates for many more years.



Attendees - Fiona Thompson (Dansac), Tim Burleigh (Coloplast), Sally Lunborg (RAH STN) and Michael Zeglinas (Southern Regional Manager Coloplast).



Master of Ceremony - Fiona Bolton STN.



Rosemary Quick (CASA President) with Councillor George Demetriou presenting to volunteer Michael Pacillo.

AASTN President's Report

Submitted by **Elaine Lambie** - AASTN National President (Australian Association of Stomal Therapy Nurses)

The second half of the year is a little quieter than the beginning of 2012.

The WCET event hosted in Adelaide was a wonderful success and all due to the organising committee in South Australia, led by Fiona Bolton.

The Colorectal Surgeons Society of Australia and New Zealand have approached the AASTN to consider joining with them for their Asia Pacific meeting to be held in Melbourne in October 2015. The AASTN is very excited about this conference and we have formed a National Subcommittee, with Helen Nodrem from Victoria as the chairperson.

In June, Elizabeth English was awarded an Officer of Australia Medal for her work and commitment to Stomal Therapy over many years. She has been an active member of the AASTN and WCET, holding many executive roles. Elizabeth has also been instrumental in the formation of education programs for STNs and overseas. She is greatly respected by her peers and is a worthy recipient of this award.

Stomal Therapy Awareness Week was well supported by STNs and Associations this year. Some STNs organised activities for the first time, which is exciting.

Abstracts are



will be an exceptional time together. Lastly, the AASTN National Executive are revisiting the use of Skype to conduct their meetings, rather than teleconferencing. It was tried a few years ago but with difficulties and we are hopeful that it will now be suitable being a few years on.

Smile A'While



by Harry Ashton

Many more years ago than I care to tell I was involved with a company making colourful canvas blinds and awnings, which we would advertise in newspapers and on radio.

When enquiries came in we would pass them to our contractor, Steve, who would call on the proposed customer to take measurements, show them the attractive samples, then give a quote and hopefully receive an order. Steve in turn employed two young men who called every morning with a truck to collect the awnings that we had manufactured and take them to be fitted at the homes of the people who had ordered them.

One morning just after I had phoned the customers to advise that we would be calling to do their job on that very day, the driver Colin phoned us to advise that his vehicle wouldn't start. Steve, who could see how worried I was after having already phoned the customers, asked me if I would go with him to see if we could do something about getting the truck going.

The address was at Randwick and as we got close to the

racecourse we could see Colin and his truck close to what looked like a very old unused horse stable. At this stage I might mention that Colin was a nice looking young man in his very early twenties who had apparently been unemployed for quite a while before Steve engaged him. His blonde hair was still very long which made me wonder if he perhaps still had money problems. Fortunately the truck was a Chevrolet which had a motor very similar to my car so luckily the problem was soon overcome and the motor was "purring" nicely.

However, before we left Colin said "if you just have a few more minutes to spare I would love to introduce you to my wife and our little baby." To my surprise he led us into that old horse stable which just had the usual trough and a few ancient items of harness hung around. There was a top shelf the full width of the building and almost its full length, accessed by a ladder which Colin was now climbing followed by Steve. When it came my turn I got the shock of my life to see his wife sitting on an old mattress feeding their little baby.

Steve and I hurried back to the office because our annual Christmas rush was on but perhaps that helped me to think of a similar instance that occurred just over 2,000 years ago.

Merry Christmas to you all.

Nobody Did It

This is a story about four people, named Everybody, Somebody, Anybody and Nobody.

There was an important task to be performed and Everybody presumed that Somebody would attend to it.

Anybody could have done it, but Nobody did it and Somebody got angry about that because it was Everybody's job.

Everybody thought
Anybody could do it but
Nobody realised that
Everybody wouldn't do it.

And so it ended up that Everybody blamed Somebody when Nobody did what Anybody could have done.



Folliculitis - A Hairy Problem

Adapted from various articles and internet sources

From time to time many people with an intestinal stoma will unfortunately suffer from irritation to the skin around their stoma (peristomal skin).

While peristomal folliculitis is not as common a problem as skin breakdown or yeast infection, it is still very annoying when it happens.

Folliculitis is an inflammation or infection of one or more hair follicles (openings in the skin that enclose hair), which starts when hair follicles are damaged. In most cases, these damaged hair-follicles then become infected with the bacterium Staphylococcus (staph).

It presents itself as reddened bumps which may be confused with a yeast infection. However, if you look carefully, the redness is only present in the hair follicle. The bump may look like a pustule.

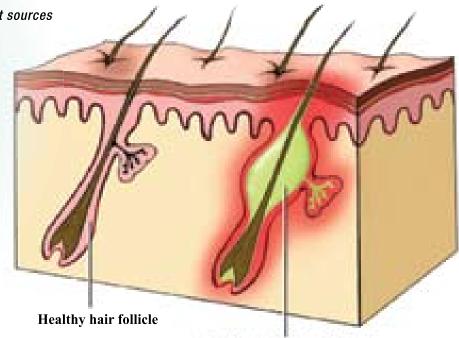
Removing a skin barrier in a rough manner, too-frequent pouch changes or dry-shaving of the peristomal skin can all lead to hair-follicle damage.

Folliculitis of the peristomal skin primarily affects hairy men, as woman seldom have much hair on their stomach. In fact, some abdominal hair can be so strong that it can grow out through a skin

barrier or waterproof barrier tape, sticking straight up like blades of grass. Needless to say, it is going to be painful when you remove a skin barrier or ostomy appliance when any abdominal hair is caught like this. It is just like those wax jobs you see on TV.

What is the solution to this hairy problem?

Many men find they must shave their peristomal skin with each change of their skin barrier or appliance. Most ostomy literature generally recommends using an electric razor and some Ostomates do very well



Infected hair follicle

with the newer small razors that are designed for trimming moustaches and sideburns. Scissors can also be used to remove excess hair.

However, if you use a safety razor be sure to apply sufficient shave-cream so that it is not a dry-shave and be very gentle when shaving close to your stoma. Most shave-creams have emollients so you will also need to very lightly wash the shaved skin with a plain soap afterwards. Then be sure to rinse your peristomal skin well so that no soap residue remains.

Always shave in the direction of hair growth, not against it.

If the skin is very irritated and itchy, application of a steroid (cortisone) spray, gel or cream should dramatically decrease the itching and irritation. Apply these solutions lightly, and then allow the area to dry completely prior to putting on your new skin barrier or appliance. Do not continue use of steroidal medication as part of your regular changing routine. Steroids are absorbed into your system through the skin and extended use of steroids will thin the skin, thereby compounding peristomal skin issues.

If there are actual pustules around each hair follicle, you may also need to use an antibiotic powder to clear the problem.

Note that ointments are not recommended as they may prevent the pouch system from adhering to the skin. Also, some of these medications may have a slightly oily base, which means your skin barrier probably may not stay on

as long as you are accustomed. However, this procedure should relieve the itching and promote healing.

Appliances should always be removed gently by slowly pushing the skin away from the appliance rather than pulling it away from the skin. Peeling should be avoided (do not "rip" quickly, as is commonly done with bandages), particularly with tape-bordered appliances.

Inflammatory or infectious conditions affecting the peristomal skin are common and may be a source of considerable itching and irritation. If you experience ongoing problems be sure to consult your Stomal Therapy Nurse.



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Scott V, Raasch D, Kennedy G, Heise C, Prospective assessment and classification of stoma related skin disorders. Poster presented at: 41st Annual Wound Ostomy and Continence Nurses Society Conference; June 6-10, 2009; Orlando, Florida.
 Hoeflok J, Guy D, Allen S, St-Cry D, A prospective multicenter evaluation of a mouldable stoma skin barrier. Ostomy Wound Manage, 2009;55(5):62-69.

^{*}U.S. Patent No. 6.840.924 B2.

There is nothing to be afraid of, it's just life. By: Joanna Maddock, VIC

In early 2009 I was a typical 14 year-old studying Year 9. I was thinking that I had my whole life of great health and enjoying life ahead of me. Every-

thing was great until something happened to my health overnight and I started experiencing blood loss from my bowel. At first I thought it would stop, so I didn't take notice but after just over a week with nothing changing, I knew something was wrong but was too "embarrassed" to tell anyone. After three weeks, I started being very ill with diarrhoea and vomiting.

On the way to the doctor, I finally told my mum about the blood. Almost three months later, after many visits to the local doctor

and one visit to a hospital, I was finally referred to a gastroenterologist.

In June 2009, my Ulcerative Colitis journey began. My healthy life as I knew it had dramatically changed. I was taken to the Royal Children's Hospital in Melbourne where I spent the next two months. This was my first hospital admittance and I experienced blood transfusions, M.R.I. scans, bone scans, x-rays, CT scans, needles and many different medications and tests. All this was really hard to adjust to for a girl who had never been very ill before.

I never thought negatively at the beginning of my journey. I just kept telling myself there is no point crying over something I cannot fix.

Over the next 3 years, I can't remember a day where I didn't wake up feeling sick and in pain. At the beginning I was told I had Ulcerative Colitis which soon changed to a Crohn's diagnosis. However, soon after I was told no one could actually decide which specific disease I had. I was then treated for both diseases, trying every medication and treatment available.

There was one thing I was told that would most likely not happen but to always have in the back of my mind - that was to have lleostomy surgery. I always told my doctor though, "We have to keep

doing everything we can to avoid the surgery, I really don't want it." So that is what we did. For the last three years, I have endured countless medications,

long hospital admissions and missed a lot of my schooling due to medications failing.

Early in 2011, I spent a long three months in hospital due to having the Ulcerative Colitis/ Crohn's slowly destroy my immune system and I ended up developing pneumonia. But it didn't stop there. I had pancreas trouble, pleurisy and about ten other things which went wrong. I had lost just over 10 kilos (not that I could afford to lose that much) and I was put on a two month diet of ONLY drinking

high protein and nutritious milkshakes. That didn't last long as they tasted horrible and it made no difference to my weight and health. It took a while to recover, but I managed to stay clear of hospital admissions until November later that year, although I still had many day trips to the hospital.

This year, 2012, is my final year of secondary school. Year 12 is meant to be about studying and getting a VCE, but my school year started off badly as I was in hospital for the first two weeks of first term. In those two weeks, I was told I didn't have any choice but to accept that I had tried all medications available but nothing had worked. It was time to have the lleostomy surgery I had been avoiding for so long. Not only did I have the surgery coming up, I also had to focus on Year 12. I was advised to complete Year 12 over two years but I was determined to graduate with my friends. All I really want is to complete my VCE.

The thought of having an Ileostomy scared me senseless. I thought my life was going to change more than it already had. My surgery was booked to be done about a fortnight after I returned from my two week hospital stay. I knew I had to go into having the surgery done with a positive attitude, or all the strength that I had developed over the previous three years would come crashing down around me. So that's what I did, I stopped looking



at the negatives and I focused on the positives.

I now have an Ileostomy bag and I am fine with it! My surgery to remove the diseased colon was performed in February 2012. From the moment I woke up from that four-hour procedure I had the biggest smile on my face. I could already feel a difference in my health and felt on top of the world.

After a two-month recovery and having missed the first term of school, I returned to living life as I always had. Even though I now have the bag, I still eat whatever I want and wear the tightest of clothing and no-one knows unless I tell them.



has been six months since I had my lleostomy surgery and during that time I celebrated my 18th birthday. I will pass Year 12 to the best I can and live a normal teenage life. Being an 18-year-old there are many changes I face as my adult life is just beginning. Friends and family are a big part of my life and everyone around me is very supportive. It is extremely hard to open up to new people

and tell them, but if someone has a problem with it, then they don't deserve to be in my life.

This whole experience has taught me so many things about life. The main thing is that "There is nothing to be afraid of, it's just life" (I am soon to have this tattooed underneath one of my scars on my stomach). You only have one chance to live life so you need to make the most out of every situation and have fun, because you never know when the life you live can be taken away from you.

I am certain that having a positive attitude towards life and believing that I was stronger than I thought, is what got me through my hard three year battle with Ulcerative Colitis/Crohn's. I chose to accept what my life had become and I accepted it with a positive attitude. It was hard but it is worth it.

There's one quote I always told my friends and family through my experience. "When life gives you a hundred reasons to cry, show life you have a

thousand reasons to smile", and that's what I did.

I am due to have my reversal surgery in early 2013. Even though I'm now used to having my lleostomy, I cannot wait! I hope in the near future I can make people aware of this "silent" disease, to make people mindful it is not something to be ashamed of, nor is having a bag something to be embarrassed about. I hope my story inspires or helps someone struggling with coming to terms with their lleostomy.



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Support Pans For her



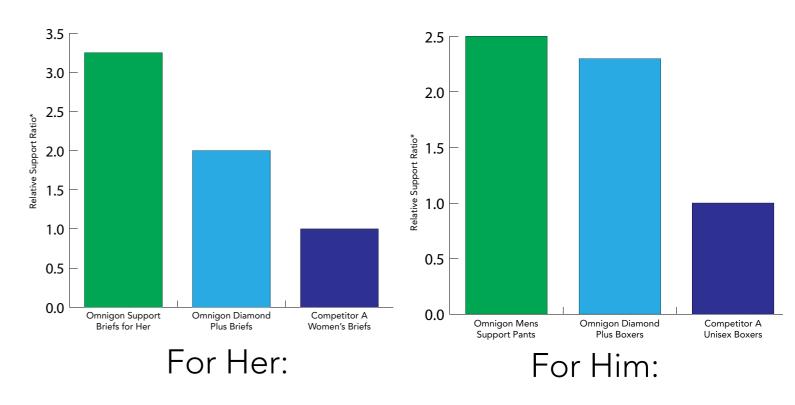
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Almost **7 out of 10** hernias develop within 1 year of surgery

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Memories of Lana Larkins from Young Ostomates United

04/05/1981 - 10/06/2012

It was with shock and disbelief that Young Ostomates United (YOU) heard of the sudden and unexpected passing of Lana in Brisbane on June 10th this year.

Lana had been such an integral part of YOU prior to moving to live and work in Brisbane in 2007. Lana was President of YOU in 2004 and 2005, which was a particularly difficult time for a group such as YOU, as we transitioned from traditional meetings to the use of social media, internet etc. Lana also represented Ostomy AUSTRALIA at world congresses in Canada in 2001 and Portugal in 2003, helping to spread

the YOU word and taking appropriate literature with her.

My memories of Lana go back many years, particularly to early 1998 when, with Anna Epifanio, we took four young ostomates to Phillip Island in Victoria for a weekend. Our aim was to help



resolve some of the many issues facing children and teenagers with an ostomy and of course to have fun. Lana was never one to beat about the bush. When one of the younger ones asked how to manage a leaking bag when out socially, Lana said "You just manage and get over it, the next time is easier."

The article that Lana wrote for 'Just for YOU' in 2003 and was reprinted for Lana's Memorial Service on 25th June says it all; she helped so many other young ostomates with her attitude to life, no matter how difficult.

Our hearts go out to Scott (Lana's partner), her parents Sue and lan, siblings Noni, Shane and

Dale, and not forgetting all her extended family and friends.

Thank you Lana for being part of YOU

From Lilian Leonard – Founder of YOU inc. in 1989 and present Committee member.

Vale - Mr Fred Cooper

It is with sadness that we report the recent passing of Mr Fred Cooper.

Fred was a Life Member of the Colostomy Association of SA, having served as a volunteer in various Committee positions.

He was also a very active member of the ACSA Committee, initially serving as Treasurer for many years before being Secretary. Fred was

widely recognised for his dedication and integrity in his work for ACSA, and was awarded Life Membership of ACSA.

Fred was universally liked for his outgoing personality and his quirky sense of humour.

ACSA and CASA are indebted to Fred for the legacy he left in the early years of both organizations.







What Type of Pouch to use?

Adapted from various articles and internet sources.

Over 40,000 people accessed Australia's Stomal Appliance Scheme (SAS) last year, which covers 420 products with 2,000 variants of these products. So which product is best for your condition and circumstance?

There is no right or wrong choice of pouching system. Each person must find the system that performs best for him or her. It is not uncommon to try several types until the best solution is found.

Your specially trained Stomal Therapy Nurse will have decided which particular type of pouching system you required immediately after your operation, ensuring that it is geared to each individual's needs. However, over time your pouching system may not be working as effectively as it once did due to changes to your stoma size, body shape, skin texture or general ageing issues. The availability of new products with improved adhesives and filters, barriers which are more skin-friendly, etc could also provide you with an improved pouching system. Free samples are readily available from suppliers for you to try.

Your pouching system may be a one-piece or two-piece system. Both one-piece and two-piece systems include a skin barrier/wafer ("faceplate" in older terminology) and a collection pouch. The pouch (one-piece or two-piece) attaches to the abdomen by the skin barrier and is fitted over and around the stoma to collect the diverted output, either stool or urine. The barrier/wafer is designed to protect the skin from the stoma output and to be as neutral to the skin as possible. These are the major types of pouching systems.

Colostomy and Ileostomy Pouches

Can be either open-ended, requiring a closing device (traditionally a clamp or tail clip); or closed and sealed at the bottom. Open-ended pouches are called drainable and are left attached to the body while emptying. Closed-end pouches are most commonly used by colostomates who can irrigate (see below) or by patients who have regular elimination patterns. Closed-end pouches are usually discarded after one use.

Two-Piece Systems

Allow changing pouches while leaving the barrier/wafer attached to the skin. The wafer/barrier is part of a "flange" unit. The pouches include a closing ring that attaches mechanically to a mating piece on the flange. A common connection mechanism consists of a pressure fit snap ring, similar to that used in Tupperware TM .

One-Piece Systems

Consist of a skin barrier/wafer and pouch joined together as a single unit. Provide greater simplicity than two-piece systems but require changing the entire unit, including skin barrier, when the pouch is changed.

Both two-piece and one-piece pouches can be either DRAINABLE or CLOSED.

Irrigation Systems

Some Colostomates can "irrigate," using a procedure analogous to an enema. This is done to clean stool directly out of the colon through the stoma. This requires a special irrigation system, consisting of an irrigation bag with a connecting tube (or catheter), a stoma cone and an irrigation sleeve. A special lubricant is sometimes used on the stoma in preparation for irrigation. Following irrigation, some colostomates can use a stoma cap, a one-piece or a two-piece system which simply covers and protects the stoma.

Urinary Pouching Systems

Urostomates can use either one or two piece systems. However, these systems also contain a special valve or spout which adapts to either a leg bag or to a night drain tube connecting to a special drainable bag or bottle.

There are also a number of styles.
For instance there are flat wafers and convex shaped wafers. There are fairly rigid and very flexible ones. There are barriers with and without adhesive backing and with and without a perimeter of tape.
Some manufacturers have introduced drainable pouches with a built-in tail closure that doesn't require a separate clip.

You may also need certain pouching accessories. Some of the most common items are:

Convex Inserts

Convex shaped plastic discs that are inserted inside the flange of specific two-piece products.

Ostomy Belts

Belts that wrap around the abdomen and attach to the loops found on certain pouches. Belts can also be used to help support the pouch or as an alternative to adhesives if skin problems develop. A belt may be helpful in maintaining an adequate seal when using a convex skin barrier.

Pouch Covers

Made with a cotton or cotton blend backing, easily fit over the pouch and protect and comfort the skin. They are often used to cover the pouch during intimate occasions. Many pouches now include built-in cloth covers on one or both sides, reducing the need for separate pouch covers.

Skin Barrier Liquid / Wipes / Powder

Wipes and powder help protect the skin under the wafer and around the stoma from irritation caused by digestive products or adhesives. They also aid in adhesion of the wafer.

Skin Barrier Paste

Paste that can be used to fill in folds, crevices or other shape or surface irregularities of the abdominal wall behind the wafer, thereby creating a better seal. Paste is used as a "caulking" material; it is not an adhesive.

Tapes

Tapes are sometimes used to help support the wafer or flange (faceplate) and for waterproofing. They are available in a wide range of materials to meet the needs of different skin sensitivities.

Adhesive Remover

Adhesive remover may be helpful in cleaning the adhesive that might stick to the skin after removing the wafer or tape, or from other adhesives.

There is no reason to stay with a poorly performing or uncomfortable pouching system. If you have any trouble with your current pouching system, discuss the issue with a Stomal Therapy Nurse and find the system that will work best for you. Be receptive to trying a different type or brand of pouching system. You are not locked into any pouching system or accessory.

Slip into something more comfortable with Simplicity®

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.



For more information, call TOLL FREE 1300 784 737 or visit www.ainscorp.com.au



Simplicity STOMA SUPPORT WEAR



- a Gastro-Intestinal (GI) Cancer diagnosis need not be a lonely journey by Gillian Anderson



Being diagnosed with cancer inevitably leads to many questions. That is why the GI Cancer Institute has launched **Engage**, a free online information network to help GI cancer patients, survivors, carers and family members persevere through this tough time.

Gastro-Intestinal cancers are cancers that affect the digestive system. This includes cancers of the oesophagus, gallbladder, liver, pancreas, stomach and colorectal organs.

Engage is a place to learn about the latest GI clinical trials and to share experiences regarding treatments. A community of people whose lives have been impacted by GI cancer, members can receive on-line information from survivors and carers who understand the challenges of GI cancer.

"A GI cancer journey is challenging, and sometimes people understandably don't know where to turn for information and advice. **Engage** means there is now a place to find trustworthy and practical information and hear and learn from others who have travelled the same road." said Dan Kent, rectal cancer survivor and chairman of the GI Cancer Institute's Consumer Advisory Panel.

"I was diagnosed with colorectal cancer in late 2005 and underwent surgery for a lower anterior resection, including the creation of a J-pouch and the provision of a temporary stoma, which was later reversed. The most important thing to me on my journey was the wonderful support and encouragement I received from my wife, family, friends and medical staff. However, living in a regional city I found it extremely difficult to find other local colorectal survivors and carers with whom we could share our cancer journey experiences and to better understand what are normal changes in our lives as survivors. **Engage** will go a long way towards fulfilling that gap." said Dan.

"Our daughter died of breast cancer and I've always had a strong interest in cancer research and learning all I can about cancer. I'm a firm believer that with more knowledge and if we change our lifestyle by doing simple things such as eating more fruit and veg and exercising regularly, we can help reduce our cancer risk." Dan added.

What does Engage offer?

Engage provides trustworthy, practical, and accessible information for patients, survivors and their carers. This includes:

- Real stories from GI cancer survivors and carers about their cancer journey;
- Information about the benefits of clinical trials and how to access them:
- News about research conducted by the Australasian Gastro-Intestinal Trials Group (AGITG), and GI Cancer Institute fundraising events;
- Practical resources to help those living with GI cancer;

- A quarterly Engage eNewsletter featuring regular updates and stories from health professionals, researches, cancer survivors and cancer trial participants;
- Recommended resources such as books and links to helpful websites:
- Nutrition information such as great recipes.

"In the future, our goal is also to run information symposiums, which will be both an opportunity for members to receive more information about GI cancer research, and a chance to network with researchers and other patients, survivors, carers and family. We also aim to provide **Engage** members with an opportunity to participate in an annual GI Cancer Advocate Program that will equip participants with knowledge and understanding of the clinical trials research process so they can be better advocates for its importance in the control and treatment of GI cancers." added Dan.

Robin Mitchell, a bowel cancer survivor and member of the Gl Cancer Institute's Consumer Advisory Panel believes that **Engage** will help those seeking information who may not be comfortable attending support groups or may not have support groups available in their local area. "My advice for people on a Gl cancer journey is this: don't be frightened to ask questions, and get as much information as you can from your specialist and from other sources. **Engage** will help to provide useful and practical information in your cancer journey".

Engage membership is free. Sign up for ENGAGE at www.gicancer.org.au or by calling 1300 666 769.

"We look forward to having you on board as an **Engage** member and to providing you with information which we know will assist you and your carers during your journey and survivorship." concluded Dan.

The GI Cancer Institute is a registered Australian charity that raises money for gastro-intestinal cancer research, in particular clinical trials conducted by the Australasian Gastro-Intestinal Trials Group (AGITG).





The Omnigon Foundation would like to thank you for voting to help change someone's life.

So far Australian ostomates have voiced their support as follows[†]:

72% Bowel Cancer Australia

14% The Smith Family Foundation

14% Fred Hollows Foundation

Have YOU voted yet?

If not, its just **2** simple steps to help change someone's life:

Step 1) Select your preferred charity from the following list

Bowel Cancer Australia

The Fred Hollows Foundation

The Smith Family Foundation

Step 2) Call FREE on 1800 065 497 to lodge your VOTE and the Omnigon Foundation will donate 50¢ on your behalf.

When YOU vote, you will receive a free gift as a token of our appreciation

[†] Data on file Omnigon 2012





As individuals, we have different reactions to food, both before and after ostomy surgery.

You may be on a bland diet for a period after surgery, but gradually you will be able to manage most foods. It may also take several weeks before your appetite returns, especially if you have been unwell for a time.

Initially, try eating small appetising meals at regular intervals and gradually introduce new foods into your diet. Dietary modification



may also be necessary at times. Ostomates can and do enjoy eating in restaurants and with friends without unpleasant side-effects. However, when introducing new foods, its best to first try them at home so that any adverse reaction (high output for example) can be monitored

and managed without embarrassment or inconvenience.

All foods, but especially nuts and seeds, should be thoroughly chewed else could cause a blockage. Blockages can also be caused by eating coconut, popcorn, some vegetables and some fruit. A blockage may cause colic pain, which is usually temporary. Seek medical advice without delay if pain persists or becomes more than a discomfort.

Some foods may cause flatulence and others may have a laxative effect creating the need for frequent emptying of your pouch. There are also some foods which have a tendency to generate strong odour for ostomates.

The following is a ready reference guide of what some foods and beverages can do to stoma output of some people. The effects of different food and beverage on stoma output **differs from person** to **person**. Some of the foods listed below may therefore not be a problem for you, while some unlisted foods may cause you problems. Just remember, everything in moderation.

Foods that can Obstruct

Apple skins, raw cabbage, raw carrots, celery, Chinese vegetables, citrus fruits, coconut, coleslaw, corn kernels, dried fruit, frankfurters, grape skins, mushrooms, nuts, peas, pineapple, popcorn, potato skins, sausage skins, seeds, tomato skins.

These need to be chewed thoroughly.

Foods & Drinks that may Increase Output

Alcohol, beef, bran cereals, broccoli, cooked cabbage, fresh fruit (except bananas), grape juice, leafy greens, liquorice, milk, prunes and prune juice, raisins, spicy foods, raw vegetables.

Foods & Drinks that may Thicken Output

Apple-sauce, stewed apples, bananas, bread, buttermilk, cheese, marshmallows, boiled milk, noodles, pasta, creamy peanut butter, pretzels, white rice, tapioca, toast, yoghurt.

Foods & Drinks that may Cause Wind

Alcohol, beans, broccoli, Brussels sprouts, cabbage, carbonated drink, cauliflower, cucumber, corn, dairy products, meringues, mushrooms, nuts, onions, peas, radishes, soy, spinach, whips.

Foods & Drinks that may Cause Odour

Asparagus, baked beans, broccoli, brussel-sprouts, cabbage, cauliflower, strong cheese, cod liver oil, eggs, fish, garlic, mustard, onions, peanut butter, spices.

Foods & Drinks that may Help with Odour Control

Buttermilk, cranberry juice, orange juice, parsley, tomato juice, voghurt.

Foods & Drinks that may Help with Constipation

Warm / hot beverages, cooked fruits, cooked vegetables, fresh fruits, fruit juices, water.

Your Stomal Therapy Nurse or hospital dietician can provide you with information on diet and nutrition.

Rule Number One

One of the rules I was brought up with was don't make rules. After all, rules are only made to be broken, which is more the reason that making a rule should only come after the event that prompts it. Only then, should you consider making a rule. Aha... but the real rule is once a rule is made, do not ever break it!

So here is my Rule Number One, and my only rule to date: *Don't have a cup of tea on waking up.*

Like what? My husband would bring me a wake-up cuppa in bed. How loving and how luxurious. And now I have imposed a household rule that has taken away one of the best parts of my day.

So I've had to say, "No thank you my love. I'll catch up with one shortly."

Why? Well, the experience is that for as long as I continue the sleeping-fasting-and-don't-eat-or-drink-anything-at-all mode, I can go through my morning shower without any untoward event.

And by breaking the rule and having a cuppa on waking up and then into the morning shower? Well, I've quickly learned that most of my time was to be taken with cleaning the *shower* rather than myself.

But I now have an alternative arrangement. Not nearly as good as the personal service with a partner delivering that cuppa, but probably as good as it will get.

Firstly, I bought a mug with a lid (most Chinese stores have heaps at *el cheapo price*).



The lid helps to keep the heat in. Secondly, it's out of bed and into the kitchen to boil the kettle. Two cups are made - one for me and one for my husband. Yes, it's he who now has the luxury

of being woken with that glorious cuppa - and he loves it. (It's a return payment, eh?) But I then pop the lid on mine and sit it on the bathroom bench, remove my pouch and jump under the shower.

Carefully timed, I'm out before things start happening. The new bag goes on. I'm a new and refreshed lady and then ... the lid is lifted and the taste of that hot cuppa is savoured.

Again, life has been found good for a bag lady.

Barbara

Do you have a rule number one? Please share it and we will establish a regular column to let everyone know.

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*Source: Product evaluation results AUS+NZ. Total respondents: 79

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Watch a video with reactions to SenSura Mio.



National Directory of Ostomy Support Groups

NEW SOUTH WALES

BATHURST

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

BROKEN HILL

Meet: Every 3rd month or as required.

Venue: Broken Hill Hospital Conference Room.

Contact: Tarndra 08 8080 1333

CENTRAL COAST

Meet: 2.00pm to 4.00pm on 20th Feb - 15th May - 21st Aug -20th Nov

Meet at a different venue each month.

For further information, phone the Stomal Therapy Service on 02 4320 3323

COFFS HARBOUR

Meets 2:00pm to 3:30 pm 14th Feb - 11th Apr - 13th Jun -8th Aug - 10th Oct - 12th Dec Venue: Club Coffs, West High Street, Coffs Harbour. Ostomates & friends welcome. Contact Mandy Hawkins STN on 02 6656 7804

EUROBODALLA REGION

Meet first Sunday in Feb, April, June, Aug, Oct, Dec. 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

Meet: first Thursday of each month from 9.00am to 11.30am Venue: Community Health Centre, 175 Queen Street, Grafton. 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 Wed. 20th Feb - 17th Apr - 19th Jun -21st Aug - 16th Oct - 18th Dec Inquiries: Keith (President) (02) 6583 3970 or Barbara (Secretary) (02) 65824206

ILLAWARRA

Meet: 10.00am to 12 noon on Wed. (2013 meeting dates TBA) Venue: Education Room, Figtree Private Hospital, Suttor Place, Figtree 2525

Contact: Helen Richards STN Monday only: 02 4225 5046

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 Saturday 25th Feb - 30th May - 25th Aug (AGM) - 24th Nov.

Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.

Enquiries: Geoff 02 4981 1799 or Maree 02 4971 4351

ORANGE & DISTRICT

Meet: Mar - June - Sept - Dec From 12 noon.

Venue: 15 Olver St, Orange. NSW Contacts: Louise: 02 6330 5676 and Joanne: 02 6362 6184

PENRITH

Meet: at 2.00pm on 22nd Feb - 3rd May - 19th Jul - 14th Sep - 23rd

Tresillian Lecture Room, Tresillian, Penrith (end of Barber Ave next to Nepean Private Hospital off Northern Rd). Parking Barber Ave or within Hospital grounds. Enquiries: Naomi Houston (Stomal

Therapist) 02 4734 3118

SHOALHAVEN

4th Feb - 6th May - 5th Aug - 18th

Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra. Contact: Margaret or Tracey on 02 4424 6300

ST.GEORGE/SOUTH EAST **SYDNEY**

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

SYDNEY SOUTH-WEST AREA

Meet: Saturdays 3pm - 5pm on 9th Mar - 18th May - 17th Aug and 6pm - 7pm on 16th Nov (followed by Christmas Dinner) The Macarthur Room, Revesby Workers Club, 2b Brett St.

Revesby (closest parking at front

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: Nerolie: 02 9487 9061

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

Meet: Second Tuesday of March, June, Sept, Dec.

Venue: Bairnsdale Neighbourhood House, 27 Dalmahoy St, Bairnsdale, VIC

Contacts: Janine: 03 5156 0933 Derelle: 0448 458 997 Email: bdosg@hotmail.com

BENALLA / WANGARATTA

Meetings held Mondays at 2.00pm: 20 Feb - 18 Jun - 15 Oct at Delatite Community Health Service, 45 Coster St, Benalla 16 Apr - 20 Aug - 17 Dec at Wangaratta Masonic Centre, 101 Appin St, Wangaratta Contact: Rex Nankervis (03) 5762 2080

Email: rexmarn@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 Road, 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: Tarndra 03 5022 3333 or Norma 0409 252 545

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

SUNRAYSIA / RIVERLAND

(2013 meeting dates TBA) 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 month - Feb to Nov at Beenleigh Community Health Centre.

10 -18 Mt. Warren Bvd. 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

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 2 months at various venues.

Private and Confidential C/- PO Box 703 Labrador, QLD 4215 Phone: 0429 126 163 Email: gcsong@live.com.au

MACKAY

Meets at Community Health Rooms, Nelson Street, Mackay. At 2pm on the second Friday every second month.

Feb - April - June - Aug - Oct - Dec Contact: Fay: Phone 07 4942 5135 Gerry: Phone 07 4956 3409

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 4928 5248

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 third Monday each month at 10am Enquiries: Winifred Preston: (07) 5476 6313 presto70@bigpond.net.au Don Lindsay: (07) 5477 0864

lindsaymar@optusnet.com.au

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

Meet for lunch 12.30pm on the third Monday in March, June, Sept and Dec.

For venue, please contact Anthony Widdowson (Launceston) on (03) 6344 9579 or mobile: 0418 595 730 email: acwiddowson@bigpond.com

SOUTH AUSTRALIA

CENTRAL

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

When: 7.45pm.

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

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

Helen - (03) 9796 6623 Web: www.vicnet.net au/~youinc Email: helshae@hotmail.com

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 Fmail:

contactpndu@gmail.com Web: www.parenteral-nutritiondown-under.webs.com



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