

Volume 23 Number 2 August 2014 Print Post Approved PP 100008088 ISSN 1329-959X



Embracing Technology

SURFERS PARADISE - OCTOBER 2014

2014 ACSA Conference



National Directory of Ostomy Associations

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

AUSTRALIAN CAPITAL TERRITORY

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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: Tanya Harber

NORTHERN TERRITORY

CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House 25 Vanderlin Drive, Casuarina Mon to Thurs 8.30am to 2.00pm Phone: (08) 8927 4888 Fax: (08) 8927 4990 Email: ostomy@cancernt.org.au Web: www.cancercouncilnt.com.au

WESTERN AUSTRALIA

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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 -1.00pm Secretary: Jess Whitehouse

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OSTOMY NSW LTD

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NTH QLD OSTOMY ASSN INC.

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

SOUTH AUSTRALIA

OSTOMY ASSN OF SA

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

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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

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VICTORIA

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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

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

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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

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



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	National Directory of Ostomy Associations	2
	From the Editorial Desk	4
	President's Message	5
	Vale, Noel Dillon	6
n	Letters to the Editor	8
	Your Say / In Your Own Write	10 - 12 - 13
	Love at First Sight - Megan's Story	16 - 17
	Ask Carmen - our Stomal Therapy Nurse	18
	2014 ACSA National Conference	20 - 21
	Ostomy: Mate or Menace?	24
	Skippy Saved my Life!	26
	Life with a Stoma - The gory details	28
	Ostomy SA - New Premises Grand Opening	29
	Smile A'While	29
	Vale, Alex Peters	30
	Bulletin Board	30
	AASTN President's Report	31
	From Loo Runs to Fun Runs	32
	I've Become a 'Gator'	34
	2014 Queen's Birthday Honours	34
	Living with a Stoma in the Remote Outback	36
	Nutrition for Ostomates - Vegetable Consumption	38 - 39
	Looking for the Good News - No Stoma Unturned	40
	National Directory of Ostomy Support Groups	42 - 43
	National Directory of Ostomy Product Suppliers	43
	Index to Advertisers:	
	Ainscorp	7 - 27 - 37
	Coloniat	11 00 00

Ainscorp	7 - 27 - 37
Coloplast	11 - 22 - 23
ConvaTec	9 - 33
Dansac	44
Hollister	19
Omnigon	14 - 15 - 25 - 35 - 41
Statina Healthcare	31

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

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

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

From The Editorial Desk

Receiving a stoma and how best to manage it often triggers a roller-coaster ride of emotions and concerns. How each new Ostomate reacts and adapts to the changes in their body's appearance and function differs from person to person. Everyone adapts and adjusts at their own pace and in their own way. For some it is a very private matter which they will learn to manage alone, while others are happier seeking help from others. However, it is important to always remain positive and not to suffer in silence.

For many, a stoma operation may also deliver a release from years of pain and other health conditions, often giving a new lease on life and allowing them to do things which were either distant memories, or only dreamt of, before their operation.

In our first article, "Love at First Sight", Megan Earls tells of a new love – her ileostomy – which she welcomed after enduring severe pain and other unpleasant complaints in her struggle with Pancolitis. Megan thankfully now has this condition under control and also sends an important message to others – always "find a doctor who listens and is willing to work with you."

Similarly, Yvonne Green, in "From Loo Runs to Fun Runs", tells how her Crohn's Disease had her running every which way, but never for exercise or enjoyment. However, since the creation of a permanent ileostomy in 2010, Yvonne has been able to work hard at her fitness to a point where she is now enjoying distance running for fun instead of running for urgency.

For Maureen Cooper, receiving an ileostomy made her into "a new woman" after battling ulcerative colitis for many years. Now twenty-five years after that operation, Maureen tells in her "Skippy Saved my Life!" article of her journey and how she continues to live life to the fullest.

Likewise Kerry Kimbrey, who as a suitable candidate for irrigation, describes in her "I've Become a 'Gator'!" article how the irrigation procedure has freed her from the need for several bag changes every day.

Timothy Pascoe in "Ostomy: Mate Or Menace?" and Andrew Bleby in "Looking for the Good News - No Stoma Unturned", also give their personal perspectives on how to avoid feeling sorry for oneself and how they go about staying cheerful.

These and our other contributions often reflect this new found freedom and how a positive approach has helped in their recovery and "new" life with a stoma.

In this issue's "Nutrition for Ostomates" article, Margaret Allan reminds us that vegetables are vital to a varied and healthy diet and need to be regularly consumed. However, many Ostomates restrict or avoid vegetable consumption due to the fibre content or other issues. Margaret provides some very useful advice on how Ostomates can increase their vegetable consumption without increasing the risk of blockages or diarrhoea.

Sadly, this issue also marks the passing of two long-time stalwarts of the Australian Ostomy community - Noel Dillon,

the previous Editor of this journal, and Alexandra Peters, NSW's very first Stomal Therapy Nurse. From all of us - rest in peace, Noel and Alex.

Thank you once again for all your letters, helpful hints and stories, as well as the articles from Ostomy Associations and support groups.

Take care and stay healthy. Kim Lyell EDITOR

Help!

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



Please send your submission in MS-Word or PDF document format via email to: Journal@AustralianStoma.com.au

Hard copy submissions may be posted to: The Editor, Ostomy AUSTRALIA PO Box 195 Frenchs Forest NSW 1640

Please ensure that your contribution does not specifically name any doctors or nurses, unless they have agreed in writing to his/her name being published. 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.

"We may encounter many

defeats but we

must not be

defeated"

MAYA ANGELOU

A Time for Change

t the Annual General Meeting of ACSA in October $oldsymbol{\Lambda}$ last year I indicated that I would be stepping down as President when my term expires in October this year. This will therefore be my last President's Message to Ostomy AUSTRALIA. Unlike our previous President, Gerry Barry, who was in the position for thirteen years, I have been President for only four years. Although this represents only two Committee terms, I have been involved with ACSA as a member of the National Executive since 1997. While many things have happened in the years since then, the underlying role and mission of ACSA has always remained the same. Our focus was then, and still is now, to maintain the outstanding level of support provided to all Ostomates in Australia and to be ever ready to meet the challenges we may encounter in the future preservation of what we have achieved. The most important part of this work has been to ensure the ongoing success of the Stoma Appliance Scheme: our best and most enduring achievement.

During my time as a member of the National Executive of ACSA, there has been three extensive reviews into the operation of the Stoma Appliance Scheme, each carried out by a different entity but all initiated by the Department of Health. While the outcome of each review resulted in some amendments, the findings of all were that the current distribution mechanism provided the best possible level of support at the lowest cost for Government. The Australian model for the supply of ostomy products to Ostomates is unique in that the operational function of the Appliance Scheme is carried out entirely by related support organisations, i.e. Ostomy Associations, which offers many benefits to members. These benefits include the availability of staff and volunteers with a specialised knowledge of products who are able to relate to the needs of Ostomates. It also enables the costs to members to be kept at a minimum through the utilisation of a large volunteer work force and dedicated staff and has resulted in Australian Ostomates having access to the world's best stoma products. Another important achievement is that we have been successful in keeping all Ostomates together as Association members so that we can deliver the support, advice and assistance to help everyone meet the challenges of the personal and lifestyle adjustments associated with living with a stoma, particularly in the immediate and post-operative period. Of course there have been many other achievements over the years and together they have made us the successful national Association we are today.

Since being elected as President in 2010, the National Executive of ACSA has continued to foster a sense of unity with member Associations and has been committed to developing meaningful working relationships with the Departments of Health and



Human Services. Both Departments recognise the vital role that ACSA plays in the provision of ostomy support to our members and their families. Our continuing work in cooperation with the Department of Health has played an important part in obtaining many improvements to the Scheme. Thankfully, the recent budget papers have indicated that the Scheme will continue to be fully funded and that new products will continue to be available. This is very reassuring considering the budget cuts announced and may also be seen to be a reflection of the excellent value for money that our distribution system provides.

This level of success has been very satisfying but it could not have been achieved without the contributions of members of the Executive, Committee Chairpersons and Coordinators, all of whom have provided support without reservation and have also worked hard in making personal contributions to the success we have enjoyed.

I could not let my final President's Message go without mentioning the passing of Noel Dillon; Noel was Editor of *Ostomy* AUSTRALIA for twelve years, standing down in 2011 due to ill health. We have been fortunate to have excellent people involved in Ostomy support over the years and Noel fitted easily into that category. The entire Australian ostomy community owes Noel and others like him a great deal. His ability to see a problem and then his preparedness to get involved with the solution to that problem epitomises the dedicated people who have gone before us.

This year the annual Conference of ACSA will be held on the Gold Coast at the Grand Chancellor Hotel Surfers Paradise Queensland from Thursday 9th October to Sunday 12th October. This will be a chance for all who are interested to attend. A busy agenda, interesting speakers and a great venue should provide an interesting couple of days.

So with that invitation I end my time as a member of the ACSA Executive and say farewell as President, confident that it is time for new blood with new ideas to continue the advancement of Ostomy support and community awareness.

Peter McQueen PRESIDENT



Vale, Noel Dillon

t is with great sadness that we report the passing of Noel Dillon, the previous Editor of the *Ostomy* AUSTRALIA journal, who lost his battle with cancer on Monday 24th February 2014, with his funeral held in Melbourne on the 6th of March. Considering that some three and a half years ago Noel was given only three to six months to live, he fought strongly to the very end, a further demonstration of his positive attitude and strength of character.



Noel arriving at Caulfield for a race meeting in 2012

Noel was a gregarious person who loved people, made friends very quickly and enjoyed nothing better than a good yarn. He had an amazing recall of people he'd met and the places where he'd lived and worked during his life. It was interesting hearing of his reflections on his years living in outback Queensland and other places, as well as his involvement in so many different activities, including sport with his prowess at high jumping as a youth, tennis, rugby league, boxing and golf.

Noel was very practical and most supportive of those in genuine need. In later life this was most apparent with

his commitment to the ostomy movement - as founder and first President of the Wide Bay Ostomy Association, and as Editor of *Ostomy* AUSTRALIA.

After becoming an Ostomate in 1992 following surgery for bowel cancer, Noel quickly recognised that there was a lack of support for Ostomates in Queensland's Wide Bay region. His key concern was the vast geographical distance between the two Brisbanebased ostomy associations and the next northern ostomy association located in Townsville. There was no other Ostomy Association to issue appliances or to provide practical assistance and moral support for Ostomates within the Wide Bay/Burnett area. Noel's perseverance and commitment paid off and following its incorporation in 1995, he became the founding President of the Wide Bay Ostomy Association. Noel held this position until he relocated to Melbourne in 2007.

Noel's role as Editor of *Ostomy* AUSTRALIA commenced in June 1999 and concluded with the August 2011 issue. During that time Noel nurtured and helped to develop the journal into a world standard publication. Each issue had to be better than the last. He took much pleasure in choosing the appropriate photo for each cover, often taking his own photo of beautiful flowers or a scene. His aim with the covers was to immediately capture a prospective reader's interest to "pick me up and read me". Wendy Taylor accepted the position of Assistant Editor in 2005 and together they proved to be a formidable team, until failing health forced Noel's resignation.

Noel also enjoyed using his bargaining skills, whether to negotiate a good deal for *Ostomy* AUSTRALIA with the various ostomy product advertisements, getting the best price for the venue of the annual ACSA Conference, or when buying food and other goods. During the ACSA Conference hosted by the combined Victorian Ostomy Associations in Melbourne in 2010, his skill in controlling costs while remaining focussed on desired outcomes was most evident. By using a firm and professional approach, Noel successfully negotiated a Conference



venue and associated activities which were thoroughly enjoyed by all delegates and observers. In fact, he visited some twentyfour likely city locations to achieve the best value for money for the organising committee and for all who attended.

Noel had a varied career including: books and publishing; the hotel industry; a volunteer radio announcer; and fishing. However, his big interests were horse racing and jazz.

Noel was a member of the Victorian Jazz Club and loved to go to live jazz band venues. His favourite group in Melbourne was "Stevenson's Rockets" who performed regularly at The Emerald Hotel on Sunday nights. He enjoyed listening to recorded music selected from his vast collection of vinyl LPs and CDs and 'appropriate' jazz programs on radio. His knowledge of instrumentalists, vocalists and the big bands of the 1930s to the 1980s especially was quite extraordinary.

He was also a volunteer announcer of the Fraser Coast (Queensland) Community Radio for many years.

Noel had an amazing store of information about horses, jockeys, trainers and the racing industry in general. In Melbourne he was a member of the Melbourne Racing Club (Caulfield and Sandown) and also attended Flemington race meetings, but not the Melbourne Cup which in his view was "all booze and bad manners!". He took great pride in knowing about and discussing everything associated with horses and racing. He laboriously studied the Form Guides and loved to place his well-considered bets. Should a particular race produce a disappointing outcome, he was wont to say: "I bet on such a good horse, but it took seven others to beat it!"

Noel dearly loved his family and often spoke highly of their personal achievements and the activities they had all shared. He was always sad that his work and geographical distance often intervened in keeping in continuous contact with his family across the years.

Noel had an amazingly varied life and was always working at "the next step forward", accepting that life presented many hurdles and challenges to be confronted and overcome, not dwelt upon.



Noel with three favourite Stomal Therapists (L-R: Robyn Hudson, Rae Bourke and Helen Nodrum)

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Letters to the Editor

Dear Editor

Re the "Belts and Braces letters" (Letters *Ostomy* AUSTRALIA Journal - December 2013 and April 2014 issues), I have exactly the same problem as Ian from Victoria, in having my stoma positioned on the belt line. (Why do they do that?). Ian is correct in saying that the usual menswear store-bought braces are ineffective. I have found they are quite useless after a couple of wears.

He is also correct in saying that these heavy duty braces are great. I purchased three of these and am very pleased with them. I must say though that my wife blanched when she first saw them. However, they are intended to do a job and aesthetics do not enter into it. They are NOT pretty so I wear them under my shirt. She is a bit more relaxed about them now!

Funny thing, I have known about Carba-Tec for their woodworking machinery and tools for years, but would never have looked to them for braces!

Thank you lan, I am grateful for your information.

Douglas Rees, NSW

Dear Editor

My husband and I spent six weeks travelling around Europe last year; a mixture of bus tours, barge and cruise trips. A few days in Venice were spent wandering along the narrow streets and canals



looking at all the sites. We walked into a square and were surprised with this sign.

I have had my ileostomy since 2000 and we have travelled every year since we retired in 2004. A stoma just makes for more interesting holiday stories.

Gayle Christie, NSW

Dear Editor

I'd just like to respond to a couple of letters in the "Your Say/In Your Own Write" of the April 2014 issue.

For anyone interested in the "Bathroom Floor Cabinet" mentioned by Lindsay Campbell, it can be obtained at a cost of \$79 each from Innovations, which is a mail order company.

In response to Lee Heylin's story "Just a Stone's Throw Away", I have had similar issues. I've had kidney stones before my diversion and have passed many of them over the years. Since the diversion, I have passed a few of varying sizes. Most of these formed in the ileal conduit itself though and not the kidneys. I am told it is not uncommon and I still get kidney stones too. The doctors suggested I keep my sodium intake to a minimum and to avoid excess protein. It might also help to take a urinary alkaliser like Sodibic Urinary Alkaliniser capsules (sodium bicarbonate). I was on about 3000mg/day but you should ask your urologist about it first.

Peter Lane-Collett, QLD

Dear Editor

I was so glad that J.M. from QLD (Letters-*Ostomy* AUSTRALIA Journal-April 2014 issue) raised the issue of monthly allowances.

My ostomy supplies are posted to me and it can take up to three days for me to receive them. They cannot be posted before the first of the month and if the first of the month falls on a weekend then they are not posted till the Monday.

I have lost count of the number of times I have had to ring the product company to have some samples sent, but they can't be delivered overnight as I don't live in a capital city.

I have Crohn's Disease which means I can have a very active stoma. I regularly get certificates from my STN for one more box only and am often made to feel as though I must be wasting them! One STN told me not long after I had the colostomy to get bigger bags and don't change them as often. I was horrified. For goodness sake, we don't eat them. I treat them like gold!

Having none left and waiting for my supplies to be delivered has been some of the most stressful days of my life. I too believe that we should be allowed extra without the need for a certificate.

I really don't think any Ostomate would waste the only thing that lets them lead a normal life.

Kerri, NSW

Dear Editor

I am new to all of this ostomy business, unfortunately due to another driver who could not keep his hands off his mobile phone, but that is another story.

I have to agree wholeheartedly with J.M. from QLD who asks for additional pouches because there is a shortfall with a daily change schedule. I am in the same position and certainly do not have any "reserve". Last month I was sweating on my supplies arriving.

As for "responsible use" - am I missing something? Is there a black market for these things? Do they make appropriate gifts for friends and family? I cannot possibly imagine how one would use an ostomy pouch irresponsibly.

What could possibly be the harm in having a few extra pouches per quarter, or even just a "bonus box" to establish a "reserve" at the beginning?

L.B. NSW

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YOUR SAY

WRITE IN

ΤΟ ΗΔΥΕ

My Toilet Paper Dispenser

Submitted by Alex Kara, VIC

I have had a colostomy for nearly two years and because of my activity I find that the quota of three ostomy bags per day is insufficient. Instead, I only use drainable bags (I eat heaps of roughage to keep the stool soft for ease of cleaning).

I have found that manipulation of normal toilet paper with one hand to be near im-

possible (often with half the roll unravelling onto the floor) and using facial tissues becomes quite expensive. Instead, I now use cheap commercial interfold tissues, which I find ideal for cleaning the open end of the bag and any 'oopsies' that may inadvertently arise. While they are not as absorbent as the normal toilet roll, their ease of use and low cost compensates for that. To pull out a single sheet (or several sheets) with one hand is simple and lets me maintain a stable grip on the neck of the ostomy bag with the other hand. I mounted the dispenser above the toilet cistern as that is my normal facing position as I go through the routine of flushing out the bag using a two-litre jug of water, which I can balance on top of the cistern.

I found that the commercial tissue dispensers in public/commercial toilets are designed to prevent easy theft of boxed tissues and extracting the empty box from these dispensers can be an unnecessarily cumbersome chore. While this is only an inconvenience, I already face enough inconveniences and I don't need that additional challenge.

Consequently I used the dimensions of a commercial dispenser to design and build several timber dispensers and installed these in various locations throughout the house. A PDF file showing all the measurements of my design (and a SketchUp* file for the more technically minded) are available via email (alexkara@aussiebb. com.au) in case anyone gets adventurous and creative enough to make their own.

Having it mounted on the back wall (to the toilet) does not interfere with any "standard" toilet users and as I am the only user, it is only my fault if the dispenser registers as empty. Having a capacity for two boxes, I have found that removing the empty box and opening a new box with one hand is not an arduous task.

*Sketchup is a free 3D drawing tool available for both PC and Mac and can be downloaded off the Internet.

Ostomy Associations in Australia are already addressing ongoing "Opportunities and Challenges"

Submitted by Ed Webster, NSW

As a former ACSA Secretary I wish to address the remarks made by Geoff Rhodes in his article entitled "Ostomy Movement in Australia: Opportunities and Challenges" in the April 2014 issue of this Journal. From my twelve years' experience as ACSA Secretary up to 2010 and my years as a delegate at ACSA Conferences I must disagree with the suggestion that the organisation and structure of ostomy support in Australia is still based on how associations operated in the 1970's. In my view nothing could be further from the truth as all associations have changed over the years to provide an improved means of supporting their members both through the Stoma Appliance Scheme and in giving them the support needed to assist in overcoming the trauma of their surgery and to resume a normal and active life.

I believe that all associations, with the support of ACSA, have emerged in the twenty-first century as progressive groups and have done more than could be expected to develop their organisation, systems and structures to meet the needs of their members. They have developed from small hospital or home based associations each catering for a few hundred members, to the current business-like entities supplying ostomy products to forty thousand members nationally, distributing over two thousand different products. The larger associations successfully manage business activities turning over high levels of stock and operate with an efficiency which would put many commercial businesses to shame. The smaller associations have also adopted modern distribution arrangements. Of course the operations of associations are not perfect and need to be continually developed but in my experience they have done this. Even with their computer management systems they have done very well in developing basic systems at a reasonable cost which meet their current needs and which have been improved over the years. No doubt there is more to be done and this is already happening in a number of associations. It should be accepted that the pace of systems development has so far met association needs. Moving to expensive new systems may eventually come about but this is part of future development and must be managed carefully in close consultation with all associations.

With the proposal in the article that a reduction in operating associations should be considered and that we should use a central mail distribution arrangement, I would like to refer to the outcomes of earlier reviews of the Stoma Appliance Scheme by the Department of





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Health. All of these reviews acknowledged the value of the present system in delivering stoma supplies in the most efficient and cost effective manner and they were happy with how well the system assisted in providing wider support for Ostomates in conjunction with the operation of the Scheme. A possible reduction of the number of associations in Australia was considered in the Carla Cranny & Associates review which reported in 2002. The option to reduce the number of associations distributing ostomy appliances was not supported by the Department of Health so it is obvious that the Department considers the way we operate provides the best value for the scheme and the associated support of Ostomates. Some associations did later consider the possibility of amalgamation but concluded that it would result in a reduction in personal local support of Ostomates and would not meet member needs as well as at present. I believe that the view still is that we have the best system in the world and we should not change to an Australia wide mega system with the inherent loss of personal contact and the problems of funding, acquiring, setting up, and staffing a central distribution warehouse. Government funding of such a proposal would not be at all likely and it would have to be paid for by associations out of their present 2.75% administration fee and membership subscriptions. I am sure this would not receive much support from associations.

The article goes on to suggest that associations need to think about restructuring their management model; better integration with STNs and better use of our volunteers. I have to say that all of these proposals have been the subject of discussion by ACSA over the years and I firmly believe that they have also been addressed by associations in the light of their knowledge of the needs of their own members. From experience at an association level I think that these days Ostomates often seek personal support at the time they get their appliances and associations have adapted to this need. I agree that the inclusion of STN support into this process would be a good idea but it is not always possible because of the lack of available STNs outside of the full time employment provided by the hospitals and community services. This is something which could be considered at a national level and one which Geoff could examine in his role as ACSA Vice President. On the suggestion of working more efficiently with suppliers and Government, finding the best way of working with suppliers is a daily task for associations and coordinating with Government is more a role for ACSA.

What I would like to see is for Geoff, as a member of the ACSA Executive, working closer with associations to understand the support they already offer and coordinate improvements at a national level. Associations are already doing a great job thinking about the issues raised in the article.

Many Years Have Passed

Submitted by **Jill Fairhall** Stomal Therapy Nurse John Hunter Hospital and Newcastle Private Hospital

I recently visited Aunty Gwen, my aunty through marriage, who resides in an aged care facility. She is ninety-eight years old, is as sharp as a tack and steams around on her walking frame.

WRITE II TO HAVE

Aunty Gwen has an ileostomy and she thinks she has had it for around sixty one years. She remembers very hard times back then: being unwell, blood transfusions, trips to Sydney hospitals and many operations.

She recalls being challenging in the early years: recovering from surgery, having young



children, ostomy bags were not available and her concerns about 'what people would think' - all this whilst her husband worked fulltime.

However, resilience prevailed and she went on to lead an active full life, playing sport and raising a family. Aunty Gwen has cared for her stoma meticulously over the years and only recently has required assistance with her care. Well done Aunty Gwen!

Paper Towels or Cloth-Type Wipes?

Submitted by Shoshanna Monk

Some time ago I started using quality kitchen paper towels instead of cloth-type wipes (such as Chux) for cleaning and wiping/drying when changing my ostomy bag. I have found that some paper-based products are more efficient, softer and easier to use. However it is very important to use only a top quality name brand. Choose a product which when wet will have the appearance and feel of cloth, and when dry is able to absorb all moisture left on the skin. Additionally I find that it is more economical in price and is occasionally on special in supermarkets. I cut lengths of two sections at a time and store these in a snap-lock bag ready to use.

I got the idea when I was in the supermarket one day and my eyes fell on the line on a name brand kitchen paper package that stated "toughest when wet"! So I thought let me test this out for myself, and honestly I haven't looked back. It has made a big difference. But I do realise that everything is individual and what works well for me may not be the same for someone else. The other day I was in a large supermarket and they were selling a two-pack of my preferred product for two dollars on special, so it was a bit of an opportunity to stock up on an essential item.

Thanks to you all for the terrific job you all do providing moral support for everyone on Planet Stoma!

I hope others may find this tip useful.

Longer Tubing Will Fix It

Submitted by Peter James. NSW

I have been an Ostomate for seven years and during that time I have learnt how to manage my condition thereby making my life a lot easier and with a lot less discomfort. At eighty years old I have become careful with my money and also other people's. From day one I couldn't see why I was allowed thirty pouches a month, when ten pouches a month is ample for me. Having said that I must say that I am very careful about cleaning the stoma area and using the right lotion to keep my skin in good condition.

I have also found what I think is a good solution for the short tubing between the pouch and the night collection bag. First cut sixty centimetres (two feet) of tubing including the plug off an S3 bag then cut the plug off an S4 bag. Next rub liquid soap on the end of the S3 tube and put the end of the S4 tube in very hot water. Then slide the two together and dip the join in cold water.

Bingo! The extra tube length means that you won't rip off your pouch every time you turn over in bed. No more waking up in the middle of the night with a stinking wet sheet, which I might add is a "downer". Another tip to stop this is to super-glue the plug to the tube adapter.

I wash out and soak the night bag in antibiotic soap and disinfectant concentrate for an hour every day. I change it on the first of every month and keep using the same S3 tube extension.

On a lighter note, forty years ago I was fixing a TV set for a lady and she asked me not to call before 10:00am because she had to take care of "Elsie" which happened to be her colostomy. Hers was the first in Australia and in memory of her I named my urostomy "Paris".

Keep Doing What You Are Used To

Submitted by Robyn Keys, QLD

I have had my stoma since September 2013 after having bladder cancer. Thankfully I haven't had any problems with rashes around the stoma, possibly because a friend suggested that I use a small paint brush to paint Betadine around the area after washing each morning and before replacing the urine bag. This has worked very well.

However, during the heat of summer I did get a rash where the plastic bag touches the top of my leg so I used Prantal Powder, which soothed the rash and it soon went.

WRITE IN TO HAVE..

YOUR S

I am seventy-four years old and love to go walking each morning. I have always played sport, so initially my stoma was quite an issue for me but I have coped well with the situation. I still go swimming when I have the opportunity and also play competitive lawn bowls, which I have been able to continue and often play three times a week. My friends know of my problem, but many others have no idea and I do not discuss it with the many friends from other clubs I meet at bowls.

It is important to keep doing what you are used to doing in your life.

Keeping It Simple

Submitted by Loris Haddock, QLD

I often ask myself when reading the Ostomy AUSTRALIA journal whether I am doing something wrong. I have had a stoma since 1977 and have had a good life, with only a few problems in the first few years. I believe in the KISS principle (acronym for "Keep It Simple, Stupid") and to work out a solution for anything that might come along. Our bathroom looks like any other, no extra fittings, etc.

After showering with my bag on I stand over a double sheet of newspaper, remove the bag, use tissues to wipe my stoma (no special brand) then clean the area with adhesive remover wipes. I also clean my skin with liquid soap and tissues. If I have any redness or itchy areas I use mercurochrome (which I have used since having my operation), let the skin dry (which only takes seconds), then on goes my new pre-cut bag. I also use Micropore tape over the side and bottom edges of the bag for extra security. All done as part of my daily hygiene.

During summer I need extra bags due to the heat so twice a year I have my doctor sign an extra supplies form. I fit this in during a normal visit. I use Gastrolyte for dehydration which is very good and not expensive. Three weeks ago I saw a Stomal Therapy Nurse for the first time in fifteen years to check on the new products available.

I stand by KISS and live my life to the fullest. I have had other health problems and addressed them as I have my Crohn's. I class myself as one of the lucky ones and have a saying "There is always someone worse than me".

I hope this letter may help someone new to the "bag club".

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

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I am not entirely sure when my symptoms started, but thinking back they must have been fairly gradual. I got to a point where I was on the toilet for about six hours a day, but

I never thought that what was happening to me wasn't right. I eventually sought help from a clinic doctor and described my symptoms - passing blood, extreme urgency, liquid stools and extreme pain until I opened my bowels. He prescribed me tablets and said that it should clear up but at this point I thought the doctor didn't think it was anything to worry about, so neither



It is a fantastic feeling not having to worry about ruining the car

should I. I put up with the symptoms and tried different diets to try to make the pain go away. Eventually my partner, Daniel, called every practice in our city until he found a wonderful doctor who was accepting new patients. We made an appointment for the next day.

After I described my symptoms to him, he said it sounded very much like a form of inflammatory bowel disease (IBD) and promptly had me lying on the bed for a rectal examination. I asked if it was Crohn's Disease or colitis; he said colitis but it would need to be diagnosed with a colonoscopy. He called the hospital's gastroenterologist to arrange an appointment and the next day I was collecting the Picoprep for my colonoscopy and gastroscopy.

I awoke after the procedures to hear the nurses saying I had Pancolitis and I was to be transferred to the ward. During my week there I was treated with intravenous steroids, given an iron transfusion and started on sulfasalazine. The doctors told me that these medications would most likely fail eventually, but I didn't believe them because I felt so good!

I returned home and couldn't believe how fantastic I felt! I would bound out of bed in the morning and actually be able to eat breakfast before needing to run to the bathroom. I even drank a whole cup of tea! I tapered my steroids according to the hospital's dosage chart and all seemed to be going well. However, the symptoms started returning when I reached the 5 mg dose and so began the constant dose changes.

After a while my symptoms worsened, with unformed stools, urgency and passing blood. My gastroenterologist booked another scope procedure for me and it became apparent that my colitis was affecting my descending bowel. I was given a prescription for medicated enemas to take every night which worked a treat despite them being slightly uncomfortable.

The next few months involved adjusting the steroid doses

and changing my medications after the current type stopped working. I developed the biggest moon face of all time, although it wasn't obvious to me. Looking back at old photos I just cannot believe it!

I started on the immunosuppressive drug, Imuran, taking it every night before bed. Eventually I found I was waking at 2.00am needing to vomit. I would race to the bathroom / toilet or laundry and be violently ill. I started experimenting by not taking the tablets some nights and these are the nights I wasn't sick. I stopped the medication and spoke to my GP, who assured me it was the right decision. He took a blood test, which showed my liver was extremely inflamed and not far off being damaged. I was now out of medication options.

Throughout my time with my current GP, he could see how this was affecting me and said that I should at least consider surgery. He told me of his brother-in-law (a surgeon) who had had a colectomy and had never looked back since. I dismissed the idea, thinking that the next drug would surely be a complete fix. How wrong I was. I also didn't realise how down this illness was making me feel. I cried at every appointment and felt exhausted, but not many people understood. They couldn't understand why I wouldn't be excited about going out or having a party. They wanted energy from me which I didn't have. My GP asked me a few questions and started me on anti-depressants after my answers revealed

I was in a major depressive episode. I don't know why I couldn't see this at the time, it was so obvious. But as they say, hindsight is 20:20.

After some time I eventually discussed the surgery with my doctor. Although I hadn't consciously thought about it, I knew it was what would make me better and that is all I wanted.

The colorectal surgeon I saw

explained to me the three surgery stages - colectomy, J-Pouch formation then takedown. He obviously thought I was mad when I asked if I had to have the J-Pouch and that I wanted to stay with the ostomy bag. I had heard stories and figured I didn't want to be back at square one. He told me most people say that, but give them three months and they are begging for the J-Pouch.

I made an appointment to see a Stomal Therapy Nurse at the hospital, but as she wasn't available on the day of my appointment I met with a male Stomal Therapy Nurse instead. I truly believe he is the reason I have been so accepting of the surgery as he took the time to explain everything and



Moon face! (not helped by the chicken curry) reassured me every step of the way. It was my birthday the next day, so I returned home and had a cake and cuppa with my family while we watched the 'Dealing with an ileostomy DVD'. Good times!

A few weeks later the surgical registrar rang and gave me a date and time for my surgery - 6th June at 11am. I held back my tears until I hung up, at which point I raced to Daniel and blurted it out. We opened a bottle of wine to celebrate, but just one sip sent me to the toilet. I think he drank the lot!

What followed was normal everyday life as we counted down the days. I was completing the Honours year of my



Straight after surgery

Bachelor of Biomedical Science degree but the disease was making it so hard for me to be in the laboratory. I was exhausted, anaemic and depressed. Daniel planned a great weekend away and upon returning I talked to my supervisor about my progress. We agreed it would be best to defer my Honours year until I had fully recovered from surgery.

Within a week I was in

the bathroom every half an hour, vomiting and losing large amounts of blood. I had to drive a distance of five-hundred meters to the shop and I went to the toilet immediately before because I knew there was a chance I would vomit or soil myself in the car. It was agony.

So back to the GP we went. Daniel came along because he knows I play down my symptoms. The doctor called the hospital emergency department and I was told to present there the following morning. The doctor said I would be in for a day, maybe two, and that they would treat me enough to enable me to get through my surgery.

The next morning I threw some things in a bag - a book, my wallet and phone - and we set off for the hospital. When we arrived I had such a wave of pain, which took a few minutes to pass before I could get out of the car. I was put straight in a bed, an intravenous-drip was connected and the registrar came to see me. I once again explained my symptoms. He returned a few minutes later to tell me that my surgeon had decided my surgery would be Tuesday (four days away).

Emotional overload! I thought that I would have weeks to prepare, both physically and mentally. I was again transferred to the ward where I had countless blood tests, injections, medications and visits from the Stomal Therapy Nurse. My friends and family were amazing; someone was with me most of the time. I had a complete breakdown one night because I thought I had made the wrong decision and maybe it wasn't that bad. Everyone assured me that I felt well only because of all the medications given to me while in hospital. I guess our brains are excellent at blocking out horrible memories.

The surgery date was then locked in for soon after lunch on Friday 24th May. The nurse changed my sign to 'Nil by Mouth' and the serious countdown began that morning.

After what seemed like an eternity, the nurse brought me a surgical gown to wear and then they took me to theatre. I passed the Stomal Therapy Nurse in the hallway and we "high-fived". I then went through the pre-op routine - speak to the anaesthetist, have the surgery explained again - and tried to imagine how much better I will be!

I woke up back in my room after four hours in surgery. There was no pain from my belly, just from my back. It eventually subsided and I was able to ask my mum and Daniel what they did while I was in. I must have been still a bit sleepy, because I apparently asked them that question about ten times. They stayed until 11pm and left only after promising me they would be back in the morning.

The next day I awoke feeling much less foggy. The nurse asked if I would like to try a little walk to the shower. I tried but I couldn't do it, but was determined (and stubborn) and we succeeded after a break of a few hours. That shower was amazing!

I love my food and that day enjoyed some solids. The doctors figured the new system is either going to work or it isn't. I ate about six nuggets and my system worked perfectly. Success! All was well. My family and Daniel's family visited on the day after surgery and made me laugh so much I was crying from the pain.

However, about three nights after I wasn't having any output. The pain was the most intense I have ever had in my life and I wouldn't wish it on anyone. I was up all night vomiting and my fresh abdominal scar felt like it was on fire.

Eventually, all was resolved, my catheter was removed and my pain medication taken away. I could now walk to the hospital entrance and around the ward. On the fifth day after my operation and after fourteen days in hospital, I was able to go home.

What followed were visits from the District Nurse, lots of movie watching, laughter and tears. It has been a crazy journey but it has taught me so much. After never having a blood test

or the flu in my first twentytwo years, I have since been to Emergency at least four times, had two colonoscopies, one gastroscopy, countless blood tests, probably hundreds of appointments (sometimes two appointments with my GP on the same day) and more tablets than I care to count.

I guess the main point of my story is to know your body, be aware of what you are and

are not capable of, remember that nothing is more important than your health and to seek a second, third or fourth opinion if you feel a 'medical professional' is not listening to you. I will never return to that first 'doctor' and I always do my best to discourage people from doing what I did. Find a doctor who listens and is willing to work with you.

PS: I am not planning to get rid of my stoma anytime soon. It saved me and for this I love it!



Love at first sight

Ask Carmen



Thank you for your responses to PW's letter about urinary tract infections (UTIs) and his request for ideas on how to manage these (Ask Carmen - April 2014 edition of the *Ostomy* AUSTRALIA journal). We hope these letters describing their UTI experiences and suggestions may be of help to others who suffer with UTIs.

I don't have an urostomy but do have to use a catheter five to six times a day to void. I have been doing this for thirteen years and have suffered with dozens and dozens of UTIs, and had life threatening urosepsis after becoming antibiotic resistant. I also had several stays in hospital with antibiotics via IV for weeks at a time.

Now, my wonderful urologist "installs" Botox in my bladder every twelve months. It smooths out the wall of the bladder so bacteria cannot stick to the surface and multiply. Four years later and I have only had two infections, which were easily treated with oral antibiotics. No more feeling miserable most of the time from infections, suffering side effects from taking so many antibiotics, developing antibiotic resistance and having so much time off work.

I also take cranberry tablets as I simply couldn't drink enough cranberry juice for it to be effective.

Jackie Bone-George, SA

Thank you Jackie for responding to PW's letter. I need to clarify for our readers that insertion of Botox into the bladder is usually done for bladder instability, i.e. having a bladder that contracts too frequently. The bladder is a smooth muscle and Botox stops its ability to contract. The fact that you have found benefit from having this treatment is wonderful but generally this is not the reason Botox is prescribed. For people with an ileal conduit/urostomy there would be no benefit in stopping the contractions of the ileal conduit. It is the peristalsis contractions that propels urine along the conduit to prevent pooling. I have not been able to find any support in the literature for using Botox to prevent urinary tract infections.

Sincerely, Carmen

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In reply to PW's letter, may I suggest 'Googling' "Apple Cider Vinegar and a cure for Urinary Tract Infection". It is interesting to read what vinegar can be used for. We are also told that it can help with diabetes as well. Hope this helps.

Thank you, J.D.

Apple cider vinegar can change the pH of urine. How much and how often one has to drink it for it to be effective in altering the pH of urine to an acidic pH is debatable. An Acid Ash diet can also change urine to an acidic pH which can make the person less susceptible to urinary tract infections.

Sincerely, Carmen

I have suffered from UTIs since October 2006, which were treated with catheters and antibiotics. I also suffered pain when moving around and passed blood at times. However in May 2009, the nurse who was



changing my catheter was not happy with my condition and what was coming from my bladder. She asked me to ring my urologist but as he was overseas and would not be back in Australia for three to four weeks, she advised me to contact another urologist who was visiting. I was able to see him and my catheter was removed following this visit but I remained on antibiotics as required.

My new urologist asked me to go to Sydney for treatment where a scan of my bladder revealed calcification. He endeavoured to remove the calcification but was unable to remove all of it. When I asked him what to do next his reply was "to remove your bladder and fit you with a stoma bag".

On Tuesday 16th February 2010 I had the operation, which took ten hours and ten minutes, but during the operation they discovered that my pubic bone was full of infection so this was also removed.

My urologist then prescribed Norfloxacin 4 mg to take each night before food. However, he suggested that I take only half a tablet as a precaution and to increase the dose should the infection return. I must admit that I have gone on trips from Dubbo and forgotten my tablets but have been lucky with no infection during these trips.

I am now approaching four years and three months since my operation and I have been free of pain. Handling my stoma and bag are no problem and am able to do my gardening and other chores. The only problem I still have is the loss of my pubic bone.

Eric Parker OAM, NSW

I truly sympathise with PW. I have a colostomy and have had lots of UTI episodes in recent years. My GP has prescribed Hiprex daily, Vagifem twice weekly, the occasional use of Ural, wiping front to back, drying front to back after showering. The Clinic Sister also advised me to shower with my bag on and to cleanse my stoma with wipes and tissues.

I am now eighty-one, have had my stoma since November 1974 and only in the past four to five years have I been troubled by UTIs. I haven't had any antibiotics for many months, thank God.

G.K. QLD

NEED MORE HELP?

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

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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Embracing Technology

2014 ACSA Conference

You're Invited to the 2014 ACSA Conference in Queensland

This year's national Conference programme, with its theme of "Embracing Technology", will be held on the Gold Coast commencing on the evening of Thursday 9th October and concluding on Sunday 12th October.

Our Conference facility is the Hotel Grand Chancellor situated in the heart of Surfers Paradise. The venue allows easy access to local restaurants, the beautiful Surfers Paradise beach and many local tourist attractions. The new Gold Coast light rail, known as the "G", can be caught close to the front door of the Hotel. Travelling between Broadbeach and Parklands, the "G" provides easy movement around the city. The Surfers Paradise tourist strip has also been refurbished so will be looking bright and beautiful by October.

The Conference program commences at the Hotel on Thursday evening with Registration from 5:00pm and a Welcome Function which commences at 6:30pm. There are a large number of restaurants and night spots available close by should you wish to step out after the Function.

Friday starts with an early registration at 8:00am for those

that missed out the previous night. ACSA's Annual General Meeting then commences at 8:30am and will be officially opened at 9:30 am by the Gold Coast Deputy Mayor -Councillor Donna Gates. Councillor Gates will also attend morning tea after which the AGM resumes.

Our first guest speaker, Sheryl Waye STN, will be welcomed at 1:30 pm. Sheryl is the principal Stomal Therapy Nurse at the new Gold Coast University Hospital and will share with us her experiences when assisting in a Nurse Training Team that visited Kenya earlier this year.

The afternoon will be filled with various meetings for the Appliance Officers, Financial Officers and The Australia Fund.

Saturday morning sees the commencement of the General Meeting, which will occupy delegates and observers until the lunch break and another "Great Comebacks" story will be told at 1:30pm.

At 2:00 pm our second keynote presentation will be provided by Dianne Jones OAM. Dianne is the Nurse Unit Manager of





SURFERS PARADISE - OCTOBER 2014

the Endoscopy Unity at Logan Hospital in Queensland. Dianne will follow our theme "Embracing Technology" and give us an insight into the amazing progress that has been made in areas of medicine.

Friday night will be a free night. The Conference Dinner will be held on Saturday evening with a wonderful buffet of fine foods to tempt your palate, accompanied by a variety of music during and after dinner. Dancing will be available and requests will be taken.

On Sunday, we will wind down with a cruise up the beautiful Broadwater on a catamaran cruiser to **McLaren's Landing** where you will be treated to a sumptuous lunch. Walking tracks and other activities are available during our stay, or just hang around and enjoy the beautiful surroundings. We will then be picked up and returned to the Hotel. What a great way to end a busy Conference!

All members of any Ostomy Association are invited. For full details and costs please contact your local Association.

Preliminary Program

Full details and relevant times will be confirmed at the Conference.

Wednesday 8 October 2014

ACSA Executive meetings

Thursday 9 October 2014

- 5.00 pm Registration desk opens
- 6.30 pm Welcome Function

Friday 10 October 2014

Annual General Meeting

- Official opening
- · Committee meetings and reports
- Presentation by STN Sheryl Waye "Kenya Training Team"

Saturday 11 October 2014

General Meeting

- Great Comebacks Story
- Presentation by Dianne Jones OAM -"Advances in Endoscopy Technology"
- Conference Dinner

Sunday 12 October 2014

Day Trip - Cruise to McLaren's Landing



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Ostomy: Mate or Menace? Submitted by: Timothy Pascoe, NSW

Shock? Fear? What was your response on first hearing you had or needed an ostomy bag? Perhaps, like me, you were still too dopey to register. Anaesthetic and morphine make a fancy cocktail. I went to theatre expecting a four-hour operation (to remove half a metre of colon) but woke eleven hours later with almost no colon and news of a permanent ileostomy. That was over a year ago. So, where am I now; and, more importantly, what have I learnt?

Using the letters of **OSTOMY**, here are six things I need to remind myself to be.

Optimistic. I like the old saying that optimists aren't right more often than pessimists, they just lead happier lives. Post operation, I was determined to re-establish my old life: working, travelling and also enjoying all the other old activities and bodily pleasures. Obviously, there were mishaps: a leaking bag, a nasty bout of dehydration and so on. At the time, each was frightening: is this mess my new life in perpetuity? But I would remind myself: Timothy, be optimistic! Over time, I learnt the disasters weren't permanent; just setbacks. And, I came to see my ileostomy as like having a somewhat unruly pet. It takes time and attention, and occasionally misbehaves - often when least expected. I also learnt that being optimistic requires intent and also action; it's not just a state. If necessary, fake it until you make it.

Self-reliant. You have to find your own path: what works for YOU. Throughout my ten days in Sydney's St Vincent's Hospital, I had conversations with my surgeon and the Stomal Therapy Nurse. Both were exceptional but I was still spaced out and I realise now that what they suggested were only general pointers. Everyone is different in terms of what products are both comfortable and effective. And, if you're like me, there may be psychological barriers. I'd been



told I could shower without my bag on. But this seemed risky, even disgusting, should the stoma start flowing. It wasn't until I had skin irritation that I risked showering. Now it's something I treasure: the one time when I have the joy of feeling fully naked. During this period I also started trying alternative bags and brands. Two disasters and two successes. Test and try! Test and try!

actile. Being over seventy and wearing a bag are not attributes I'd include if dating online. But, that doesn't say I can't enjoy everything I used to: keeping fit, eating, hugging, and yes, sex. A body-beautiful was never my claim to fame, so neither aging nor the bag has caused major self-image problems. From the start I have been open with everyone around me: not just my wife but also my family, friends and colleagues. Most are not only accepting but in many cases take a keen interest - and joke with me about the occasional mishaps. Only a few seem disturbed and I respect that. Above all though, it's my body and it's a relationship I nurture and enjoy.

Open. While you have to be selfreliant, you also need to be open to support from family and friends (as above). On technical issues, I also found it valuable to look beyond the core medical team. Your local pharmacist can be amazing: knowing about a huge range of medicines but, even more importantly, how their customers have responded to them. When I had the skin irritation problem, this was where my solution came from. Further out from the medical circle are alternative healers. One I've known for years provided amazing assistance in settling my digestive system after the operation - and removing post-operative muscular tensions in my body.

Methodical. Every new activity requires discipline - whether taking up a new sport or programming the TV (though I admit failure on the latter). I've found similar discipline helpful with my bag: storing everything together in its own place in the bathroom - all neat, tidy and accessible. And, when changing my bag, laying everything out in advance. And, always travelling with spares. Also, keeping past order forms filed for easy reference as to product specifications. It's the old motto: be prepared. Similarly, reducing clutter: throwing out products that didn't work for me or I no longer need. Over time, everything becomes easier but being organised reduces tension. For me, the psychological is as important as the physical.

You-centred. Let me end, where I started. The bag game is all about you and me as individuals. We're each different and need to manage our own program: how we think about it and what we do. If we're all different, then what's the point of my writing about my six adjectives? First, to force me to codify these guide points as a reminder about what I need to keep doing better. Second, to offer a platform for you to make your own list. Some of my experiences may be relevant - others not at all.

In closing, let me send you best wishes and a final thought. I'm probably happier today than ever before. Age and illness have their costs but have also benefited me by reminding me how wonderful life is and that I better enjoy it while it's still mine.

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I have lived with ulcerative colitis for twenty-five years and have written my story in the hope it will help folk who also have this awful complaint, as there is nothing more lowering to your health than this awful bowel disease.

It all began in 1964 when Maxine, our youngest daughter, was just three years old. I saw blood in my

stools but just thought it was piles. Having three little girls to look after I tried to ignore it, but when it got really bad I went to see our family doctor and explained the pain and the symptoms that went with it. He made an appointment for me to go to hospital for a colonoscopy and I was told to start taking a new Swedish drug. They also booked me in for an operation to remove my large bowel as soon as a bed was available. In England in those days you did not know how long the wait would be. In the meantime, I had to take these large tablets - two of them four times a day. Surprisingly, only ten days later I had a date to go into hospital. I was only twenty-seven at the time and I cried all the way to the hospital at the thought of having an ostomy bag. My husband was driving and he assured me that he would still love me with a bag as it made no difference to him. After I was admitted to the ward the doctor said that I would be having another colonoscopy the next afternoon (I can't count how many

colonoscopies I have had over the years). At the end of a week I was still in one piece - no surgery and still being given eight tablets a day. Another week went by and I was to have another colonoscopy. Eventually the chief surgeon came to my bedside and said he was sending me home on a reprieve as there had been a big improvement to my colon in such a short time. I was to keep taking the tablets and he would see me in six weeks.

After another colonoscopy he said "I will see you in three months" and later it was "see you in six months". It kept on like this for some years and my husband suggested that we emigrate to Australia. It was 1972 and I had to go to the hospital for (yes, another) colonoscopy and I told the doctor at the Out Patients Department that we had sent our emigration forms to Australia House in London and could I please be taken off the hospital listings as I didn't want to mention that I had a health problem. He said, "Maureen, it doesn't matter if you go to live in Scotland, Wales or to Timbuctoo, one day you will have to have surgery. It is like this, if I take an apple that had a mark on it we can keep that apple from going bad for a short time but it will never be a ripe rosy apple again. This medication you are taking is keeping it at bay, but you will have to have an ostomy bag before too long." He wished us luck in our new life and I will never forget his words about the apple.

We settled into our new home in Adelaide and our two oldest daughters started work while Maxine, who had just turned twelve, went to school. My husband, a motor mechanic, found work right away and I also got myself

a good sales job in a furniture store and loved it.

All was going well for some years and I must admit I did stop taking the tablets now and then. However, knowing that things were not too good I sought another doctor in Adelaide and - you guessed it - more colonoscopies! I was also told that if I didn't get it fixed soon then I was a prime candidate for colon cancer. This was a month before Maxine, who was twenty-eight by then, was due to get married. After the operation I was in intensive care for four days then put into a ward. During one family visit Maxine asked "Have you got a bag now Mom?". I said "No, I have a pouch". "A pouch?" she replied, "Golly, we will have to call you Skippy" and from that day my ileostomy has been known as "Skippy".

When I returned home after all those years with ulcerative colitis, I had never felt so alive and well. I had had blood transfusions while in hospital and said to the doctor

"Whoever gave that blood needs a medal as I feel so well now." He said all bowel problems make you feel so low, but the disease had been taken away and I should count myself as a new and very lucky woman. As I said, Maxine and Robin got married not long after I was out of hospital and I danced at their wedding.

It is now February 2014 and my "Skippy" is twenty-five years old and still serving me very well. It is also Maxine's and Robin's Silver Anniversary in March.

Just one thing I forgot to tell you. It is recommended that all three of my daughters have regular colonoscopies. Our oldest daughter went two years ago only to be told that she needed an operation for bowel cancer. Luckily she only lost fifteen inches of bowel and her surgeon said he could have taken less but was pleased to say she didn't have to have chemotherapy or radiation. He was very pleased that she was someone who had regular check-ups.

As for living life to the fullest, an ostomy pouch (or bag) does not stop you doing everything you want. I swim and until recently played bowls. Life goes on just as you want it to, even in the bedroom.





Skippy Saved my

Submitted by: Maureen Cooper, QLD

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Life with a Stoma - The gory details

Submitted by: Katrina Roads

My stoma was created on 2nd June 2013 during an emergency colon cancer operation (my sigmoid colon had a large Stage 4 adenocarcinoma and was fully obstructed, my bowel had perforated, I was very ill and my life was in danger). When I was told by the surgeon of the possibility of me getting a stoma, I had only twelve hours to get used to the idea.

Prior to my surgery, I had never heard of the word "stoma" and did not know what one looked like, how it worked, what it was or what to do with it. I'd never seen a colostomy bag nor knew how to apply one. It was all one big shock and learning curve for me. Thankfully, the Stomal Therapy Nurses were very patient and kind with me, as for weeks I cried every time they saw me.

It took many months to get used to. I was very upset having it at first and angry about it. I felt unsexy, hated seeing poo come out of my tummy and having no control over that process.

I've called the stoma my "tummy bum" (which our nineyear-old son thinks is very funny) and my other bottom my "phantom bum"! The reason I call it the "phantom bum" is that occasionally I have this strong urge to go to the toilet and there is a really intense downward pushing feeling. I go but of course nothing happens. I suppose it's like a phantom limb.

I Now Dress Differently

At first I was terrified that everyone could see the shape of the bag showing through my dress and were staring at it; at me. I hated the way it showed through my dresses, so after a time, I thought to buy some short cotton sports/bike style pants and wore them under all my dresses. It has worked very well to flatten my tummy and also helps to prevent stoma prolapse. I tried a specific stoma waistband but they were way too tight, too long, and too hard to get on and off plus really made me perspire under it.

I've had to change the way I dress. Before the stoma I wore fitted tops and skirts. But I needed to go out and buy new clothes because either the skirt band, or waistband of jeans and pants sat uncomfortably over the stoma, or the top of the bag was visible through the clothing. I purchased baggy T-shirts, loose flowing dresses and larger shirts. And wore a second singlet under a T-shirt or singlet to flatten out the ostomy bag. I wanted it to be invisible to others.

When I do wear shorts or pants I need a belt to hold them on properly as I fold the top of the stoma down and tuck it into the waistband so that the top part, where the charcoal vent is, doesn't poke out through my top.

Some of my pants and jeans I cannot wear if the waistband sits on top of the stoma as it rubs and hurts if I sit down. I've bought skirts that are not tight in the waist and pants that sit above or below the stoma site.

I needed to purchase new style underwear too! My regular undies came up too high and I needed to go and find bikini style briefs that would comfortably fit under the ostomy bag's adhesive area.

Peculiarities of a Stoma!

Some days I feel hugely embarrassed as air (wind, farts, flatulence, ...) comes out of the stoma without me having any



control and when it does people stare in disbelief. Then they can't figure out what they really heard because farts come from bums and mine sure didn't come from down under, so what was that noise?

I love it when I go to noisy shopping centres because no one can hear it! And ...my farts don't smell! I do like that! Silent but not deadly. Sometimes they're so loud you would think I was a human whoopee cushion, which our son thinks is hilarious. He says I should go on a talent show as the Magical Farting Tummy Bum Mum!

Charcoal tablets work a treat at minimising or eliminating wind, gas or flatulence in the gut. However, finding colostomy bags that didn't puff up like a balloon with wind wasn't easy and no brand I tried was reliable in this way.

To prepare me to go out, I bought some cute little makeup bags and placed in each a couple of ostomy bags, wipes, adhesive remover, (magic) spray and nappy sacks. One makeup bag stays in my handbag and the other in the car for when I need them while out and about during the day.

I remember the first time I was caught out without the ostomy bag on. I was having a shower in a hotel room, when the stoma began producing and I had to hold out my hands to catch it. It was a little horrifying and I felt really embarrassed, even though I was the only person in the room! But now I watch with fascination what comes



My stoma"purse"

out and how, because when the poo comes out down below you don't get this birds-eye view of your bodily functions!

Where I'm At Now

Eight months on, after continuing to be very honest with myself about how I felt about the stoma, and allowing my tears and tantrums to come and go, I am now used to it. I can't say I like it, but I am used to it, have adapted to living with it, enjoy the ease of going to the toilet in a way I never have before.

However, I still feel sexually inhibited, unattractive with it and do what I can to hide it from people. I tell people about it when appropriate, so I can get past the shame I feel; and that works. Hiding from my feelings didn't work for me. Being honest did. As part of my healing from cancer, I've been seeing a psychologist weekly, and that has helped me to adjust to the stoma and all that came with the cancer and after.

It is the end of February 2014 today and I am waiting on a phone call from the hospital to undergo a stoma reversal. That will be a whole new journey. All the best with yours.

THE GRAND OPENING - New Premises for OSTOMY SA

Submitted by: Ruth Horne, SA

We at Ostomy SA were proud to hold the formal opening of our new premises at 1 Keele Place, Kidman Park recently. The Governor of South Australia (His Excellency Rear Admiral Kevin Scarce AC CSC RANR), our local Mayor (Ms Kirsten Alexander) and State Legislative Council MP Kelly Vincent (Dignity for Disability MP) were all pleased to attend and speak at the opening.

We were joined by approximately seventy guests, including STNs, supplier representatives, members and our wonderful volunteers and staff. Speeches, champagne, canapés and friendly chatter were the order of the evening and everyone had a wonderful time.

Our dignitaries each spoke of the importance of volunteers in being available to help service charitable organisations such as ours. We are extremely lucky at Ostomy SA to have over forty volunteers who assist in a myriad of capacities: roles that vary from phone calls to new Ostomates, to packers for postal parcel deliveries, and to counter staff who help members collect their monthly supplies. Our volunteers help from a few hours a month up to twelve hours per week and we certainly could not operate without them.

Ms Vincent also spoke on the difficulties faced by organisations such as ourselves in fundraising. She raised the issue of the "silent" or "hidden" or "unsexy" disabilities compared to the more community recognised charities such as cancer, diabetes, etc. It was heartening to hear these words spoken by such a knowledgeable outsider. Ostomy associations need to be smarter in our drive to get a fair piece of the charity dollar and increasing our exposure to the greater community must be an integral part of this drive.

We are extremely proud of our new premises and many visitors have remarked on what a wonderful investment we have made in our future. Our new, and now officially open premises, will allow us to prosper and improve on our core business - providing support services to all of our members.

Please feel free to visit on any weekday between 10.30am and 2.30pm.

We would love to show you around.



OASA Secretary

Ruth Horne

Hon Kelly Vincent MLC Mayor Kirsten Alexander



Governor Kevin Scarce



B Harvey & Mayor Alexander



B Harvey Hon K Vincent & R Horne

Smile A'While

TEN LAMB CHOPS, PLEASE

A butcher is trying to shoo a dog from his shop when he sees \$10 and a note in his mouth, reading: *"Ten lamb chops, please."* Amazed, he takes the money, puts a bag of lamb chops in the dog's mouth and quickly closes the shop.

He follows the dog and watches him wait for a green light, look both ways and trot across the road to a bus-stop. The dog then checks the timetable and sits on the bench. When a bus arrives, he walks around to the front and looks at the number, then boards the bus.

The butcher follows, dumbstruck.

As the bus travels out into the suburbs, the dog takes in the scenery. After a while he stands on his back paws to push the "Stop" bell, then the butcher follows him off the bus.



From Warren Rayment, QLD

The dog runs up to a house and drops his bag on the front step. He then goes back down the path, takes a long run and throws himself - WHAP! - against the door. He does this again and again.

No answer. So he jumps onto a wall, walks around the garden, beats his head against a window, jumps off and waits at the front door again.

A big man opens it and starts cursing and shouting at the dog.

The butcher runs up and screams at the man: "What the hell are you doing? This dog's a genius!"

The owner responds, "Genius? It's the second time this week he's forgotten his key!"

Vale, Alexandra Peters (Alex)

Submitted by: Janet Forsyth CNC Stomal Therapy and colleague of Alex

In the early 1970s, whilst employed by Sydney Home Nursing Service, Alex Peters was appointed as the first Stomal Therapist in NSW. In a 2007 article about those early days, Alex wrote "there were no courses to teach me what was needed, in fact only one other person in Australia was interested in this field and she worked in Victoria. I was given a diary, use of a Holden Kingswood and two months to learn all about it (thirty years later I still haven't"). Regardless of this difficult start, Alex continued to provide expert patient care as a Stomal Therapy Nurse Consultant until 2011 when she retired from running her twice-monthly patient clinic at the Colostomy Association of NSW.

Alex had a unique and sometimes complex personality; she was both resilient and extremely resourceful. In her early days of Stomal Therapy nursing there were no appliances as we know them today. Rubber bags, skin bond cement and lots of sore skin was the norm of those days and this was an area where Alex really excelled with her incredible ability to always come up with a solution.

In late 1972 or early 1973, Dr Malcolm Stuart returned from the USA with a colostomy irrigation kit and taught its use to Alex. This method was soon in high demand for Ostomates who suited the criteria and Alex became known as the "irrigation lady" instead of "the bag lady". Alex remained a firm advocate of this procedure and participated in the making of a patient and nurse education video.

For many of those early years Alex was required to provide Stomal Therapy services to a large portion of the Sydney metropolitan region. She had identified fairly early in her new role that many of the problems experienced by patients in the community could be avoided with early intervention at the hospital level. Alex had a lot of support from some surgeons but others could see no reason for her to "coddle their patients". In spite of this her role was then extended to include pre and post-operative hospital visits.

A big part of her role was to encourage and educate hospital staff on the needs of stoma patients and to convince hospital administration of their responsibility to provide this specialist care. As a result, an interested nurse would be identified at each hospital to accompany Alex to patient consultations and over a period of time they were encouraged to complete a Stomal Therapy Nursing course, which by this time had been introduced at Sydney Hospital and later transferred to St Vincent's Hospital. Several major Sydney hospitals (including St George, Sutherland and Prince of Wales) subsequently obtained Stomal Therapy nursing positions thanks to the interaction and determination of Alex.



Alex did not always feel she or Sydney Home Nursing Service received due recognition for the significant contribution made by them to Stomal Therapy nursing. However, those of us who knew and worked with Alex quietly applauded and continue to acknowledge and admire the long commitment she made to this specialty service. All of us in some way owe a great deal to Alex for the work she did. She also demonstrated extreme dedication to the Colostomy Association of NSW, diligently attending her clinics and regularly speaking at meetings on many aspects of Stomal Therapy nursing.

Alex will be remembered for not only her contribution to Stomal Therapy and health care but also her uniqueness as an individual. She cannot be replaced but her memory will last and many anecdotes will be recounted as so often happens with legends. People pass on but their memory lives on with us forever and we will celebrate all that Alex achieved.

Rest in peace Alexandra Peters.



AASTN President's Report

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

The AASTN recently held their AGM via teleconference at the Nurses Memorial Centre in Melbourne, preceded by a very successful education morning put on by the Victorian Branch.

At the start of the meeting we observed a minute silence in memory of Merle Boree. Fiona Bolton later penned some beautiful words reflecting on Merle's life and her contribution to nursing, in particular Stomal Therapy nursing.

Elizabeth English now represents the AASTN on the Stoma Product Appliance Panel (SPAP), bringing with her a wealth of knowledge and will

work with Bill Tyrell on this Panel. Thank you Dianna Hayes and Joanne Campbell for the many years that you contributed to SPAP.

Wendy Sansom provided a brief overview of the Stoma Industry Group (SIG), which consists of company representatives, Department of Health officials and other stakeholders. This group ensures that the current Scheme remains viable and sustainable while delivering optimal and favourable outcomes. These meetings are an excellent conduit, enabling the AASTN to raise concerns or comments at a Government level.

The AASTN, along with other stakeholders, also administers scholarships to undertake research or to attend courses and conferences. This year the Smith and Nephew Scholarship was awarded to Julia Shabranov, who will do a Stomal Therapy course offered by the College of Nursing. Fiona Bolton was awarded the Travel Grant to attend a Wound, Ostomy and Continence Nurses Society (WOCN) Annual Conference in the USA later this year. The Research Grant was awarded to the AASTN's Education and Professional Development Subcommittee for their fantastic survey last year. Finally, the Coloplast WCET Scholarship was awarded at the AGM to a very excited Alison Carlin of Victoria.

Carmen George provided an outline of the WCET's Norma N. Gill Foundation (NNGF) and its achievements. Donations to NNGF enable scholarships for members, non-members and health professionals to bring a better quality of life to people with ostomy, wound and continence needs around the globe. After some discussion, a proposal to donate an ongoing \$2 per full AASTN membership to the NNGF was accepted with a unanimous vote from all those present. We hope that the AASTN has set a precedent which other associations will follow.

Congratulations to the incoming Committee: Sue Delanty (Tasmania who deserves a gold star!) as Vice President, Lisa Glending (Western Australia) as Treasurer, Louise Linke (NSW) and Lynda Staruckovich (Victoria) as General Committee representatives. A huge thanks to our outgoing Committee: Treasurer Sharon Gibbons (NSW), Web coordinator and Vice President Sue Vaughan (Victoria), General Committee representatives

Sue Delanty (Tasmania) and Louise Walker (Queensland). Thanks also to Carol Stott, who for many years has held the AASTN's Public Officer position and has now handed the reins over to Jackie Johnstone.

Your dedication to the ASSTN is fabulous and I thank you all for the work you have done over the past two years.



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From Loo Runs to Fun Runs

Submitted by: Yvonne Green, ACT

T 've had Crohn's Disease all my Life and so have always been a sprinter. I can tell you to the nearest second how long it takes to get from any one point in a shopping centre or museum to the bathroom. If you want to get from the pasta section in the supermarket to the public toilets in a hurry, just ask me the fastest way. I even know where the toilets are in the Eiffel Tower, London's Victoria and Albert Museum and St Peter's in Rome - and all the short cuts to get there. I know bushes that give the most privacy on the favoured route of the ex-pat morning walk in Port Moresby and at Turtle Beach outside Honiara in Samoa. I know how to make a privacy wall of backpacks near the summit of Kilimanjaro where there are no trees to hide behind. But lasting a long time without a toilet that I didn't know about.

Finally, I couldn't get to work without stopping once or twice. I couldn't make it around the supermarket on a Saturday morning without abandoning my trolley and running for a bathroom. While not the catalyst, this was one of many symptoms that led to the removal of my bowel in October 2010, and the creation of a stoma and permanent ileostomy.

Just how long I can now last has taken a while to sink in - but on a trip to London last year I suddenly realised I was walking past all those discreet toilet doors hidden around the Victoria and Albert that had before taken so much detective work to track down, and the germ of an idea developed.

Since my surgery I've worked hard at my fitness - but always exercised in the safe environment of a gym with bathrooms nearby. Then last August I saw an advertisement for the Canberra Times Fun Run and on a whim I signed up for a five kilometre Fun Run, which was only a month away. As I slogged away on the treadmill I knew I'd have to face reality and start training outside. So I headed to Lake Burley Griffin and to my surprise comfortably jogged my way around the five kilometre central basin. The Fun Run came and went - I had a fantastic time and huge support from friends and family.

So I got a bit carried away and committed for a ten kilometre Fun Run in April, which is also a part of the Australian Festival of Running. It took six months of hard work and I made it to ten kilometres. First on my good friend the treadmill and then twice around the Lake. Race day dawned and this time instead of five kilometre fun-runners interspersed with people wearing gorilla suits, I was surrounded by a sea of serious faces, overhearing conversations about PBs (personal best times) and other races held throughout Australia. But I kept calm and jogged along - past the old and new Parliament Houses, the various national institutes and down by the Lake. A team of friends were waiting at the finish line to cheer me over the line. It was really fun! Then I saw that the Mother's Day Classic was just a month away in May - a choice between five or ten kilometres and I chose the ten

The Mother's Day Classic is a breast cancer fund raiser so I added pink nail-polish and a pink hair ribbon to my now well-worn running outfit and hit the Lake-side path. At the four kilometre mark I was lapped by the lead runner sprinting past. I (and others nearby) cheered him on and kept going, and going - twice round the Lake to be greeted again by my happy friends at the finish line.

My best time for ten kilometres is one hour and six minutes and my worst is one hour and fourteen minutes. But all of these times are good as I jog past the public toilets without a smile, wondering what is going on in the other runners' brains and what their histories might be.

So now I have a small collection of running medals hanging from my dressing table mirror and certificates stuck on my fridge. The loo runs are now behind me and more fun runs are ahead.







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References: 1. Szewczyk MT, Majewska GM, Cabral MV, Hölzel-Piontek K. Osmose Study: Multinational Evaluation of the Peristomal Condition in Ostomates Using Moldable Skin Barriers. Poster presented at ECET, Paris, France, June 2013. TM indicates trademarks of ConvaTec Inc. © 2014 ConvaTec Inc. AP-014415-MM

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I received my colostomy in 2012 as a result of bowel cancer and I quickly discovered that I have a very active stoma. After talking to our Stomal Therapy Nurses in Wollongong, I was deemed to be a suitable candidate for colonic irrigation. Suitability is based on having a permanent colostomy and whether the stoma is in the descending or sigmoid part of the colon.

I ordered the necessary equipment (water bag, cone, irrigation sleeves), had a lesson from our STN and I was away. I have never looked back. Irrigation has changed my life and made it so much more normal. And according to people in a USA-based internet forum, we call ourselves **'Gators'**.

Irrigation starts with removing my colostomy bag and attaching a long plastic sleeve, the end of which sits in the toilet. I then hang a bag of warm water on the wall. The water bag has a plastic tube attached to it with a simple regulator at the end. The cone is attached with plastic tubing to the regulator. When everything is ready, I insert the tip of the cone into my stoma and use

the regulator to control the rate at which the water flows in. This process takes about two to three minutes - and "voila", I'm almost done. Over the next twenty minutes or so, the colon empties straight into the toilet. Patience is required during this process so the added bonus is that I get twenty minutes of uninterrupted reading!

All that's left to do is rinsing, removing and discarding the sleeve, and attaching another bag (or mini-cap) over my stoma, just in case.

I have now reached the stage where I mostly only need to irrigate every two days, with no output in between. This is a vast difference to having several bag changes every day and there is no smelly waste because everything gets flushed down the loo. Furthermore, I no longer have any flatulence problems either during the day or overnight.

Irrigation doesn't suit everyone and of course there are good things and bad things about everything. The down side of irrigating is that it requires up to an hour, every day or two, but I can choose the time that best suits me.



We travel a lot, but as usual if I plan ahead there are no issues. Irrigation is easy on a cruise ship, great for long flights and it means that I'm never looking for somewhere to change and discard the bag in the middle of the day. In addition, there are never any issues with gas build-up or leakage and the bag is still empty after a good night's sleep.

As a blond nomad, the ideal facility is a disabled bathroom but these are not always available. Last year we did the outback of South Australia, New South Wales, Victoria and Queensland in our camper trailer and we were quite remote at times. However, I discovered that irrigation can be done under a shady tree, into a plastic lined bucket and hidden from view on the other side of the car. There I was on the Birdsville Track, happily irrigating while waving to the occasional car that passed - they had no idea what I was doing!

In July we are heading across to Western Australia to do the Kimberley region and Pilbara so I have just made an "irrigation annexe" for our 4WD. Made out of "ripstop" tent fabric, it has three sides and a roof, clips onto the

back of the roof-rack, wraps around the open back door of the

car and has a couple of poles to hold it up. When there is nowhere else, I'll be able to irrigate inside and use the back of the car to lay out my equipment.



Here's a couple of links to good forums on colonic irrigation:

www.c3life.com/ostomy/forum/Forum16-1.aspx www.uoaa.org/forum/viewforum.php?f=12&sid=dbf8f4e

Their motto seems to be "As good as you can, most of the time".

I'm happy to talk to anyone who wants some advice, and I wholeheartedly recommend irrigation to anyone suitable. If you are interested in finding out more, contact your local STN for advice on your suitability and training.

Always speak to your doctor or STN before commencing irrigation.

Congratulations!

2014 Queen's Birthday Honours

Hearty congratulations to **Tom Flood** who received a **Medal (OAM) of the Order Of Australia** in the General Division of this year's Queen's Birthday Honours.

Tom received his OAM for *"service to community health through leadership and advocacy for people living with stomas."*

Tom has held positions of President and Chairman at Ostomy NSW (formerly the lleostomy Association of NSW) since 1998, and a Director since 1990. He was recently also appointed Vice-President of BEECH (Bladder Exstrophy, Epispadias, Cloacal Exstrophy and Hypospadias) Australia Community.

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Living with a Stoma in the Remote Outback

Maureen's Story Submitted by: Maureen Challinor, NT

Just before I turned twenty-one I had a bad case of diarrhoea which persisted. After various X-rays I was diagnosed with Crohn's Disease and Ulcerative Colitis all through my large intestines. Oh, lucky me!

I was treated with various antibiotics and had regular biopsies for cancer. I was asked if I would consider having all my bowel removed and a colostomy created but being only twenty-one and not having a boyfriend I said no, even though I was told I could be



dead by thirty years of age.

Anyway, for another seven years I led as normal a life as I could until I had a car accident in which I hit the steering wheel and my bowel was perforated, resulting in an ileostomy, created with my

mum's permission as I was out to it. Over time I had more small bowel removed due to ongoing Crohn's Disease but in 1990 I finally got the all clear and have been in remission ever since.

When I was thirty I met a most wonderful man, who totally accepted me - warts and all. Now, twenty-seven years later, we are still together.

Garry and I moved in together and decided to start an adventure to the Northern Territory, just winging it and seeing what came along. We started by holidaying in Darwin, then Borroloola in the Gulf of Carpentaria where only approximately two hundred people reside. We camped on the river bank for a couple of months, showering at the local caravan park and just fished and explored the region.

We decided to stay so travelled back to NSW and packed up. We arrived back in the Northern Territory and started living at Tennant Creek where we worked for approximately eighteen months repairing Government bores and windmills along the main highways. We camped for weeks at a time, sometimes in 50°C heat, with only a bucket and tarp for me to change my appliances and wash. Trees and bushes were not very convenient toilets. I came to realise what men mean when they say there is nothing like a cold beer, as one day we were working in 50°C heat and had to just lie under the truck (there were no trees) to try and cool off. We headed to a roadhouse down the highway and I had the most wonderful cold beer ever.

We also worked on a station outside Alice Springs for quite a few months, erecting a shed that would house three full size road trains with three trailers each. That was a wonderful job as we also had a lot of fun hunting rabbits and looking for precious stones. We also had whatever beef we wanted from the cool room - the T-bone steaks from those Hereford cattle took up a whole dinnersize plate and the old fashioned corned beef was to die for.

After Tennant Creek we headed back to Borroloola for the next twelve years where we operated our own engineering business and I also worked at the local takeaway where it was common to dodge spears and beer bottles when the local indigenous people were angry or there was fighting between tribes. For many years I also taught the shop owner's two girls on School of the Air, where lessons are held over the radio. We also had sports days when we would play tennis and do gymnastics. The youngest girl now owns a gymnastics business and both girls have become very successful in life.

We then gave professional mud-crabbing a go for a couple of years, living on our thirty-foot boat. Boy, was that the lifestyle - private BBQ's and wine on the little islands at sunset. One day, when Garry was doing repairs on our boat's motor, Tishy (our beautiful dog) and I decided to fish and have a little picnic on the river bank when all of a sudden a crocodile appeared, wanting Tishy for his lunch. I immediately dropped the fishing rod and we all ran to where our boat was moored - boy those prehistoric reptiles can run fast on land! But we made it safely to our boat.

For a couple of years we lived in a mining camp at Bing Bong, just outside of Borroloola, where there is a port from which the ship "Aburri" takes ore from the McArthur River Mine out to ships waiting at sea. We would extend a large boom from our ship over the hold of the other ship and unload our product. I worked as a cook/cleaner on board. Sometime we had very rough seas and had to batten down the hatches. We were stuck at sea for about three weeks once due to a brewing cyclone.

After twelve years in the remote outback we were offered work on a major project in Melbourne so went from the Northern Territory to live in South Yarra for approximately eighteen months, then to Portland in western Victoria to work on wind farms for the next five years.

We then moved back to the Northern Territory to carry on operating our engineering business and are still here now, living in our little house on five acres with a very, very spoilt dog named Scoobie.

I now battle with renal failure resulting from many years of suffering from diarrhoea due to having virtually no small bowel left. So far I have avoided dialysis and have a wonderful doctor who prescribes regular intravenous infusions of magnesium, etc for me.

Anyway, we are now working towards semi-retirement in the next five years or so and plan to spend time down south during the very steamy Northern Territory's "build up" (pre-monsoonal season between October and December).



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Nutrition for Ostomates

Submitted by: Margaret Allan, VIC



Margaret Allan is a qualified Nutritionist. She advises Ostomates and the general public on diet and healthrelated matters. Margaret is based in Melbourne and is available for clinical and telephone consultations by

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

In this article Margaret discusses issues surrounding vegetable consumption for Ostomates, and provides some potential solutions.



A survey that was the largest and most comprehensive health survey ever conducted in Australia was carried out between 2011 and 2013. It was appropriately called the Australian Health Survey (AHS) and had some interesting findings. The aspect of the findings I would like to focus on for the purposes of this article is vegetable consumption.

It was determined via the AHS that vegetable products and dishes are consumed by 75% of the Australian population, with potatoes making up 25% by weight of all vegetables consumed. Self-reporting by survey participants indicated that only 6.8% of the population consumes the recommended usual intake of vegetables, which is at least five serves per day. One serving of vegetables is 75 grams, which equates to half a cup of cooked vegetables or one cup of raw green leafy vegetables.

I have to say that these findings concerned me. My first thought was that if only 6.8% of the general population who have a supposedly intact and healthy intestinal tract are consuming the recommended intake of vegetables, then the statistic will be much lower for Ostomates.

The fact is that many Ostomates experience issues with vegetables due to their fibre content, and so they avoid or restrict their consumption. Fear of blockages from too much fibre is rife amongst Ostomates, especially in the older demographic in whom digestive function and motility have slowed down. Conversely,

Vegetable	f	rams of ibre per of food
Squash - Button	Boiled	0.6 g
Zucchini	Boiled Stir fried	1.4 g 1.7 g
Mushrooms	Raw Stir fried	1.5 g 2.9 g
Celery	Raw Stir fried	1.5 g 1.8 g
Turnip	Boiled	1.8 g
Potato - Desiree	Boiled Baked	1.7 g 2.6 g
Potato - Coliban	Boiled Baked	2.0 g 1.7 g
Potato - Pontiac	Boiled Baked	2.1 g 3.2 g
Pumpkin - Butternut	Boiled Baked	1.9 g 2.1 g
Pumpkin - Queensland Blue	Boiled Baked	2.8 g 3.2 g
Beans - green - fresh	Boiled	2.5 g
Beans - green - frozen	Boiled	3.1 g
Beans - butter - fresh Beans - broad	Boiled Boiled	2.5 g 7.6 g
Asparagus - fresh Asparagus	Boiled Canned	2.7 g 3.9 g
Sweet Corn - kernels Sweet Corn - creamed	Canned Canned	2.7 g 3.4 g
Sweet Corn - frozen on cob	Boiled	3.5 g
Sweet Corn - fresh on cob	Boiled	4.8 g
Cauliflower	Boiled	2.8 g
Broccoli - fresh	Microwaved	2.9 g
Broccoli - fresh	Boiled	3.8 g
Broccoli - frozen	Boiled	4.1 g
Carrot - baby Carrot - baby	Canned Raw	3.0 g 3.3 g
Carrot - baby	Boiled	3.5 g
Carrot - mature	Boiled	3.3 g
Carrot - mature	Raw	3.9 g
Sweet potato	Boiled Baked	3.2 g 3.7 g
Beetroot	Boiled Canned	3.8 g 3.8 g
Parsnip	Boiled Baked	3.9 g 4.4 g

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

for some Ostomates too much fibre results in copious diarrhoea which also has its consequences.

But the fact remains that vegetables are vital to a varied and healthy diet and need to be consumed regularly to increase nutrient intake and ward off disease. Fermentation of fibre in the intestinal tract increases both water and sodium absorption in the colon, enhances cell proliferation so the intestinal tract remains healthy, acidifies the colon which may be protective against colon cancer, and provides some energy to skeletal and heart muscle. Therefore it is important for Ostomates to consume as much fibre as possible without causing issues.

One strategy of addressing this issue of low vegetable consumption due to fibre concerns is to firstly become aware of the fibre content of different vegetables. Several ostomy patients I have been working with recently have found it extremely helpful to know which vegetables are lower and which are higher in fibre, and what mix of vegetables would be appropriate for their circumstances.

To this end I have put together a table which illustrates the amounts of fibre in different vegetables and also how the fibre levels differ in the same vegetables according to how they are prepared / cooked.

From this table we can see that:

- Boiling zucchini results in a lower fibre content than stir frying it,
- Raw mushrooms contain less fibre than those that are stir fried,
- Desiree and Pontiac potatoes contain more fibre when baked rather than boiled, whereas Coliban potatoes contain more fibre when boiled,
- Butternut pumpkin, either boiled or baked, contains less fibre than Queensland Blue pumpkin,
- Fresh green beans and butter beans when boiled contain less fibre than green beans boiled from frozen,
- Fresh asparagus has a lower fibre content than canned asparagus,
- Canned sweet corn kernels contain less fibre than either fresh, frozen or creamed,
- Fresh broccoli that has been microwaved contains less fibre than either fresh or frozen broccoli that has been boiled, and
- Raw baby carrots contain the same amount of fibre as boiled mature carrots, which is less than boiled baby carrots.

Therefore, depending on your individual circumstances, it may be prudent to choose different methods of preparation / cooking to reduce the overall fibre content of the meal or to extend the range of vegetables that are incorporated into the meal. For example, choosing to add a little grated baby carrot to a salad during summer rather than grated mature carrot, or microwaving fresh broccoli rather than boiling it during winter, can result in less fibre being consumed. Similarly, adding a teaspoon of canned corn kernels to your salad or vegetable repertoire can increase the colour and variety of foods and nutrients consumed that day without adding as much fibre as fresh or frozen corn kernels.

Another method of increasing the intake of vegetables without simultaneously increasing the risk of blockages or diarrhoea is incorporating them into a soup. Many vegetables that would not be suitable for consumption in any other fashion can be consumed in small amounts in a pureed form in a soup. For example, if the fibre content of raw or boiled carrots is too high for them to be consumed safely and comfortably, then adding a small amount into a soup can be beneficial. Pumpkin has a low fibre content and is safe for most Ostomates to consume. Adding a small amount of carrot into a pumpkin soup and pureeing the final product can increase the amount of vegetables being consumed without causing issues.

Similarly, if broccoli is a food that is avoided due to fear of a blockage, then making a broccoli soup can both extend the menu and increase nutrient intake. Celery is often avoided because of its stringy texture but adding it to soups that are pureed at the end is generally safer for most Ostomates.

Soups are also easy to prepare and can be made in one pot with a minimum of fuss. For a person who is experiencing fatigue, making a soup that will last a few meals is a good option. During the winter months I make a soup most Sundays. Some goes into the fridge for consumption during the week and the rest goes into the freezer for later enjoyment.

Vegetables can also be incorporated safely into the meal and extend the menu in the form of a mash. Our stock standard mash in Australia is mashed potato, however combining potato with pumpkin or sweet potato can create variety without adding too much extra fibre. Cauliflower can also be made into a mash for a different flavour.

I encourage you all to endeavour to meet the Australian recommendation of five servings of vegetables per day as often as possible, remembering that **one serve is equivalent to half a cup** of cooked vegetables.

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

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

In our next issue: Diet hints to help lower the pH of urine.

Looking for the Good News – No Stoma Unturned

Submitted by: Andrew Bleby, VIC

Can we talk? I don't usually talk about my urostomy to others as it's not very interesting to them and possibly a bit yucky. But we're among friends here in the *Ostomy* AUSTRALIA Journal, aren't we?

Now and again, the joy of beating cancer (and what a joy that is!) can be somewhat dampened by knowing that for the rest of my life I'll have a plastic bag stuck over a hole in my stomach. But I realised early on that there was absolutely no point in musing on the downsides of a stoma - given the alternative. In fact, there aren't too many downsides when compared to so many other medical conditions. After all, we can generally lead a pretty normal life without getting sick and without constant medication. It is after all, just a (rather complex) plumbing alteration.

So if people ever ask me how difficult it is to live with a stoma, my response is usually "Well, I imagine it's no more bother than it is for a woman who wears a bra and has a period."

But there are those times when self-

pity seems like a reasonable position to take. So to counter any tendencies towards feeling sorry for ourselves, we need to cheer ourselves up. I've started a list of my moans and groans, but for every bit of bad news I've looked for a sliver of good news to counteract it.

To amuse myself I've put them into a handy little table for you – so that if you're thinking a 'bad news' thought, you can quickly look across at the 'good news' which goes with it. You can then probably add your own:

THE BAD NEWS IS ...

- 1. I have to have all this expensive ostomy gear bags, seals, wipes etc.
- **2.** I have to hook on an overnight bag when I go to bed each night.
- **3.** During the day I have to go to the toilet more often every two or three hours.
- **4.** My chemotherapy killed many of the nerves in my feet.
- **5.** On a long aeroplane flight I need to be on the aisle so I can go to the toilet often without climbing over other passengers.
- **6.** If I travel to other countries, I might have trouble finding medical help if I need it.
- **7.** I have a card saying I have a "disability" of a stoma.
- **8.** I have to remember to go to the toilet because I don't get any physical sensations telling me to go.
- **9.** I've lost my prostate along with my bladder.
- 10. Losing my prostate means I don't ejaculate.
- **11.** I got cancer, had massive surgery and five months of chemotherapy, got really sick and had to deal with infection and a deep vein thrombosis. Since then I'll never be quite the same again.

BUT THE GOOD NEWS IS ...



- **1.** I get it all for free! Thanks to our national health system and the marvellous volunteers.
- **2.** I never have to get up to pee in the night! Now this feature can be the envy of men of a certain age!
- **3.** If you're a woman, you can pee standing up in the bushes. And if you're a man, you can still pee at a urinal but you can often be quicker about it!
- 4. I'm now available for fire-walking demonstrations!
- 5. Now I don't I can discreetly hook up to a night bag which I place inside a cloth shoulder bag on the floor and settle in to a window seat for a long snooze. I amaze other passengers by not having to go to the toilet at all except at the very end carrying a shoulder bag!
- **6.** Wherever you go, there are others with stomas even "Stomatological Hospitals" (see picture).
- 7. This card means I can use the disabled toilets which is great when there are long queues at the other toilets! (Pity it doesn't give me a disabled parking permit too but then that wouldn't be right).
- 8. I never get that desperate, leg-crossing urge that makes you want to wriggle about. And one more thing if I need to provide a urine sample I don't need to feel the urge to go I can deliver anytime!
- 9. That's one common form of cancer I'll never get!
- **10.** No wet patch in the bed!
- 11. I'm clear of cancer and I'm not dead!

So you see, for every dark downside you count on your self-pity scorecard, there's a shining upside. Just count the good news to see how fortunate you are! And let's continue to thank our lucky stars for the inventors of the stoma, the skill of our surgeons and oncologists, and the makers of all those un-sexy ostomy bags and seals.

After all, how many other people do you know who genuinely and consciously understand what a gift and a joy it is that they are not dead yet?



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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: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting.

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

COFFS HARBOUR

Meets 2:00pm to 3:30 pm 13th Feb - 10th Apr - 12th Jun -14th Aug - 9th Oct - 11th Dec Venue: Club Coffs, West High Street, Coffs Harbour. Ostomates & friends welcome. Contact Mandy Hawkins STN on (02) 6656 7804

EUROBODALLA REGION

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

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

FAR SOUTH COAST

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

Geraldine. Phone: (02) 6492 2530

GRAFTON & DISTRICT

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

GRIFFITH & DISTRICT

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

HASTINGS MACLEAY

Meet: The Old Hospital in Room 4 at 10am to 12noon on the third Wednesday in Feb - Apr - Jun -Aug - Oct - Dec. Inquiries: Noel (President) 0407 932 647 or Jenny (Secretary) (02) 6586 0270

ILLAWARRA

Meet: 10.00am to 12 noon on Wednesdays in the Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525. For further information, contact Helen Richards STN on (02) 4225 5046 (Monday only)

MANNING/GREAT LAKES

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

NEWCASTLE DISTRICT

Meet at 1.30pm on last Saturday in Feb - May - Aug (AGM) - Nov. Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton. Enquiries: Geoff 02 4981 1799 or Eleanor (02) 4997 5141 or Maree (02) 4971 4351

ORANGE & DISTRICT

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

SHOALHAVEN

Meet: 2.00pm on 3rd Feb - 5th May - 4th Aug - 17th Nov Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra. Contact: Margaret or Tracey on (02) 4424 6300

SYDNEY – LIVERPOOL / CAMPBELLTOWN AREA

Meets Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden). 20th Feb - 17th Apr - 19th Jun -21st Aug - 16th Oct For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SYDNEY - PENRITH AREA

Meets: Feb - Apr - Jun - Aug - Oct commencing 2.00pm. Tresillian Meeting Room, Tresillian, Penrith (next to Nepean Specialist Centre and Nepean Private Hospital). Parking is at Nepean Private Hospital or on Barber Ave. Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

SYDNEY - SOUTH-WEST AREA

Meet: Saturdays 3pm - 5pm on 8th Mar - 17th May - 9th Aug and 5:30pm -6:00pm on 22nd Nov (followed by Christmas Dinner) The Macarthur Room, Revesby Workers Club, 2b Brett St. Revesby (closest parking at front of Club) Contact: Ann-Marce McDonald

Contact: Ann-Maree McDonald STN Phone: (02) 9722 7196

SYDNEY - NORTHERN AREA Meet: First Wed. 10.00am -

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

SYDNEY - ST. GEORGE / SOUTH EAST AREA

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

WAGGA & DISTRICT

Meetings on first Monday of the month from 10am to 12 noon. Venue: Horizon Club, Yathong St, Wagga Wagga (located rear of Yathong Lodge, Wagga Wagga Base Hospital) Enquiries: David (02) 6971 3346 or Baz (02) 6922 4132

VICTORIA

BAIRNSDALE & DISTRICT

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

BENALLA / WANGARATTA

Meets 2.00pm on the third Monday of each second month. Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug – Dec and Benalla Community Health Service, 45 Coster Street, Benalla in Feb - Jun – Oct. 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

SOUTH GIPPSLAND

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

SUNRAYSIA / RIVERLAND

(2013 meeting dates TBA) Venue: Sunraysia Cancer Centre Enquiries: Norma Murphy 0409 252 545

WAVERLEY

Meetings are held every two months on a Wednesday from 2pm-4pm at Ostomy Association of Melbourne Centre, 71/170 Forster Road, Mount Waverley Contact Ron Butler via email to crocite@gmail.com or enquires@ oam.org.au

WESTERN AUSTRALIA

ALBANY

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

BUNBURY

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

GERALDTON

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

MANDURAH / ROCKINGHAM

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

QUEENSLAND

BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre, 10 -18 Mt. Warren 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

ΜΔCΚΔΥ

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov)

Venue: Gordon White Library on Phillip Street, Mt Pleasant. Contact: Graham Stabler for further information on 0428 776 258 or email grahamstabler@bigpond.com

BRISBANE

Operated in the Greater Brisbane Area by QLD Colostomy Assn and **QLD Stoma Association** Phone: (07) 3359 6500 Website: gldstoma.asn.au/bosvs.htm Operating hours: 7 days, 8am to 8pm

GOLD COAST

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

REDCLIFFE

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

ROCKHAMPTON

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

SOUTH BURNETT

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

SUNSHINE COAST

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

WIDE BAY

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

TASMANIA

"Semi Colons" – a support group for men and women impacted by Colorectal cancer. Meets in Hobart on the third Thursday of every month, from 3.00 pm to 4.15 pm. Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on (03) 6233 2072.

SOUTH AUSTRALIA

CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov. When: 2pm. Where: lleostomy Assoc Centre, 73 Roebuck St, Mile End. Information: Val: (08) 8381 1646

FLEURIEU

Meet: 3rd Mar - 30th Jun - 20th Oct from 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor, Please contact Sue McKay STN for further information on 0412 692 418

SOUTHERN

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

YOUTH GROUP

Doris Steyer, Telephone: (02) 4296 5354

YOUNG OSTOMATES

UNITED (YOU) Tel: Helen (03) 9796 6623 or Karen 0452 513 191 Web: www.youinc.org.au Email: helshae@hotmail.com Facebook: Young Ostomates United

BOWEL GROUP FOR KIDS INC

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

PARENTERAL NUTRITION DOWN UNDER

Secretary on (02) 9987 1978 Email: contactpndu@gmail.com Web: www.parenteral-nutritiondown-under.webs.com



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