

Ostomy

A U S T R A L I A

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National Directory of Ostomy Associations

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

AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSN INC.

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

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

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WA OSTOMY ASSN INC.

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

NEW SOUTH WALES

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Unit 5, 7-29 Bridge Road,
Stanmore 2048
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Operating hours: Mon to Thurs
9.00am - 4.00pm and
Friday 9.00am - 2.00pm
Office Manager: Mrs Jenny Kemp
Secretary: Norma Toohey
Telephone: 1300 OSTOMY or
(02) 9565 4315
Fax: (02) 9565 4317
Email: ostomy@inet.net.au
Website:
www.ColostomyNSW.com.au

OSTOMY NSW LTD

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

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8 Dunkirk Close, Arundel 4214
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Fax: (07) 5571 7481
Email: gcoa@bigpond.com
Operating hours:
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Office Manager: Norm Kelly

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Telephone/Fax: (07) 4775 2303
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All correspondence & orders to:
PO Box 1017
Hyde Park, Castletown 4812
Operating hours:
Monday 9.00am - 4.00pm
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Secretary: Barbara Myles
A/H (07) 4775 2303

QLD COLOSTOMY ASSN INC.

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

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

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

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

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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

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

160 South Road, Torrensview 5031
Telephone: (08) 8354 2618
Fax: (08) 8354 2621
Email: colosa@colostomysa.org.au
Web Site: www.colostomysa.org.au
Operating Hours:
Mon - Fri 10.30am - 2.30pm
Secretary: Ruth Horne

ILEOSTOMY ASSN OF SA INC.

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

TASMANIA

OSTOMY TASMANIA INC

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

VICTORIA

BENDIGO & DISTRICT OSTOMY ASSN INC.

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

COLOSTOMY ASSN OF VIC.

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

GEELONG OSTOMY INC.

Geelong Ostomy Inc.
6 Lewalan St. Grovedale VIC 3216
Postal Address: PO Box 1069,
Grovedale VIC 3216
Telephone: (03) 5243 3664
Fax: (03) 5243 6335
Email: goinc@geelongostomy.com.au
Website: www.geelongostomy.com.au
Operating hours: Monday,
Wednesday, Friday 9.30am to 2.30pm
Administrator: Joanne Holmes

ILEOSTOMY ASSN (VIC) INC.

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

OSTOMY ASSN OF MELBOURNE INC.

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

PENINSULA OSTOMY ASSN INC.

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

VICTORIAN CHILDREN'S OSTOMY ASSN.

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

WARRNAMBOOL & DISTRICT OSTOMY ASSN INC.

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

Editor: Kim Lyell

Editorial Contributors:

Margaret Allan, Harry Ashton, Kirsti Dixon,
Tim Jackson, Kim Lyell, Kylie McGrory,
Peter McQueen, Lee-Anne Robertson,
Saied Sabeti, Carmen Smith, Lila Smith,
Caroline Turner

Correspondence/Contributions to:

The Editor, *Ostomy AUSTRALIA*
PO Box 195, Frenchs Forest, NSW, 1640
Phone: (02) 8011 3535
Email: Journal@AustralianStoma.com.au
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Patron:

Her Excellency Ms Quentin Bryce AC
Governor-General of the Commonwealth of
Australia

Executive Members:

Peter McQueen - President
P.O. Box 283, Bentleigh East, VIC 3165
Email: petermcqueen1@bigpond.com

Geoff Rhodes - Vice President
P.O. Box 152, Wanniasa ACT 2903

Peter Lopez - Treasurer
P.O. Box 427, Miami, QLD 4220

Rosemary Quick - Secretary
PO Box 2427, Salisbury Downs, SA 5108
Email: acsasec@australianstoma.com.au

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Trekking in the Tian Shan mountains
of Kyrgyzstan
Photo supplied by Tim Jackson
(see Tim's story on page 18)



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

Courage and a positive approach to life continue to be recurring themes in the many stories we receive from Ostomates in all parts of Australia. We try to include as many of their stories as possible while also providing interesting ostomy-related articles and product information to support Australia's Ostomate community.

Our first article in this issue, *"Just Keep Smiling"* by Lee-Anne Robertson, tells of her courageous daughter, Isabella, who developed Necrotising Enterocolitis when less than two weeks old. The surgeons were able to bypass the affected area of bowel and provided Isabella with a stoma. Isabella has thrived since and remained a very happy baby through it all.

Similarly, Caroline Turner's *"Me and Mr Stoma"* tells of how she developed Pseudo-obstruction soon after the birth of her baby boy, Spike, while overseas. She spent two weeks in ICU, three weeks in high dependency wards and was given a temporary Ileostomy as part of her overall treatment. Caroline's recovery from her recent Ileostomy reversal has thankfully gone very well.

Lila Smith in her *"Life After Bowel Cancer"* story also describes her twenty-five years with a Colostomy, which she received in 1988 as part of her overall treatment for bowel cancer. Now ninety-one, Lila played tennis till aged seventy, then took up line-dancing and looked after her home and garden for many years. To quote Lila, *"After the shock wears off, keep to your same pattern of life and with God's help, you will be able to enjoy many years of quality health"*.

In his article *"My Kyrgyzstan Trek"*, Tim Jackson describes his exciting trek through the mountains and glaciers of Kyrgyzstan. Though he had bowel cancer eight years ago and has worn an ostomy bag ever since, he won't let it get in the way of him living an active life. It is all about attitude and he intends to continue visiting remote and interesting places as long as his legs and wallet will let him. Tim also features on the front cover of this issue.

In our previous journal ("Letters to the Editor" section - August 2013 issue), Suzanne from Victoria asked for assistance from other Ostomates on how they have dealt with weight gain since becoming an Ostomate. A number of people replied and several of their letters are included in our *"Weight Control for a High-Output Ileostomy"* article, in the hope that these might benefit other Ostomates as well.

In this issue we also welcome back Margaret Allan, a qualified Nutritionist who advises Ostomates and the general public on diet and health-related matters. Initially, we have reprinted Margaret's *"Hydration for Ostomates"* article to provide some important points for Ostomates to consider in staying healthy during the hot summer months. Margaret has also kindly offered to write articles on different aspects of nutrition for Ostomates in future issues.

This year's ACSA National Conference, with its theme of "Unity is Strength", was held at the Wrest Point Hotel Casino in beautiful Hobart on 18th and 19th October. It was a great opportunity to meet up with old friends, make some new ones and keep our Australian Council of Stoma Associations a strong and energetic group striving to do the best for Ostomates throughout Australia.

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

"Nobody gets to live life backward. Look ahead, that is where your future lies"

Ann Landers

Help!

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

Please send your submissions via Email,
Word or PDF documents to:

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

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

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

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

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

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



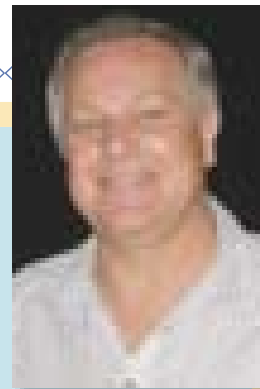
Like to be on the front cover of this journal?

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

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

Photographs must be high-resolution JPEG files and preferably in portrait aspect (i.e. vertical format). We are unable to use hard-copy photos as scanning does not deliver images with sufficient clarity and sharpness for the front cover.

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



50th Anniversary of ACSA

The year 2013 marks the "50th Anniversary of ACSA" which is certainly a significant anniversary in the support of Ostomates in Australia. The foundations of ACSA can be linked to the formation of the first Australian ostomy association, "Q.T. Australia" (now called the Ileostomy Association of Victoria), in Melbourne in 1957. The establishment of this Melbourne-based association was quickly followed by the Incorporation of associations in NSW and South Australia and then by the formation of associations in other States. However it was not until September 1963 that two delegates each from New South Wales, Victoria, South Australia and Queensland met at the Balmain and District Hospital in Sydney and a national body, the "Federal Ileostomy Council of Australia", was formed.

The major outcomes of the inaugural meeting of the Federal Ileostomy Council of Australia was an agreement to advocate for additional items to be included in the Pharmaceutical Benefits list and the decision to make representation to the Federal Government for an amendment of the National Health Act 1953 - 1959 so that ostomy appliances could be granted free of cost to persons with an Ileostomy.

While the activities of the Federal Ileostomy Council between the years of 1964 to 1970 are vague, we do know that the inaugural meeting of the Australian and New Zealand Council of Stoma Associations (which superseded the Federal Ileostomy Council) was held on Saturday 4th April 1970 in Canberra. This meeting was convened by Mr E.S.R. Hughes (later knighted in 1977) with the objective of establishing a national body to give a collective voice to all Ostomates when dealing with government bodies. Without going into too much detail, the most significant date in our history was the 28th November 1974 when a Government Bill, to set up legislation enabling the issue of free appliances to persons living with a stoma, was introduced to Federal parliament as a result of the excellent work of the Council. This favourable decision became effective in October 1975 under Section 9 of the Health Act. In the interim, the Council was heavily involved in the "expert working party on appliance appraisal".

As Australian Ostomates in 2013, we must acknowledge the early associations of the 1950's and 1960's for their tenacity and initiative in forming a national body to lobby Government. Their perseverance in those early years has continued to be of benefit to all Australian Ostomates and will continue to be of benefit well into

the future. As the first ostomy association formed in Australia, the Ileostomy Association of Victoria has a very special place in our history and, as such, was involved along with the other original associations in forming first the original "Federal Ileostomy Council of Australia" in 1963 and then the "Australian Council of Stoma Associations" in 1970. When reflecting back over the last fifty years, it is possible to see the formation of the first associations and the National Council as the beginning of a remarkable journey of ostomy support in Australia. From those first steps has grown a network of twenty-two ostomy associations that have a unique place in providing practical and emotional support to over forty thousand Ostomates throughout Australia. What makes the journey so remarkable is that the ostomy associations, as part of the practical support they provide, also have the responsibility of supplying ostomy appliances and associated requirements to all of those forty thousand Ostomates through the Stoma Appliance Scheme.

Australia is the only country in the world where ostomy supplies are provided wholly by the work of primarily volunteer-based associations. As a result, members are able to obtain the supplies they need from an association that provides the world's best ostomy products for the cost of an annual administration fee equalling less than \$1.00 per week. On payment of this small fee, all forty thousand of our Australian Ostomates are able to order their supplies from a list of over two thousand separate Stoma Appliance Scheme listed products. Consider for a minute the work that needs to be done to purchase the items necessary to fill up to forty thousand different orders every one or two months throughout the year and then make these orders into parcels containing the exact brand and size that each member needs. The productivity generated by our volunteer associations would put many large profit making businesses to shame!

Looking back over the past fifty years of ACSA, our member associations can take pride in their performance and the way they have evolved in adapting to ongoing changes over the years. In acknowledging our success we can be confident that, with careful planning and dedication to our mission of providing the world's best support to our members, we will succeed in meeting the challenges of the next fifty years and beyond.

Peter McQueen PRESIDENT



Letters to the Editor

Dear Editor

I often shed a few tears when I read all the inspirational stories in our wonderful journal, including those from the parents of baby Hudson and of little Charli in the August 2013 issue.

My stoma suddenly arrived after I was diagnosed with ulcerative colitis and required emergency surgery. I was quite shocked and unprepared, and had no choice but to accept this new companion. Several months later I had more surgery for removal of my rectum and anus followed by a further three months of home nursing as my wound was very slow to heal. My stoma is now my friend, and is a small price to pay for having one's life.

Thank you for the wonderful and inspiring stories, the interesting news and for just being there when I felt "different" and needed support. I am so proud to belong to this amazing group of Ostomates and so very impressed by the way they cope with the associated problems and still manage to live life to the full.

Valerie Jack, NSW

Dear Editor

The *Ostomy AUSTRALIA* journal is always interesting and with the latest issue (August 2013) I found the need to write in. In particular, the letter from Suzanne (VIC) really resonated with me and I am looking forward to reading some interesting responses. Helen Miller's (NSW) letter also touched the right spot for me.

I have an Ileostomy, my second, which chooses to be difficult at times. I am so grateful for all the help and free supplies that I have received over the last thirteen-and-a-half years but I am amazed when some people complain about often relatively minor things. Our fees are more than reasonable considering that much of the support work is done by volunteers. I so wish that there was an association close to where I live as I would love to volunteer a day each week. Also, the various supply companies are very helpful when I need to change styles for some reason or other, and I do. How can you complain given such caring people and the luxury of the ostomy goods supplied free to each of us? I just don't know, but I for one am truly grateful!

An article in the Ostomy Tasmania August 2013 Newsletter (page seven) about storage of supplies also prompted me to include how I store my supplies, in the hope that it may perhaps help some others. I cadge from my local vegie-market supplier, those big, white polystyrene boxes (with lids) that vegetables and fruit are delivered in. They are very happy to be rid of some, and after I have given the box a good wash and then sun-dried it, I am able to keep all of my ostomy supplies dry, clean, protected from bugs, away from inquisitive kids and dogs – the benefits are endless! They are temperature-neutral and so keep my supplies insulated from

heat and cold fluctuations. I rely on two polystyrene boxes so the amount of stock I have doesn't get out of hand and stock rotation can be easily managed. These boxes are also neat, tidy and very easy to store.

Jennifer Schrami, TAS

Dear Editor

For the last fifteen years I have coordinated the **Mackay Ostomy Support Group**. I have loved every minute of that time and have made some wonderful friends.

Unfortunately it is time for me to resign. At present there is no one prepared to take on this position. For that reason I must ask you to remove all details referring to the Support Group from the National Directory of Ostomy Support Groups.

Fay Russell, QLD

Dear Editor

My name is Jo-Ann L. Tremblay and I am a member of the United Ostomy Association of Canada, National Capital Region Support Group. After a lengthy illness and emergency life-saving surgery, a Colostomy (which I affectionately call "Percy") was created.

Now a permanent Ostomate and an author, I have since written and published a book, "*Better With A Bag Than In A Bag*" plus have created an online blog called *THE OSTOMY FACTOR* (joanntremblay.wordpress.com). These have been created in an effort to enhance ostomy awareness and to benefit people with bowel disease, colorectal cancer, fellow Ostomates, their caregivers/advocates, medical professionals, and our community around the world.

"*Better With A Bag Than In a Bag*" is about the human spirit within all of us, telling my tale from the brink of death to recovery, through humour and inspiration. Hopefully, "*Better With A Bag Than In a Bag*" will inspire anyone who wants to live life to the fullest, in spite of it all. A second chance at life is the icing on the cake, the cherry on top.

THE OSTOMY FACTOR is a candid blog telling the story of the adventures of an Ostomate from mine and Percy's (stoma) point of view. With a mix of humour, inspiration, and a large dollop of empathy in celebration of second chances at creating and living a full and joyous quality of life, this blog shares everyday stories that will give you a chuckle as you enjoy a good read.

Jo-Ann L. Tremblay, CANADA

"*Better With A Bag Than In A Bag*" is available in KINDLE and paperback format from Amazon.com

THE OSTOMY FACTOR Blog (joanntremblay.wordpress.com)

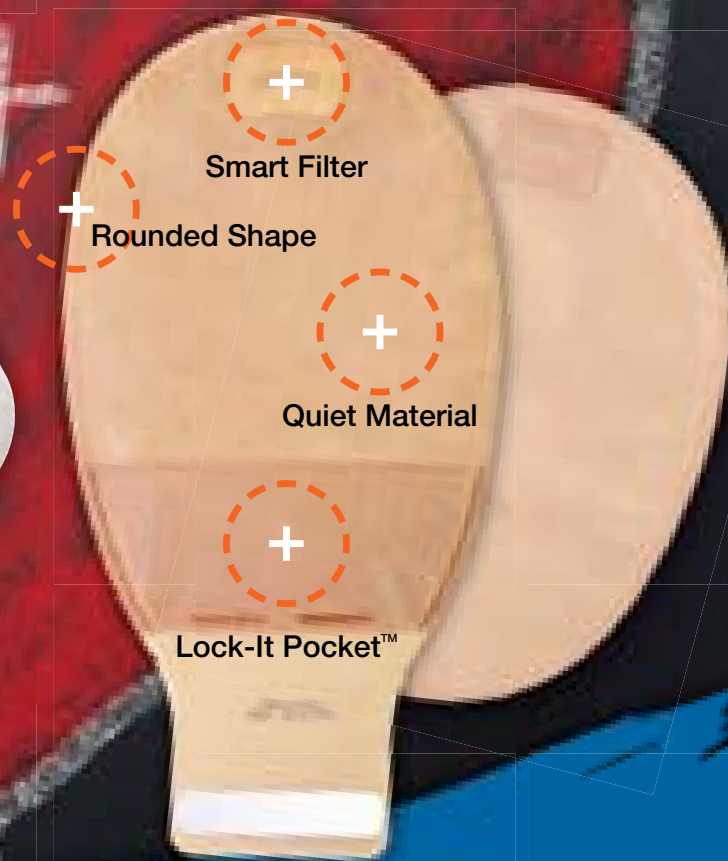
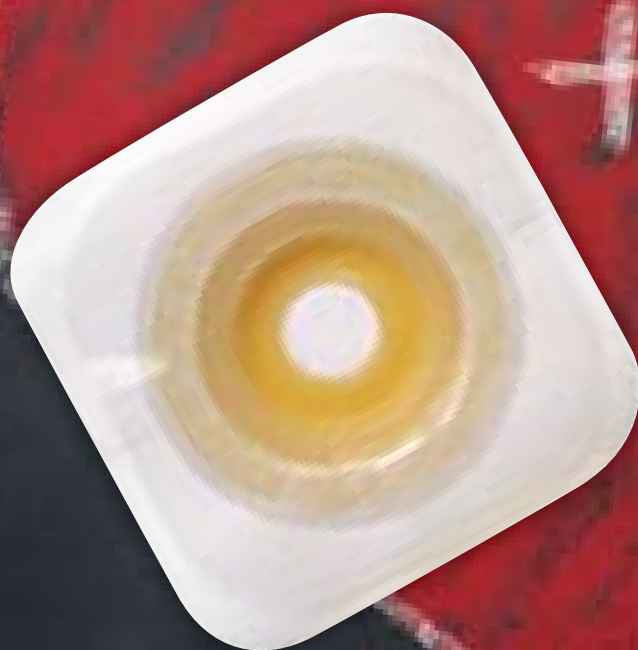
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April 2013 O377

Security Check in Beijing

Submitted by **Sam Harrison, VIC**



I would like to thank a previous correspondent who advised of the strict airport screening in China and the issues this creates for Ostomates. My awareness of what might occur meant that I was prepared when it happened to me.

When recently exiting China via Beijing's airport, I was given a thorough pat down at Customs and Quarantine, which of course revealed my ostomy bag. While I stood on a small pedestal receiving my pat down, they kept lifting my shirt and looking at it quizzically. Which is fair enough. I think most people would not know what it is. I had no idea what one looked like until I acquired one myself.

So I stood patiently on my pedestal, with my ostomy bag on display for all the world to see. Each time they would lift my top, I would pull it down again and say the word "privacy" but knowing they would have no idea what I was talking about. I showed them my doctor's letter, which was somewhat inconveniently written in English.

A young man was despatched to get the testing kit, and moments later he was swabbing down my ostomy bag and my stomach with all manner of absorbent white pads. That was my breaking point. I pulled down my top and demanded a private room.

The closest thing on offer was the small gap between a wall and the manager's work-station. I was accompanied there by two female security guards. I arranged them in front of me so they could both see everything. I lifted my top and tucked it up. They looked at the bag with eyes agog. I then clicked the clip that released the base plate grip and unclipped the bag to show them what lies beneath.

They gasped and recoiled. One actually extended her arms out defensively as she backed away. My little stoma stared back at them and peristalsis made him throb a little, as if he had his own little heart-beat. He was bright, shiny and red.

"Sorry! Sorry!" was all the guards could say as they backed away, perhaps feeling regret for having asked to have a closer look.

I clipped myself back together, pulled down my shirt, grabbed my doctor's letter from the manager's counter-top, slung my backpack over my shoulder then defiantly walked out of there with my head held high.

I hope I rated a mention in their tearoom later that night.

Belts or Braces - Problems Solved?

Submitted by **Elwynne & John Kift, VIC**

We have now solved a problem, which I am sure that others also have solved. John is now eighteen months post-surgery for a Colostomy, and he had a bit of a problem! His tracksuit pants, which he finds enormously comfortable, keep wanting to slide down. We purchased braces, in fact three pairs from different stores, and all their clips failed after some time. He wore the pants without the braces, but there was nearly a drama!

Knowing that this would be an embarrassment to him, I investigated with a fireman what their braces were like, and was eventually told that STEWART AND HEATON is the firm where the Fire Brigade purchase their braces. As well as Melbourne (Preston), they also have offices in Brisbane, Sydney, Canberra, Adelaide and Perth.

These braces have leather ends, and it will entail you having to sew on buttons to the track suit band, but you should feel secure from then on. We hope that this little "tip" helps someone else!

Belting Your Stoma

Submitted by **Brian Hunter, QLD**

Following extensive colorectal surgery in 1998 which resulted in a left-side colostomy, I have been monitoring the slow (apparently inevitable) development of a peristomal hernia. The prolapse is well below the stoma and the stoma itself is not affected.

My stoma showed no problems in the early years, although I did develop a significant surgical hernia on the right side. When this latter hernia had grown to football size, it was corrected with reinforcing mesh in 2003.

I recently had a surgeon review my peristomal hernia and it seems that further surgery is now probably inevitable. So what's my problem? My problem is that whereas surgical correction was recommended, the advice came with the usual disturbing caveat, i.e. such surgery is not always a permanent fix.

So what to do? I accepted that something should be done. And it wasn't just the obstruction risk, there is also the vanity factor. I am seventy-five years old so I suppose vanity should not count, but I must admit it still does.

In the meantime, what about support garments? I've been dabbling with support belts for the last decade but my practice has been to use belts only when committed to prolonged walking or when attempting significant physical effort (such as digging, lifting, etc) and I rarely wore them inside the house. I found

them inconvenient for three reasons, namely that they obstruct stomal emissions, accelerate flange failure and are hot (in Queensland summers).

Lately however, I've been forced to review this practice. About six months ago I began to notice a few events of dull abdominal pain. This was accompanied by a hardening of the abdomen, and it seemed to me it was a precursor-warning of possible strangulation. My response was to begin to wear belts more often, even around the house.

So why am I relating all of this? I'm sure you've heard this before as it is an old story.

Well the reason is I have found an interim fix to the obstruction problem. It occurred to me that most of the abdominal 'sag' zone occurs BELOW my stoma and if that is so, I don't really need major support on or above my stoma. So I began to experiment with the belts and I found that lightweight belts easily cooperated.

How? Well, by wearing the belt with the Velcro join at the back, I can simply fold down the top edge (in the vicinity of the stoma) so it's worn OVER the bottom sector of flange, but UNDER the appended bag. This I am finding is a sensible interim solution, i.e. the stoma is not obstructed and the major weight of the prolapse is still supported. So, it seems that this is the best solution for me. Of course, when the stoma is not 'working' (discharging) I can wear the belt in the usual way.

I should also add that the belts don't wear out and are virtually indestructible. It is the Velcro that fails due to the loop tape eventually breaking down. The hook tape is still OK when this happens. Perhaps belt manufacturers could, if they put their minds to it, solve this problem. How? They could insert a vertical panel, say 120mm wide, in the centre of the belt length. This panel would be non-elastic and would reliably accommodate a reinforced aperture.

In closing let me also add a request: If any of you have had long term success with correctional hernia surgery, please write to the Editor and share your experience. But for now, let me just sign off with best wishes and 'Happy Hernias' to you all.

There is Always Someone Else Who is Worse Off

Submitted by Stephen Pulsford, VIC

I turned sixty-one years old today and think it was about this time last year when I started to have some problems. I was passing blood and my bowel movements were becoming quite frequent and a little painful. I didn't read too much into it but I did see my GP and had the usual tests which caused no concern at the time as I had no history of bowel problems.

Then, on a Saturday afternoon in November 2012, I really started to feel unwell so took myself off to the Emergency Department at Wodonga Hospital. After a few hours there I was seen by a doctor, given an enema and then sent home feeling a little better.

However, the next day I felt quite ill again. After a few more days of severe pain, nausea, and passing a lot of blood I went back to the hospital, put on a drip, admitted and scheduled to have a colonoscopy the next morning. I was told after the procedure that I had Ulcerative Colitis and was placed on the usual cortisone therapy. I was sent home one week later with instructions to take a course of tablets over the next three weeks.

From that point on my condition deteriorated rapidly and about a fortnight later I called for an ambulance. I had spent the most awful night in extreme pain and was feeling most unwell. I was admitted again and the drug therapy continued. About eight days later whilst still in hospital, I started to feel rather ill again and on Friday 14th December my bowel perforated. I was taken to Albury Base Hospital at about 7.00pm and I was on the operating table at 8.30pm.

I remember waking up in Intensive Care sometime the next day! I was told by my surgeon that my large bowel was toxic compounded by peritonitis and a proctocolectomy had been performed plus the formation of an Ileostomy. I was still very sick and it took me some days to fully realise just what had happened and just how close I came to dying. I spent the worst five days of my life in Intensive Care, attached with various tubes to all manner of machines.

I live on my own with just my two dogs for company and I missed them so much during this time as I have no immediate family. I felt a little better when I was transferred to the ward but all I wanted was to go home. I had lost a lot of weight and then realisation set in with regards to the stoma and its effect on my daily life.

I went home on New Year's Eve. It was very hard at first but I had good support from my neighbours and was also well supported with home visits by the Tallangatta Health Service. I have dealt with all the problems of leaking pouches but those issues have since been solved and life is not so bad.

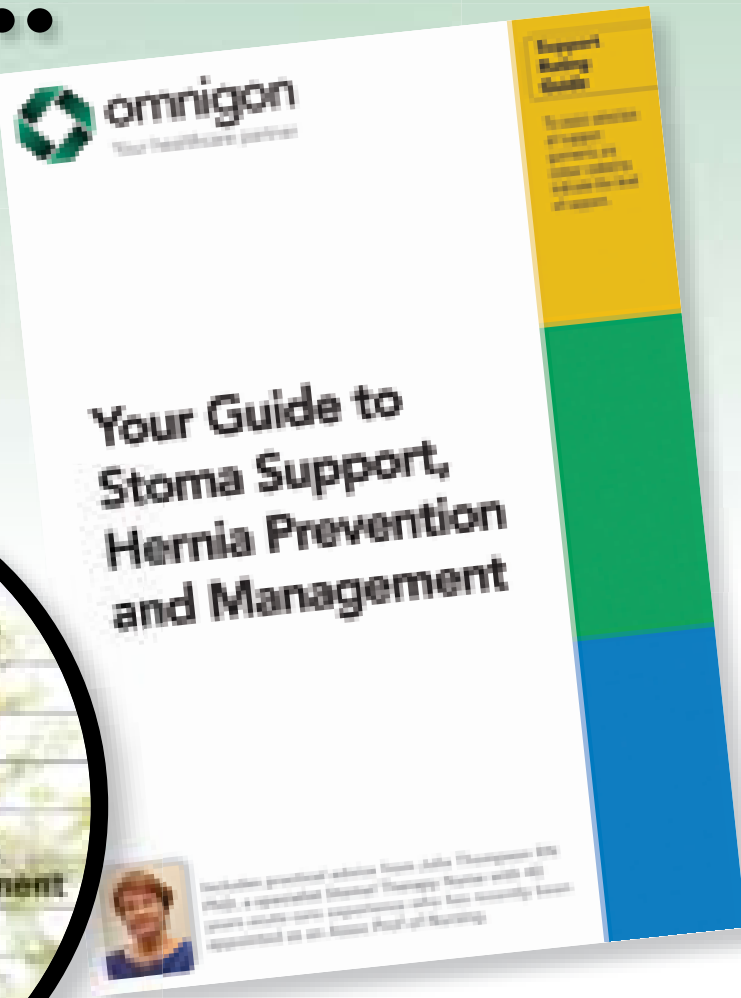
I have nothing but admiration for my surgeon and the staff both at Wodonga Hospital and Albury Base Hospital. I see my surgeon next month where we will discuss the possibility of reversal. He has been very pleased with my progress to date.

One thing that was so apparent to me especially while I was in Intensive Care is that my situation was not so bad and the old saying that "there is always someone else who is worse off" comes to mind. ●

3 out of 10 people with a stoma will develop a hernia¹...

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 Support Garments
 Support Rating Guide



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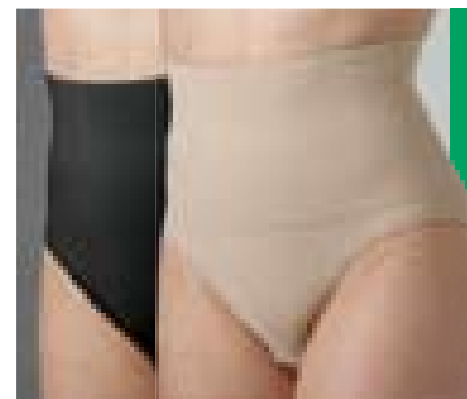
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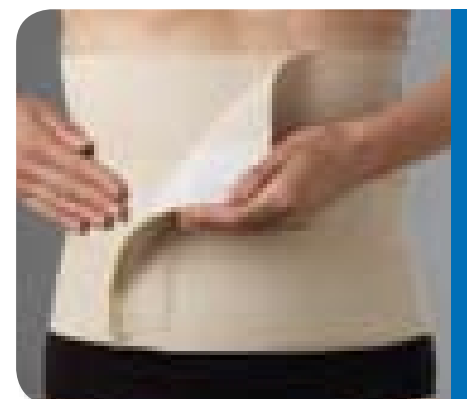
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¹: Data on file Omnigon 2012 ²: A review of 16,470 on the American United Ostomy Association Register revealed 30% incidence over all types of stomas. (Gray et al, 2005)

Just Keep Smiling

Isabella's Story

Submitted by: **Lee-Anne Robertson**, TAS



I would like to introduce you to my daughter Isabella, my miracle baby.

Isabella's journey began before she was born when the doctors discovered Isabella wasn't growing properly. Isabella was born twelve weeks early at twenty-eight weeks plus one day, weighing just a tiny 588 grams.

Isabella developed **Necrotising Enterocolitis (NEC)** on day thirteen of life. This cruel disease has no rhyme nor reason when choosing who gets it and there is no cure but to remove any affected bowel. The surgeons were able to bypass the affected area of bowel and provide Isabella with her first stoma.

I was then trained in the ongoing care of her stoma by the Stomal Therapist at the hospital.

Isabella succumbed to NEC a second time (not common) seven weeks after her first bout, but the doctors tried to

avoid a second surgery and chose to wait. The NEC did clear on its own this time, however, Isabella had formed strictures in her bowel which was not allowing her to process any food.

Isabella underwent her second surgery to remove as much dead bowel as possible and create a new stoma. Eventually, two hundred and one days after birth, she was transferred to our local hospital for an overnight stay before finally coming home.

Since being home it hasn't always been easy dealing with Isabella's stoma. It was only ever intended as a temporary measure therefore she was never given the final touches such as fat placed under her scar to level her tummy. Isabella has a stoma that is located in the centre of her scar which she has now grown around creating a gully where the stoma sits.

I am sure other ostomates can imagine the difficulty we some-

times have trying to get a good seal on her stoma bag in this situation and can imagine how many times we deal with leaks.

I must admit I have a fairly good attitude towards Isabella's care and have created my own rating chart for her leaks, starting with a small scale leak being called just that a "poo leak", then comes a medium scale problem where there is clothes and baby washing involved which is known as a "poospllosion". This then leaves the big daddy of leaks which generally involves just throwing the clothes away and hosing Isabella off in the bath with the hand held shower head and this is known as a "poonami". If you look up the definition of a tsunami you will understand the correlation.

Through all of this though, Isabella has remained a very happy baby and continues to amaze me with what she has achieved. I particularly love people's reactions when they discover she has a stoma and bag. They all generally make the same comment that they would never have guessed.

Isabella is scheduled for another surgery in January 2014, by which time she will be twenty-five months old. We are not sure yet whether this will be to revise her stoma to make it easier to manage or whether her stoma will be closed. This will depend on whether enough bowel has grown which we will only know after her check-up in December.

In the meantime we will both just keep smiling and enjoying life because after all, that's all anyone can do. ●

Necrotising Enterocolitis (NEC) is a medical condition where portions of the bowel undergo necrosis (tissue death).

The condition is typically seen in premature infants, and the timing of its onset is generally inversely proportional to the gestational age of the baby at birth, i.e. the earlier a baby is born, the later that signs of NEC are typically seen.

Initial symptoms include feeding intolerance, increased gastric residuals, abdominal distension and bloody stools. Symptoms may progress rapidly to abdominal discoloration with intestinal perforation, peritonitis and systemic hypotension requiring intensive medical support. It is the second most common cause of morbidity in premature infants and requires intensive care over an extended period.

Parents of Aussie Kids with IBD

We are a new group seeking to support parents at any stage of their child's illness - newly diagnosed through to post surgery (Colostomy, Ileostomy or J-Pouch). Via our Facebook page, we want to bring Aussie parents together to ask any questions, share experiences or just have a chat about life caring for a child with IBD.

www.facebook.com/groups/Parentsofaussieibdkids/

This is a closed Facebook support group for the parents of children with Ulcerative Colitis or Crohn's Disease. Being a closed group your entries do not appear on your own Facebook page thus keeping private the details of your children's situation. Only other members can see your Facebook posts.

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*After switching, this ostomate's
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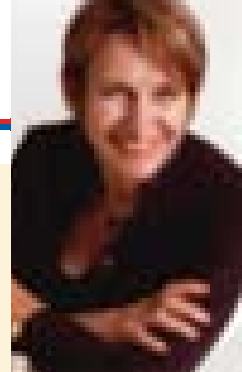
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Dear Carmen

I have an Ileostomy which I can handle fairly well, and I also have Auto-immune Hepatitis which recurs about twice a year.

These two conflicting conditions tend to pose major problems of diet. For the Ileostomy I know that nuts, lots of fibre, etc should be left out of my diet, but for my Hepatitis lots of fats and carbs are out.

Can you please advise me? Can I use a wider variety of vegetables if they are used in soups that are mashed and smashed? Are there any ideas you can give me regarding dealing with these dietary problems so that my stoma won't get blocked but I am still taking care of my liver?

Thank you, J.H.

Dear J.H.

Having an Ileostomy does not exclude you from eating from a wide range of foods.

Highly fibrous foods such as nuts, celery, etc are advised against as there is the potential that long strands of indigestible fibre could clump together, a bit like a fur ball in a cat. This could then potentially cause a blockage of your Ileostomy.

Technically, when you have an Ileostomy you don't need fibre as one does when the waste has to be moved along the large bowel. The Ileostomy being upstream from where fibre is useful.

In my experience people with Ileostomies occasionally get blockages when their bowel is still swollen after surgery or if they have a history of Crohn's disease as they may have strictures in their bowel from previous episodes of Crohn's.

Protein such as meat, eggs, fish and soya products can be low in both fat and carbohydrates, and certainly most vegetables are also low fat and low carbohydrate. I suggest you see a dietician/nutritionist to more precisely discuss your individual needs.

Many people with Ileostomies do not restrict their diet at all.

Sincerely, Carmen



NEED MORE HELP?

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

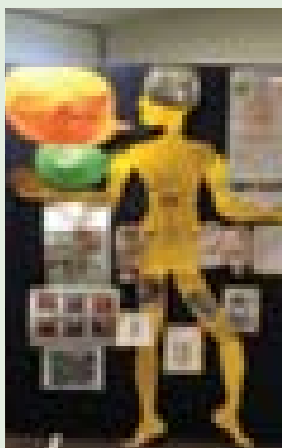
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AASTN President's Report

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

Well, last time we were in the throes of winter, albeit a very mild one here in the Snowy Mountains. Spring has now well and truly sprung, and it is beautiful weather here in the mountains. Spring is certainly a beautiful time of year, but by the time you read this summer will be here and Christmas only a matter of days away!

The AASTN held their annual Stomal Therapy Awareness Week from 10th to 16th June, with many of the departments and associations putting on a great display for staff and clients alike. One I would like to particularly mention is Kelly Dunk and her team at the Wesley Hospital in Queensland (see photo). It is fabulous to see such enthusiasm out there in the community.



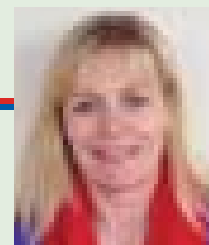
In December last year, Elaine Lambie talked about the possibility of the AASTN joining forces with the Colorectal Surgical Society of Australia and New Zealand for our next conference in 2015. Well this has come to fruition. It is going to be a truly unique conference being driven by Helen Nodrem in Victoria. She has a trusty team from all over Australia who are helping her plan this great event. Watch this space for updates!

Elizabeth English OA, whomanyofyouwillknow from Adelaide, has always had a passion for stoma education, especially in countries that are less fortunate than ourselves. Elizabeth has taken a 'leap of faith' and has organised a stomal therapy

course to be held in Kenya later this year. The course will be self-directed for the students, however they will have some 'face to face' learning experiences, which will be provided by a group of Stomal Therapy Nurses volunteering their time to this valuable exercise.

The course is being run in conjunction with the Aga Khan University Hospital in Nairobi and is known as the WCET Australian/Kenyan Twinning Project. The AASTN and WCET are helping to get this project off the ground, but full credit must go to Elizabeth for pursuing this wonderful educational experience for the nurses of Kenya. I will endeavour to keep you up to date with their travels and experiences.

Please have a safe and happy Christmas. If you are travelling on the roads, take care and above all relax over the Christmas period.



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Life After Bowel Cancer

Submitted by: **Lila Smith**, VIC

Lila's Story

Twenty-five years ago I was a healthy fit person aged sixty-five and busy trying to get my life together, after losing my soul mate and financial supporter after thirty-eight years of marriage. He was a primary school teacher with the Victorian Education Department for forty years with four years away on active service with the AIF during World War Two.

We married in January 1946 after the war ended and reared four children until they reached the age of twenty/twenty-one and started their own careers. Two became primary school teachers and two joined CBA. They were all married with children when their dad became a victim of pancreatic cancer after only five years of retirement, aged sixty-five. I was sixty-one at that time. Hence my story.

I developed a soreness in my rectum and was treated for haemorrhoids (piles) for three months but without improvement. I then had a show of blood after a bowel action and was sent to see a specialist. Imagine my reaction on being told I had a tumour which was probably cancerous. Regardless, it had to be removed and being so low in my rectum I most likely would need to wear a colostomy bag.

Being fit and active having played tennis two or three days a week, attending dance evenings and being very involved with church activities and various community activities, I was stunned with this news. I became angry and determined that this body blow wasn't going to take our children's mother. I was advised by family and friends to seek a second opinion, so I had an appointment with a surgeon at Frances Xavier Cabrini Hospital in Melbourne but the outcome was the same. I still needed to have the surgery.

It was December 1988 and I still had a two week wait before the surgery, so I had time to get my Christmas cooking, present and card preparations in order before the big event that changed my way of living, but not really changed my life. I had three weeks in Cabrini Hospital

including Christmas and New Year and returned home on January 12th 1989.

I received a wonderful welcome home from my family, neighbours and many friends. I was under the care of my good friend and Stomal Therapy Nurse who was at my side whenever I needed her, and I did have a few teething problems, mainly skin irritations. Of course I was afraid to eat lots of foods and was always anxious once I started to go out shopping and visiting. My tennis friends also coaxed me into having a hit, and by Easter I was back on the team.

About six months after the surgery I developed a large hernia around my stoma that didn't cause me any problems other than being unsightly. After eighteen months I had to have further surgery to repair the hernia which gave me back a nicer body shape. I had regular check-ups and returned to my normal good health.

I played tennis till aged seventy when I fell on the court and broke my left wrist. I was rather sore when attending to my appliance chores. I took up line dancing and looked forward to these nights with my friends and I still managed my home and garden.

As I've had arthritis for fifty years, I've always had pain in some area of my body. My left hip has been worn out for eight years so I had to have a hip replacement operation, then after seven weeks of excruciating pain, a spinal operation to fix a bulging spinal disc.

After a heart attack in 2008 followed by a perforated gastric ulcer and urgent surgery I decided to give up looking after myself and went into Care in October 2008. I am extremely happy here and am really quite well except for some pain in my shoulder and knees (arthritis) but with the care, rest and medication, I really can't complain. I am able to go out and about, when and where I like and my walking-frame is a great friend.

My main problem at present is my

vision. I have lost the sight in one eye due to macular degeneration and also have cataracts on both eyes. I have an appointment with our local eye surgeon for treatment so hopefully he can improve my sight for a bit more quality of life.

I turned ninety last October and have an extensive family, my main reason to stay around and enjoy their love and companionship.

So I hope my story will help support other people who have been told they have cancer. After the shock wears off, keep to your same pattern of life and with God's help, you will be able to enjoy many years of quality health. ●



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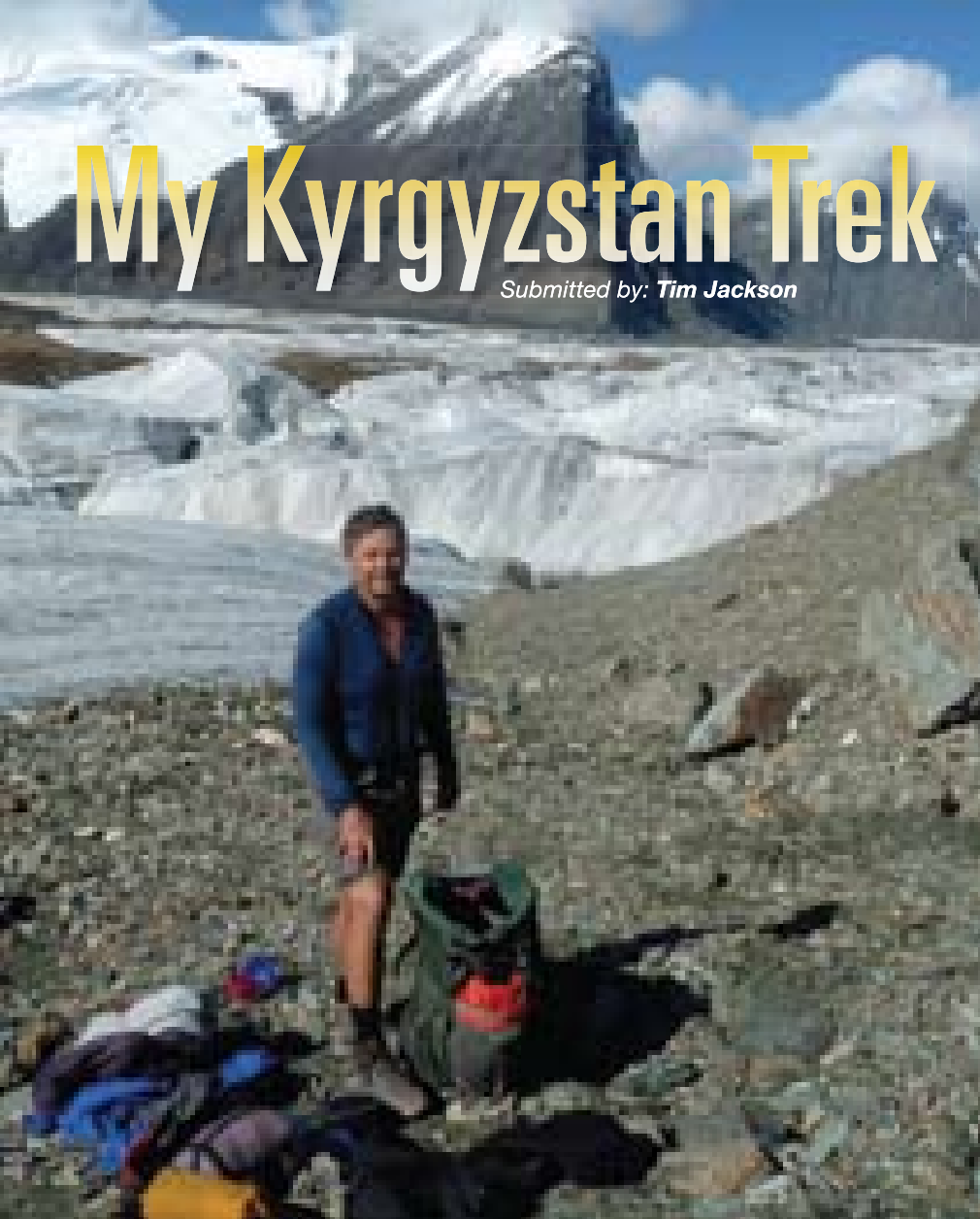
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My Kyrgyzstan Trek

Submitted by: **Tim Jackson**



After trekking in Australia, Nepal, Argentina and India I decided that I was ready for somewhere a bit more remote. Trekking in Kyrgyzstan proved to be just the ticket. For those of you wondering where in the world Kyrgyzstan is, find Russia on a map and look just below it for the country of Kazakhstan, and below that is Kyrgyzstan. Kazakhstan and Kyrgyzstan are two of the 'stan' countries formed after the Soviet Union disbanded in 1991. To get there my partner and I flew from Adelaide to Kazakhstan via Turkey, and then travelled by train down the length of Kazakhstan to Bishkek, the capital of Kyrgyzstan.

We arrived at around 1:00am and were met by our guide Vadim, a tall blond, blue-eyed athletic man who, we discovered as we travelled, was into bathing in freezing cold lakes as we moved up and across glaciers.



Vadim transported us to our hotel and a very comfortable bed, promising to pick us up at ten in the morning for a day of sightseeing before leaving for our trek.

We had chosen Vadim and the trekking company he represented through the

Lonely Planet guide. Our aim was to go with a local business rather than a foreign company as that way we not only kept the cost down but knew we would also be supporting the local economy.

Bishkek is full of Soviet-looking buildings – all concrete and straight lines but also green leafy parks to wander through. In fact it is a very green city with water off the surrounding mountains flowing fast down the street gutters.

To get to the start of our trek we drove to the foot of the Tien Shan range. Eighty-five per cent of the country is mountainous. Along the way we saw many fruit trees and huge marijuana bushes growing side by

side. We passed Lake Issyk-Kol, the second largest glacial lake in the world, where we stopped for a quick dip in beautifully clean and surprisingly warmish water.

That night we stayed at the Green Yard Hotel in a town called Karakol. A very pleasant place with a great breakfast consisting of fruit, pancakes, eggs and bread - all freshly made with local ingredients.

The next morning we climbed into a Russian ex-army troop mover which lumbered up the sides of the mountains for the best part of the day to get us to the start of our trek. As well as our excellent guide Vadim we had his off-sider, an Australian called Patrick, and two porters who bounded up and over glaciers in light footwear without a care in the world. Smoking all the way.

The deal was that we would carry our clothes, sleeping mats and bags and they would carry our tent and all the other camping gear.

Having not trekked up glaciers before I was unaware what was actually required. I soon realised that shouldering a heavy pack was going to slow me down somewhat.



My partner, Penny, was able to offload some of her gear from the third day but I managed to persevere with the loan of one of her walking poles.

The Tian Shan range is a very remote place to trek. In the six days it took us to reach base-camp we only saw one local party, which was coming down the glaciers (a much easier way to go, and more popular we were told).

There are two sorts of terrains when crossing glaciers. They are either exposed ice, or shale and stones on top of the ice. Strangely the exposed ice terrain is much easier to walk on as it is very firm and crunchy underfoot. As the day warms up

the ice under the rocks and shale melts, so you have to watch where you place your feet to avoid slipping over and getting a wet bottom.

Our first day walking consisted of wading through fast flowing mountain rivers that started off as a stream early in the morning but became wider deeper, colder and faster as the day warmed up and the ice from the mountains thawed, to the extent that if we did not cross them early enough we couldn't cross at all. There was a lot of taking our boots off and back on and the rocks on either sides of the streams were sharp and painful.

That night we camped next to a mountain lake. It was truly idyllic with the mountains around us reflected in the water. The next day the ground was very shady as we started traversing glaciers and leaving signs of vegetation behind us. We camped at one of the allocated camping grounds, a flat area with tents and meals you could buy if you didn't have your own gear. By now the snowy peaks around us were much more obvious but still sufficiently distant not to be a problem. The third camp we stayed at was populated by a German team of scientists who were monitoring the depth of the glaciers to find whether it was changing over time. The glaciers currently measure 360 metres deep.

Each morning helicopters flew over us delivering provisions to the various camps along the way and picking up people at base-camp. They disappeared in late morning as the weather then becomes more uncertain.

Our way was marked by cairns (small stacks of stones) that guided us across the glaciers, little man-made beacons that stopped us wandering off the track never to be seen again.

The next evening, after trekking all day, we realised we were not going to make the allocated camp-site so we camped on the glacier. It was pretty cold and we ate in our tent. It snowed a little overnight but apparently nothing like the year before. The weather was on our side.

By this stage the porters had shed a bit of their load as we ate our way along the trek and were able to take some of my partner Penny's gear. I still had all of mine so it was slow going and long, long days.

The following day was our last before base-camp. It turned out that Vadim wasn't too sure of the way as he confided in us that

this was only his second time on this route. We took the long way round. We discovered this after spending some hours clamouring over and around huge red boulders and then over the largest snowy glacier. We hit base-camp mid-afternoon. The big news was that we had tents on platforms you could actually stand up in and with an electric light switch and bulb, although these actually didn't work.

The other gem at 4,000 metres was the sack sauna, which was divided into three compartments - one for dressing, one for splashing ice-cold water over ourselves and the last for the sauna itself. It was gas-fired so made a bit of a noise but actually worked well.

We spent three nights at base-camp waiting for our turn in the helicopter. There were many mountaineers who passed by our tent as they commenced their attempts to climb the 7,000 metre peaks around us. The day before we arrived there had been a death on one of them during an avalanche during the night.

In fact there were distant avalanches on a regular basis and the constant sound of rocks rolling down the mountain-sides was our constant background music.

During the day at base-camp, we lay around relaxing and recuperating. On the second day we did a five-hour hike to the base of one of the 7,000 metre high mountains just for the hell of it. Can't have too much walking!

On the last day we had to walk from one base-camp to the other to catch the helicopter. It was a relatively short distance - about one-and-a-half hours, which was easy until the last little bit. To get to the

helipad we needed to cross an ice-bridge, which was a narrow bridge of slippery ice with drops of seven metres on either side. It was too narrow for me to cross wearing my pack, but thankfully Vadim took it over for me. Penny had some apprehension in crossing but there was no way round it. She inched across while clinging to Vadim's arm and we managed to get to the other side with only a few minutes to spare before the arrival of our helicopter.

The helicopter ride was also a bit of an adventure. As there had been an accident upon take-off a few years ago, the helicopter couldn't take off with all twenty passengers plus their gear at the same time. This was because the proximity of the surrounding mountains didn't leave enough space for the helicopter to manoeuvre if the wind picked up.

So ten of us plus everyone's gear was loaded on board. We then flew to the nearest glacier where we offloaded and the helicopter returned for the rest of the people. When it landed on the glacier again, we all got back in as quickly as possible and off we went, flying back down to the green pastures and sparkling streams from 4,500 metres. The back window of the helicopter was left open so we could take photos on the way down. It was fantastic to get a birds-eye view of the terrain we had travelled up.

Once back on the ground, we were picked up and driven back to the Green Yard Hotel where there were plenty of hot showers and comfy beds waiting for us. The next day we drove back to the capital where we spent a day shopping and preparing for our visit to Uzbekistan. ●



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In the August 2013 issue of *Ostomy Australia* ("Letters to the Editor" section), Suzanne from Victoria asked for assistance from other Ostomates on how they have dealt with weight gain since becoming an Ostomate (Suzanne's letter is reprinted below).



I am wondering how other Ostomates deal with weight gain. Over the six years I have had my stoma I have tried to keep my weight at a healthy level but am finding this increasingly difficult as I am restricted in what I can digest. I tend to eat more carbohydrates which has resulted in a weight level that I am not comfortable with. Not being able to eat high fibre foods, salads, nuts, etc (all the things recommended when trying to lose weight) is proving to be a constant battle. Consulting with dieticians has also not been successful. I would really like to hear from others how they deal with this problem.

Thank you to all those who replied. Several of the letters are published below in the hope that they might be of benefit to other Ostomates as well.

Fruit and Vegetables Without the Fibre

Submitted by **Margaret Tonks, VIC**

I find our journal very supportive and helpful, especially the letters from others coping with a stoma bag and diet I need to follow.

Suzanne's letter particularly rang a bell regarding the difficulty of keeping her weight in check. Because I have to minimise fibre, I was also missing the emphasis on fruit and vegetables I previously had in my diet. I felt I was missing out on vitamins.

My children partly solved my problem by giving me a fruit and vegetable juicer, which eliminates all the fibre and I feel I am still getting the vitamins I need. I make enough juice for two days from a kilogram of carrots, five sticks of celery, four apples and a piece of ginger root. I enjoy experimenting with other fruit like rock melon, water melon, kiwi fruit and strawberries but I keep the carrots and celery with every batch.

I wonder if there would be space in the journal to print recipes from other readers that would give us more ideas. My meals can get boring at times so recipes from readers or dieticians would be most helpful.

A Super Smooth Menu

Submitted by **Sarah Larcombe, SA**

I am 21, and have had a permanent Ileostomy since I was seventeen. Having lost twenty kilograms over the eighteen months following my Ileostomy surgery, I was told to eat lots of meat, pastas, breads, McDonalds, pastries, well cooked vegetables (no greens though), hot chips, processed foods, plus add salt to everything possible etc. With me being so young my parents and I always wondered how my body and arteries would handle this later in life.

Then at one of my routine check-ups, my gastroenterologist told me that I was all healed and without any sign of Crohn's. He told me to start adding fibre back into my diet, and to try liquid Metamucil first.

Well in my opinion Metamucil tasted horrible and made me gag, so I started with lettuce and fruit because these are my favourites. I gained a bit more weight than I had wanted to, so now I eat as clean, organic, natural and raw as possible and don't have any problems. Sometimes, I might have an issue if I forget to chew a lot, but I've found it's fine as long as you chew the food properly. For breakfast I have heated oats topped with fruit and yoghurt to help clear my vancomycin-resistant enterococci (VRE), salad for lunch (cooked quinoa, lettuce, spinach, tomato, avocado, cashews, almonds, bean-shoots, beetroot, capsicum, onion) which I eat raw (except the quinoa), and without dressing (dressing is high kilojoule). If you must have dressing just squeeze some lemon over it. For dinner I have either a chicken stir-fry, or some form of meat with vegetables.

For snacks you can also make super smoothies which have bananas, blueberries, spinach, celery, etc - basically whatever you want - plus I often add protein powder which helps to turn fat into lean muscle.

These smoothies can also be an alternative for breakfast if you like. For lunch you could try a fried/boiled/poached egg, with avocado spread onto organic spelt bread (much healthier and less kilojoules than wheat bread, and very easy to digest), and for dinner if you have trouble digesting raw-ish type foods, just steam your vegetables until they are very soft, and have with turkey or lean chicken or fish, or you could try a good home-made soup.

Also, my personal favourite is protein pancakes (for any meal). My recipe is one banana, half a cup of oats, and a scoop of protein powder, put in a blender until smooth, cook in coconut oil in a pan, then serve topped with honey and fruit if desired. Easy to digest, very filling and no unhealthy components! And always exercise. I know going to the gym or running/walking is hard for us sometimes, but Yoga and Pilates works you out without exhausting you.

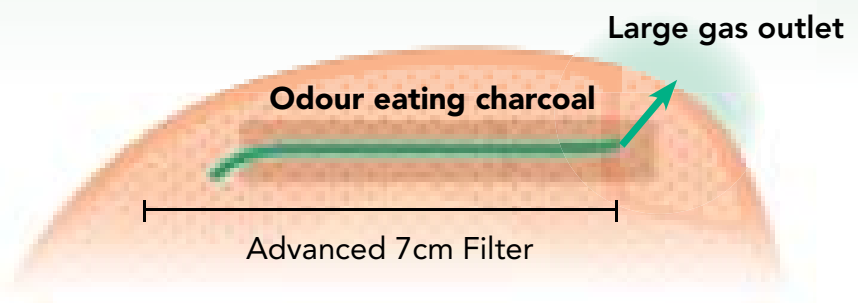
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Motivation and Reframing My Thinking Helped Me

Submitted by **M.S. NSW**

I'm writing in reply to Suzanne's letter. I have a high output Ileostomy and I too have struggled with weight management for six years since my last stoma surgery. I have counted calories and kilojoules, consulted a dietician and tried a well known system which allocates points to all foods and drinks. The latter has been the most successful for me. I've also tried the proprietary shakes and bars but actually gained weight with that system.

Having lost almost sixty kilograms while in hospital, I soon gained weight with my new diet of limited vegetables and needing more salt, I also ate more high energy, fatty foods as vehicles for the salt. Tiredness, limited exercise options, and emotional eating also contributed. I've had to face many losses after a long, traumatic time in hospital. When I found a system that worked for me, I lost fifteen kilograms, then with emotional eating I gained six. Having gained some insight into my emotional "triggers", I am now trying to lose what I last gained and then some.

With two large hernias and very serious complications in previous hernia surgeries, I have to be very careful when exercising. However, after much trial and error, I've found a few essential points: hydration; don't compare yourself to others; have a structure for whichever system you find suits you; record both your intake and exercise throughout the day; accept that increments of weight loss might be small but be thankful when weight heads in the right direction, and decide on your motivation - make it one which is positive for you.

After recording my stoma output at the suggestion of my surgeon, I found I was almost constantly dehydrated due to my very high stoma output, which is why I was always tired and was eating salty and sugary foods to gain energy. My Stomal Therapist suggested a medically developed drink formula which I make up each day combining glucose, salt and bicarbonate soda in exact amounts in water with a little cordial. Sipping this throughout the

day has meant I am more able to control my food because I am hydrated and not consuming many high calorie foods as vehicles for my salt consumption.

Having the correct bowel fluid balance also means I feel full for longer. Interestingly, when I was dehydrated I was constantly hungry. So, I have found effective hydration to be the key to controlling my food intake.

Yes, it is more difficult for those of us who are limited with vegetables, salads and high fibre foods. That is where diligently recording intake is essential. We might have high carbohydrate foods, but at least the daily total is within a recommended weight loss range for whichever system works.

Our exercise might also need to be gentle because of our surgeries. I can manage fifteen to twenty minutes of gentle walking at a time. With increases of intensity or length of time being dangerous for my hernias, I aim to increase the frequency of short walks each week and have consulted a physiotherapist for a range of gentle, safe exercises. I do everything with my trusty support garments. Just keep moving when you can and don't underestimate the value of incidental exercise. Walking railway platforms can also be good because they are flat and long.

I also found it important to have a motivation which is positive for me. I was trying to force myself to lose weight to be safe for more surgery. However, being ever so frightened of having a sixteenth operation in six years, I ate more to deal with my fear. So, I've had to re-frame my thinking and motivation. My new aim is to feel good about being able to accomplish something.

Many of my previous activities have been lost to me due to the ten medical conditions with which I now live. Each day that I stay on goal, I feel competent again. Attitudinally, I've made weight loss my "job". I've had to learn to accept that weight loss increments might be as small as 100 grams per week, but that's better than maintaining or gaining weight. 125 grams is half a stick of butter which is significant. It is slow, individual and challenging, but it is possible. ●

Sunshine Coast Stoma Support Group

The Sunshine Coast Stoma Support Group has been operating for many years from its meeting venue at the Headland Bowls Club.

The group is indebted to the Bowls Club which has provided free meeting facilities for the entire period.

The Group has approximately twenty Ostomates who, together with their partners, meet on a bi-monthly basis to discuss matters of mutual interest and to listen to guest speakers.

Meetings commence at 10:00am on the third Monday of even-numbered months. Regular social outings are also held. Difficulty has been experienced in spreading the word locally of our existence, but with the cooperation of Stomal Therapy Nurses, new Ostomates are now being supplied with our details.

Contact with the Group can be made by phoning:

Winnifred Preston on **(07) 5476 6313** or Don Lindsay on **(07) 5477 0864**



Ostomates and their partners at our June meeting

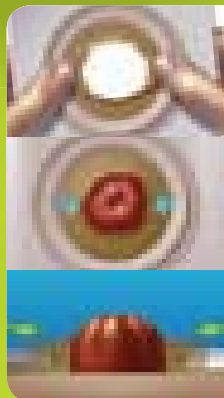
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¹ Scott V, Raasch D, Kennedy G, Heise C. Prospective assessment and classification of stoma related skin disorders. Poster presented at: 41st Annual Wound Ostomy and Continence Nurses Society Conference; June 6-10, 2009; Orlando, Florida.

² Hoeflok J, Guy D, Allen S, St-Cry D. A prospective multicenter evaluation of a moldable stoma skin barrier. *Ostomy Wound Manage.* 2009;55(5):62-69.

* U.S. Patent No. 6,840,924 B2

I'm rare, but not that rare.

No one tells you that this can happen in pregnancy or labour. They certainly don't tell you in antenatal class, or in the thousands of baby books, or indeed in our social circles.

No one tells you it could kill you, leaving a twelve-day-old baby. No one tells you that you could end up with an Ileostomy either.

We were living overseas at the time. My pregnancy was healthy and I loved every minute of it. We were excited and overjoyed to welcome our little baby boy. While we didn't have family support there we were confident we'd be OK, just the three of us.

The labour began well but eventually it wasn't progressing. I chose to have a general anaesthetic for my emergency C-section as I was shaking terribly and am petrified of epidurals. That was the beginning of the fight of my life. The next day my bowels had swollen and stopped moving. It's called a Pseudo-obstruction. The bowel thinks there is an obstruction, or is just plain unhappy to have been touched, so goes into panic mode. In my case, coupled with an emergency operation and a very hard labour, my poor bowel didn't know how to cope. My surgeons, in fact, can't be sure that this is why it happened but it is the only logical explanation given the pathology on my bowel came back with no conclusive results.

I spent the next four days in hospital, having different but very unproductive procedures done. All the while trying to get to know my baby, trying to breastfeed and cope with my caesarean wound. Things started to show signs that I may be getting better so we left hospital to take our baby home.

I was readmitted via emergency ambulance eight days later. An X-ray was taken showing that my caecum (the bit that joins the small and large bowel) had perforated and was leaking into my gut. I was entering septic shock. It was emergency life-saving surgery time and I only had hours.

What my surgeons found inside was even surprising to them. Five litres of pus, faecal matter and undigested food

is quite shocking. Ten centimetres of my small bowel plus my caecum, appendix and half of my ascending colon were removed, thus creating "Mr Stoma", my double-barrel Ileostomy.

But Mr Stoma wasn't the main player in this story; it was the wounds from my operation and the subsequent infection of it and my abdominal cavity. Peritonitis! I underwent two more operations to clean and close me up, spending two weeks in total in ICU and three weeks in the high dependency wards. It took that long as the abdomen has so many nooks and hiding places that it was impossible to clear all the infection via surgery alone. I entered a hard core regime of antibiotics, a chest drain to remove 1.5 litres of fluid on my lung (called a pleural effusion) and a drain was inserted to clean a large pocket of pus right near my stomach. Not to mention a dose of shingles to top it all off.

While all this was happening I thought that my stoma was the big deal. My mother had a Colostomy, which she named "Colin", so I was aware of what it was but didn't fully understand how mine worked. It took my mind off what may well have killed me many times over - the infection. It was the stoma that saved my life and made it possible for me to celebrate my son's first Christmas and his first birthday in March this year. It was Mr Stoma's first birthday that month too and a time that I continue to celebrate surviving.

Being in another country, away from our beloved families and lying in that hospital bed for so long really took a toll on me. The days were long and the nights even longer. Being in the high dependency ward, my observations were taken religiously. I had an automatic blood pressure cuff that would

take a reading every half an hour, but the oxygen tube rubbed against my nose and the tension stitches inserted in my stomach to keep the wound shut were cutting through my skin like a razor blade. This was the hardest thing I had ever been put through. There were days when I didn't want to do my exercises or get out of bed. There were days where my optimism was unshakeable and I learned to just do whatever made me feel better in that moment. All this on top of my feelings of immense guilt for leaving my so-young baby, and for almost leaving him

Me and Mr Stoma

Caroline's Story

Submitted by: **Caroline Turner, NSW**

Intestinal Pseudo-obstruction

is a clinical syndrome caused by severe impairment in the ability of the intestines to push food through.

It is characterised by the signs and symptoms of intestinal obstruction without any lesion in the intestinal lumen.

Clinical features can include abdominal pain, nausea, severe

distension, vomiting, dysphagia, diarrhoea and constipation, depending upon the part of the gastrointestinal tract involved.

The condition can begin at any age and it can be a

primary condition (idiopathic or inherited) or caused by another disease (secondary).

It can be chronic or acute.

forever. One's mortality becomes so crystal clear. I'm very, very, lucky to be alive.

We have now been home and close to our families for over a year. Without them, well, I'm not sure how we would have coped. My partner was brilliant throughout this ordeal. While struggling with all sorts of scary emotions and "what if" thoughts, he was also steadfast in his support of me and my recovery. He was also learning to be a father to a newborn baby, who was at home without his mother. We were lucky, and I thank every lucky star that my partner's mother, Grandma, was visiting us when I went back into hospital.

She became our little baby's primary carer and stayed for two months to look after us all. We will be forever indebted to her for that time and the love she gave us. She and her newest grandson will forever have a very special bond. My sister, an ICU nurse, also came to stay with us while I was very sick and having her and her expertise there was immensely helpful. I think the doctors were pleased to speak to someone who could "talk the talk".

My surgeons and nurses were without doubt the most amazing people. They fought hard for me and were so very careful with me. They wanted me to be home with our baby as much as we did. They cared for me with extra vigilance and became my friends, bringing me special drinks, food and magazines. I owe them everything and I thank them every day. They will have a special place in my heart for as long it is beating.

So after this long ordeal, I was now left with Mr Stoma, to find a rhythm of our own and to become, dare I say it, friends. However, untimely noises, leaks in the supermarket or trying to change the bag while there is a little person needing a cuddle is not exactly fun. There was a time after leaving hospital, where I would get faint while trying to change the bag due to overwhelming thoughts that I now have to do this. We now know all the tricks (thanks to our lovely Stomal Therapy Nurses) and it has become quite predictable.

As much as we have become accustomed to each other, Mr Stoma's days were always numbered. I was given the stoma in the first place so that my newly cut and shortened bowel could recover. I was originally told the reversal could happen three or four months after its creation. However, upon meeting my new surgeon (read: "hero"), he advised us to wait another year taking my time with Mr Stoma to eighteen months in total.

I am now just over a month post reversal. I was excited and petrified in equal measure during the lead up. Some

days I felt very morbid about it and others I felt quite excited by the prospect of using my large bowel again.

My surgeon had thought that he would have to open my whole tummy (along the previous laparotomy scars) due to the many adhesions. However, he started with just using the stoma hole and to everyone's surprise he was able to use only that, which saved me from yet another painful recovery. My bowel did swell a little and stop for a few days post operation but after a lot of walking, hoping and strong coffee, things started moving. And what a pleasure!! We take our bowels and bottoms so much for granted!

So far my recovery has been unremarkable which I feel so incredibly lucky to say. I was preparing for non-stop bowel movements (note to self: DO NOT read forums on the internet!), a lot of pain and not being able to eat anything. Apart from a few accidents, a little bit of constipation and a manageable amount of pain, I am coping well. So well that I surprise even myself. I have to pinch myself that I have been through all of this. It can feel like a dream. I am now just waiting to get back into the normality of family life and enjoy all the things I was too anxious to enjoy while Mr Stoma was around.

I guess what I have learnt throughout this whole ordeal is that we really don't know what is around the corner for us and that life really is short so we need to make the most of it. Saying that, I haven't booked a ticket to go bungee jumping or to climb the Himalayas but I do take extra pleasure now in watching my son grow, spending time with my partner, sharing tea with my

sister, kindness, chocolate, baking, sewing and all the little things we can often overlook.

I hope that I can repay all of the kindness we have received from all the doctors, nurses, family and friends. Without them this story would not have had such a happy ending.

I fought hard in those hospital beds after each of my five operations. I will also put up a fight to keep out of those hospital beds and be by the side of my partner and son, having a wonderful time.

You can read more about me and my stoma findings at:

<http://stomamumma.blogspot.com.au>

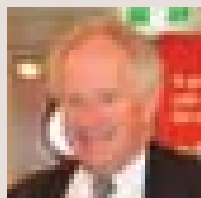


Submitted by: **Kim Lyell**

The 2013 Conference of the Australian Council of Stoma Associations (ACSA) embracing the 13th Annual General Meeting and 44th General Meeting was held at Wrest Point Hotel in Hobart on 18th and 19th October, with a social day on Sunday 20th. Delegates and observers from twenty of the twenty-two national ostomy associations attended.

Interspersed across the ACSA Conference business, social activities were greatly enjoyed and offered opportunities for delegates, observers and company representatives to further exchange views and ideas. The "Conference Welcome" function of drinks and finger-food on Thursday evening was a great opportunity to catch up with old friends and meet newcomers to the annual ACSA event.

The Conference was officially opened on Friday morning by Alderman Leo Foley (pictured right) of Hobart City Council.



Alderman Foley addressed delegates and told them how important organisations such as ACSA were in bringing people together in a support capacity and he thanked all associations for their commitment. The 50th Anniversary of both ACSA and the Ostomy Tasmania association were also celebrated at this time with the cutting of an appropriately decorated cake.

ACSA President Peter McQueen provided information on the ACSA Executive activities over the past year and took the opportunity to ask delegates to remember those that had passed away and to keep in their thoughts those former delegates experiencing health issues which have prevented them from attending this year's Conference. The President also expressed his gratitude that attendance at the 2013 Conference was the best for many years.

Representatives from the Department of Health spoke on the Stoma Appliance Scheme (SAS) and the recently completed stages of the new SAS pricing framework. Delegates were advised that during the 2012/2013 tax year, over 40,000 people accessed the SAS which covers 420 products and 2,000+ variants of these products. The overall SAS cost was eighty-three million dollars over this period.

Ostomy product suppliers were also more closely involved at the Conference this



Sue Hoyle (Ostomy Tasmania) with the 50th Anniversary cake

year, with brief presentations delivered by the Gold Sponsors (Convatec and Liberty Medical) followed by a very productive work-shop where attendees broke into four groups and then discussed delivery chain issues and service improvement opportunities.

The first of our keynote guest speakers was **Dr Jane Tolman**, Director of Aged Care at the Royal Hobart Hospital in Tasmania and Associate Professor of Aged Care at the University of Tasmania's Wicking Dementia Education and Research Centre. Dr Tolman gave a very informative talk on the stages of dementia, identifying the various signs as it develops and the rights of people to live independently when possible. Her current goal is to develop and implement a Tasmania-wide plan to support those with dementia, their families and carers, and their health-care providers.

Our second keynote speaker, **Louise Walker** CNC Stomal Therapy/Wound Management (Mater Private Hospital Brisbane), gave a very interesting presentation on the Great Comebacks® Program which began in the USA in 1984 under the leadership of Rolf Benirschke. It was designed to raise awareness of quality of life issues for people living with Crohn's disease, ulcerative colitis, colorectal cancer or other diseases that can lead to ostomy surgery. Today the Great Comebacks® community has spread far beyond its original borders, raising awareness around the globe through inspirational individuals who have chosen to share their stories and offer hope to others facing these diseases and transitioning to life after surgery. Louise also announced that the Great Comebacks® Program is to be launched in Australia next year with support from ConvaTec. The meeting confirmed that ACSA and associations would also support this new program. Louise also mentioned that "*we are stronger together than as individuals*" which is very appropriate given that "**Unity is Strength**" was our Conference theme.

In closing the Conference, President Peter McQueen, thanked Ostomy Tasmania for hosting the Conference, and thanked all Delegates and Observers for their contributions. Peter also noted that he would not be standing for re-election at next year's Conference, advising that after seventeen years on the ACSA Executive Committee it was now time for him to step down.

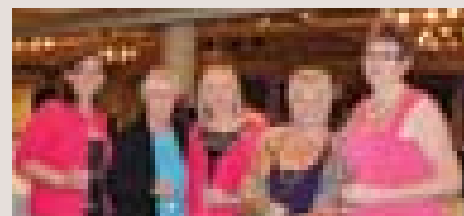
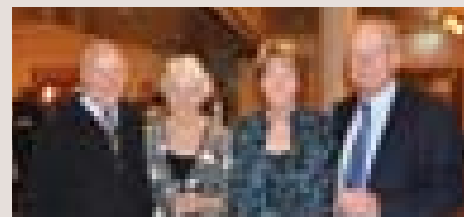
The traditional Saturday evening Conference Dinner Dance included presentation of ACSA Merit Awards to Charles Spiegel and Gerry Barry AM, both well-deserved recipients for their outstanding contribution to the welfare of Ostomates over many years. After the award presentations and meal, everyone got into the swing of things dancing well into the night to live music provided by a great five-piece band.



L to R: Peter McQueen, Sue Hoyle and Charles Spiegel

Sunday saw fifty-seven of us firstly travelling by fast ferry to the Museum of Old and New Art (MONA) then on a red double-decker bus to lunch and a walk through the Royal Tasmanian Botanical Gardens, Australia's second oldest botanical gardens. After a slow bus trip back to Wrest Point it was time for our final farewells until next year.

The next AGM and General Meeting of Council, co-hosted by Queensland's six ostomy associations, will be held on 10th and 11th October 2014 at the Hotel Grand Chancellor in Surfers Paradise. The theme of our next Conference will be "**Embracing Technology**". ●



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2. A retention component that provides non-adhesive fixation of the StomaLife device to the stoma site.
3. A Digital Pressure Control valve that allows the user to release gas and faeces as and when required;



StomaLife utilises a magnetic implant in order to provide a reliable and concealed mechanism which prevents leakage. To pass faeces, the user simply connects a tube to the device then opens the valve and the faeces can be released into a toilet bowl and flushed away in a hygienic way. It also has a mechanism with a self-gauging pressure release button which allows personal control of gaseous release via a charcoal filter at the user's convenience.

Saied advises that he has spent seven years and over two hundred thousand dollars of his own on research and development of this new device and it is now ready to undergo trials prior to marketing. The next stage requires some funding assistance and the successful completion of technical trials (initially with animals and then with thirty human volunteers).

**StomaLife
IS NOT YET
AVAILABLE**

Contact: Saied Sabeti
Company: StomaLife Pty Ltd
Address: 16 Madrid Terrace, Hocking, WA 6065
Email: saied@stomalife.com.au
Website: www.stomalife.com.au



Couples and Families Needed for Research into Bladder Cancer

Submitted by **Susan Heyes**

We are looking for volunteers to take part in a study on bladder cancer.

My PhD research at Flinders University's School of Nursing and Midwifery explores the effects of bladder cancer on couples and families.

This research will determine the quality of life of people with bladder cancer and their partner/family/caregivers in order to develop a model of care that is more suited to their needs.

To take part in this study you need to either be diagnosed with bladder cancer or be the partner, family member or caregiver of someone with bladder cancer (whoever looks after the person with bladder cancer).

As participants in this study you and your partner/family/caregivers will be asked to complete a questionnaire each, on one occasion only. The questionnaire should take approximately 30-50 minutes to complete.

The questionnaire is entirely **anonymous and confidential**. We are not asking for your names, addresses, telephone numbers or any other personal details. You will be provided with sealable, pre-paid envelopes in which to return your completed questionnaires. You are free to withdraw from the study at any time.

For more information about this study or to volunteer for this study please contact **Susan Heyes** on **0408 892 948** or susan.heyese@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5956). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email: human.researchethics@flinders.edu.au

Bulletin Board

Ostomy Association Changes

**ILEOSTOMY ASSOCIATION OF
VICTORIA INC.**

New Email Address

The new email address for Ileostomy Association of Victoria is: ileovic@onestream.com.au

Ostomy Support Group Changes

MACKAY OSTOMY SUPPORT GROUP
Mackay Meetings Discontinued

Due to the lack of a coordinator the Mackay Ostomy Support Group meetings have become inactive.

PARENTS OF AUSSIE KIDS WITH IBD
Now on FACEBOOK

We are a new group seeking to support parents of children with a Colostomy, Ileostomy or J-Pouch via our closed Facebook page
www.facebook.com/groups/Parentsofaussieibdkids/



A BACKWARD GLANCE

by Harry Ashton

One time we bought a barbeque, all knobs and shiny new,
which didn't draw a crowd the way the old one used to do;
No fire for kids to make their toast while oldies swapped a joke,
and something else was missing, Grandad said it was the smoke.

Spare a thought for poor old Grandma, who never drove a car,
and dressed from neck to ankle, she could not walk very far;
But if she found a boyfriend then her luck was in for sure,
while in those days girls who married went out to work no more.

The milkman came at daybreak and the baker called at light,
his basket full of bread so warm, a slice would sure be great!
The meat-boy on his Harley and we can't forget of course,
the dear old fruit and veggie man, upon his cart and horse.

No more we hear the Salvo Band on Christmas Eve and sure,
no longer carols loud and clear come from the music store;
No more the shouts of children in the street they dare not play;
Oh what I'd give to let them have a bygone Christmas Day!



The Letter E

Some say the most
unfortunate letter in the
alphabet is the letter E.

It is always out of cash,
forever in debt and never
out of danger.

While that is all true, it is
still never in war, always
in peace and always in
something to eat.

It is the beginning
of existence, the
commencement of ease
and the end of trouble.

Without it there would be
no life or no heaven.

It is the centre of honesty
and always in love.

It is the beginning of
encouragement and
endeavour, and the end
of failure.

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A technological landmark
Tests show the Corsinel underwear reestablishes a normal body profile, both sitting and standing.

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Contact your local Stoma Association or
Statina Healthcare Australia Pty Ltd on:
1300 365 404.

statina
Stoma Healthcare Australia

www.statina.com.au



1. *I would like to know what products I am entitled to receive as a registrant of the Stoma Appliance Scheme. Can you please tell me where I can obtain a catalogue of what I can get and in what quantities.*

Because of the number of individual products listed on the Stoma Appliance Scheme and the diversity of stoma sizes and shapes for which these products are used, it is not viable for a comprehensive catalogue to be produced and sent to all registrants of the Scheme. A full listing of products including description and product code can however be found on the Department of Health's website. The most recent Schedule information, including upcoming product additions and deletion information, can be found by selecting "Stoma Appliance Scheme Schedule" on this website. A revised Schedule is usually released in April, June, September and October of each year.

While the Schedule does specify all products available through the Stoma Appliance Scheme and the monthly allowances of those products, restrictions do apply on the issue of some products, particularly when ordering products that have the same purpose or which fall within the same group or sub-group. Your ostomy association can provide further information on product quantities.

Please remember that it is essential to seek the advice of an appropriately qualified medical professional when adding any new products to your stoma management regime.

2. *I would like to travel throughout the United Kingdom and Europe for an extended period but am very concerned about where I will get my stoma supplies while travelling and how much they will cost.*

In terms of Clause 6.5.5 of the Operational Guidelines for Stoma Associations, a registrant of the Stoma Appliance Scheme can obtain up to six month's supply if travelling overseas. Persons wishing to access more than two month's supply and up to six month's supply for the purpose of overseas travel must supply supporting documentation such as a travel itinerary to their association at the time of placing the order. The order must also be placed well in advance of the expected travel date so that the association has plenty of time to obtain the required supplies within normal operational timeframes.

The Australian Government has Reciprocal Health Care Agreements in place with a number of countries including those in the United Kingdom and some European countries. This means that you may be able to access medically necessary treatment and pharmaceuticals including your stoma appliance needs during your travels to the extent that a stoma appliance payment scheme or similar is in place in the country within which you are travelling. While

travelling throughout the United Kingdom, you should be able to access appliances free of charge by consulting a General Practitioner and advising that you want to be treated as an NHS patient. You may

need to show your Australian Passport and Medicare Card as proof of nationality. When travelling in other countries throughout Europe, it is best to contact a local ostomy association for information on where and how to obtain ostomy supplies and any costs involved. A list of European associations affiliated with the International Ostomy Association can be found at **www.OstomyEurope.org**

For more information about Australia's Reciprocal Health care Agreement with the United Kingdom and other countries, please refer to the Department of Human Services website **www.humanservices.gov.au/customer/services/medicare/reciprocal-health-care-agreements**

3. *My partner has a stoma and has been told to wear a stoma support belt. The styles of those currently available in Australia are not suitable but we have found one online which seems to be very popular in the United States. We contacted our association to see if they could get one for us but were told that only those belts listed on the Stoma Appliance Scheme could be obtained free of charge. How do we get the belt that we like listed on the Stoma Appliance Scheme so that it is available in Australia at no charge for people like my partner?*

For an item to be listed on the Stoma Appliance Scheme (SAS), the manufacturer or supplier of an ostomy-related product must make an application to list the product with the Stoma Products Assessment Panel (SPAP). The SPAP is an independent committee made up of individuals with expertise in current clinical practice (e.g. Stomal Therapy Nurses); individuals with expertise in reviewing and interpreting clinical evidence; an individual with expertise in reviewing economic analysis and valuation of health gain; a consumer representative and an independent chair. The role of the SPAP is to provide advice to the Department about which ostomy-related products are suitable for listing on the SAS schedule.

The Panel currently meets three times per year in March, July and November to assess current applications.

For more information about the listing process, please refer to the website **www.health.gov.au/internet/main/publishing.nsf/Content/health-stoma-spap-index.htm** ●

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

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

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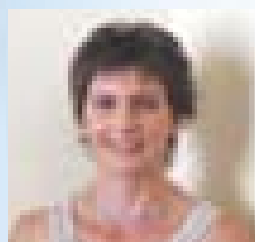


Bowel Cancer Australia

Hydration for Ostomates

Submitted by: **Margaret Allan**, VIC

Margaret Allan is a qualified Nutritionist who advises Ostomates and the general public on diet and health-related matters. In this article she emphasises the importance of staying hydrated during the summer months.



Margaret is based in Melbourne and is available for clinical and telephone consultations by appointment. Margaret can be contacted via email on margaret@foodfirst.com.au

The summer months are here and, whilst it is a great time of year with lots of fun, frivolity and relaxation, there are also some important considerations for Ostomates in staying healthy during this time. And one of them is to remain hydrated during the warmer weather.

Hydration is very important for Ostomates, much more so than for the average person. This is due to the fact that part of their intestine has been removed and intestinal function is compromised. Three main factors will influence the degree to which fluid balance is affected in an individual Ostomate – the part of the bowel that has been removed, and the quantity and consistency of output.

Different parts of the gastrointestinal tract perform different functions, with the small intestine mainly digesting and absorbing nutrients from the foods that are eaten, and the large intestine mainly absorbing water and electrolytes back into the body.

Therefore, for Colostomates who have only had a small part of the large intestine removed, their ability to absorb water may not have been affected very much and they may not need to compensate for reduced fluid absorption. However, for an Ileostomate who has had all of their large bowel removed and perhaps some of the small intestine too, the need for additional fluids is greater. Over time, the small intestine will begin to compensate for the functions of the large intestine, but it takes time for this adaptation to occur.

The requirement for extra fluid is also affected by the nature of the stomal output. If it is very liquid and resembles water, then it is imperative to replenish this fluid loss. However, if the output has a thicker consistency and is more like a paste, then less fluid is lost from the body and the need to replace it is not as dire.

In a person with full intestinal function (i.e. no surgery),

approximately 2.5 litres of fluid are lost from the body each day via the lungs (breathing), the skin (sweating), the kidneys (urination) and the intestines. Of this 2.5 litres, only 100 millilitres is usually lost via the intestines. However, for an Ostomate, the amount of fluid lost from the intestine can be far greater, depending on the consistency and quantity of the output. Therefore, in a person who has had stomal surgery and has a liquid output, this quantity could be much higher.

Fluid intake is usually via both moist foods (approximately 700 millilitres) and ingested liquids (usually approximately 1,600 millilitres per day), with around 200 millilitres of fluid being produced within the body itself via metabolic processes. Therefore fluid intake usually totals approximately 2.5 litres per day, which would normally keep a person in positive fluid balance. However, as previously mentioned, if the output from the gastrointestinal tract is higher than 100 millilitres, which is often the case for an Ostomate and for an Ileostomate in particular, then fluid intake needs to be much higher than this.

The first step for an Ostomate in assessing fluid balance is to determine their level of output. This can easily be done by noting the number of times the bag



is emptied per day and estimating how many millilitres were in the bag each time (if the output is purely fluid). Multiplying the two figures over a whole day will give a rough estimation of output. It is then important to make sure this figure is at least exceeded, if not doubled, throughout the day to replenish fluid loss.

But, apart from assessing fluid balance, how else can you tell if you are dehydrated?

Some of the most common symptoms are dry mouth, headaches, irritability, fatigue, poor concentration, constipation and dry skin. Low blood pressure and fainting spells can also be indicative that fluid levels in the body are low.

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An important fact to be aware of in maintaining hydration levels is that the thirst mechanism becomes less reliable as we age. By this I mean that the sensation of thirst starts to weaken, and it isn't triggered as often as it used to be. Therefore, as we get older, it is important not to rely on the sensation of thirst to tell us when to drink. A more useful tool can be to use a visual reminder to drink fluid. For me, this takes the form of a jug on my desk or kitchen bench that I fill up each morning, and I have set the rule that it must be emptied by lunchtime and again when I finish work, or late afternoon. That way I know I am drinking at least two litres of fluid every day.

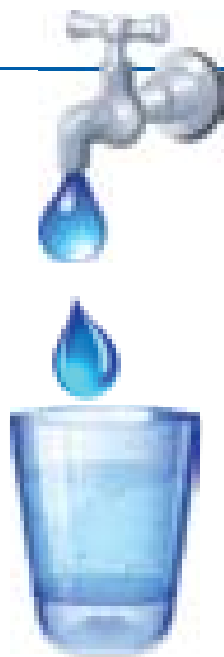
Using drink bottles can also help to provide a visual reminder to drink fluid, as well as providing a measuring tool for knowing how much fluid has been consumed. However, a note of caution - don't consume fluid from a plastic drink bottle that has been left sitting in the sun or in the car during summer. If the bottle has heated up, there is a risk that chemicals from the plastic bottle may have leached into the fluid in the bottle. These chemicals may be hazardous to your health. During the summer months it can be safer to drink from glass or metal containers if possible.

When it comes to fluid replenishment, it is also important for Ileostomates especially to sip water and not gulp in large quantities. If large quantities of water are drunk rapidly, they have a tendency to leave the body as fast as they entered!

Another important consideration in fluid balance is that excessive amounts of fluids such as alcohol, tea and coffee may not be hydrating and fluid replenishing, but may actually be dehydrating and fluid depleting.

Alcohol is a potent diuretic and will increase fluid loss from the body. Caffeine is a more moderate diuretic. Approximately one millilitre of fluid is lost for every one milligram of caffeine consumed. A 250 millilitre cup of instant coffee that contains approximately 80 milligrams of caffeine is therefore mainly hydrating. However, a short black espresso in a tiny cup contains much more caffeine and much less water so is more dehydrating. Tea contains less caffeine than coffee. The quantities of each of these that are consumed on a daily basis can therefore have a considerable effect on your fluid balance.

Therefore, when it comes to replacing fluid in the body, water is best. For those who are not fond of the taste of water, adding some fresh lime or lemon juice, or a dash of apple, orange or pineapple juice can improve the taste. This can also help with absorption. Switching to herbal teas can also help to rehydrate the body. If having to get up to go to the toilet during the night is a problem, drink more fluid earlier in the day and less after 3.00 pm.



Fluid intake can also be boosted by eating watery foods such as watermelon, mango, juicy peaches and nectarines, and grapes. Just be aware that they may also loosen stools and therefore increase output, so keep the quantity moderate. Milk drinks and soups can also add to the total fluid intake for the day.

I often get asked if sports drinks are appropriate for Ostomates. My answer to this is yes, if you are replacing general fluid loss on a hot day, for example. However, if you are seriously dehydrated due to excessive diarrhoea for example, then oral rehydration solutions such as Hydralyte or Gastrolite which can be purchased

from the chemist might be more appropriate. But be mindful that due to the sodium content of these beverages, caution needs to be taken by those on a low sodium diet.

In relation to hydration, an Ileostomate recently made a very valid comment as we were talking on this subject.

She said, "It is not on the hot days over 30°C when you are at greater risk of dehydration, because you are conscious of consuming more fluid on those days. It is when the temperature is between 25°C and 30°C that you are more likely to forget to drink extra fluid." And she is right! Many years of experience have taught her that.

So my advice during the warmer weather is to drink up! Let's all Toast to a positive fluid balance during summer and better health for everyone!

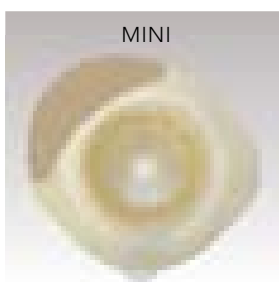
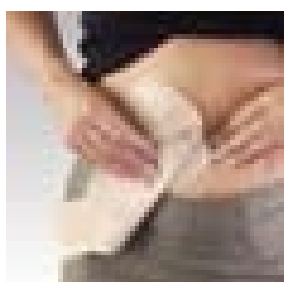
Wishing you good health and happy days,
Margaret.



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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

Meet first Sunday in Feb, April, June, Aug, Oct, Dec. 11am
Venue: Laughter Room, Moruya Hospital.
Phone: Betty (02) 4476 2746

FAR NORTH COAST

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

FAR SOUTH COAST

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

GRAFTON

Meet: first Thursday of each month from 9.00am to 11.30am
Venue: Community Health Centre, 175 Queen Street, Grafton.
Contact: Anne: (02) 6641 8200

GRIFFITH & DISTRICT

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

HASTINGS MACLEAY

Meet: The Old Hospital in Room 4 at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries: Keith (President)
(02) 6583 3970 or Barbara (Secretary) (02) 65824206

ILLAWARRA

Meet: 10.00am to 12 noon on Wednesdays 12th Feb - 2nd Apr - 11th Jun - 13th Aug - 15th Oct - 10th Dec (Christmas Party) in the Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525. For further information contact Helen Richards CNC STN on (02) 4225 5046 (Monday only) or Julia Kittscha CNC STN on 0414 421 021

MANNING/GREAT LAKES

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

NEWCASTLE DISTRICT

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

ORANGE & DISTRICT

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

SHOALHAVEN

Meet: 2.00pm on 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

Meet: 2014 meeting dates and venue to be advised.
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-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

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

OSTWEST

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

MILDURA

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

NORTHERN

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

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

BRISBANE

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

GOLD COAST

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

REDCLIFFE

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

ROCKHAMPTON

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

SOUTH BURNETT

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

SUNSHINE COAST

Meets at Headland Bowls Club, Syd Lingard Drive, Buderim
Meetings commence at 10am on the third Monday of even numbered months.
Enquiries: Winifred Preston:
(07) 5476 6313
presto70@bigpond.net.au
Don Lindsay: (07) 5477 0864
lindsaymar@optusnet.com.au

WIDE BAY

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

TASMANIA

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

SOUTHERN

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

YOUTH GROUP

Doris Steyer,
Telephone: (02) 4296 5354

YOUNG OSTOMATES UNITED (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-nutrition-down-under.webs.com



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Website: www.dansac.com.au



Coloplast

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Freecall: 1800 653 317
Email: au.care@coloplast.com
Website: www.coloplast.com.au



ConvaTec

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Email: connection.au@convatec.com
Website: www.convatec.com.au



Future Environmental Services

PO Box 155, Caulfield South, Victoria 3162
Phone: +61 3 9569 2329
Email: health@futenv.com.au
Website: www.futenv.com.au



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1. Data on file, P12-520-320