

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

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

NORTHERN TERRITORY

CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House
25 Vanderlin Drive, Casuarina
Mon to Thurs 8.30am to 2.00pm
Phone: (08) 8927 4888
Fax: (08) 8927 4990
Email: ostomy@cancernt.org.au
Web: <http://nt.cancer.org.au/>

WESTERN AUSTRALIA

WA OSTOMY ASSN INC.

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

NEW SOUTH WALES

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Operating hours: Mon to Thurs
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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
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Telephone: (02) 9542 1300
Fax: (02) 9542 1400
Email: orders@ostomynsw.org.au
Website: www.ostomynsw.org.au

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

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Telephone/Fax: (07) 4775 2303
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Hyde Park, Castletown 4812
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A/H (07) 4775 2303

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P.O. Box 198 Moorooka 4105
Operating hours: Tues & Thurs
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Secretary: (07) 3848 0138
Fax: (07) 3848 0561
Email: admin@qldcolostomy.org
Web: www.qldcolostomy.org

QLD STOMA ASSN INC.

Unit 1/10 Valente Close,
Chermside 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, Chermside 4032
Email: admin@qldstoma.asn.au

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

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

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

SOUTH AUSTRALIA

OSTOMY ASSN OF SA

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

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

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:
Monday to Thursday 9.00am -
2.00pm
Stomal Therapy Nurse
Wednesday 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:
Mon to Thurs 9.30am - 2.00pm
Secretary: Wendy Taylor

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
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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@swh.net.au
Operating hours:
Friday 12 noon - 4.00pm
Secretary: Heather Love



Editor: Kim Lyell

Editorial Contributors:

Margaret Allan, Genevieve Cahir, Kirsti Dixon, Luke Escombe, Sonia Khatri, Emma Kilpatrick, Kim Lyell, Kylie McGrory, Warren Rayment, Margaret Sanft, Annette Shears, Geoff Rhodes

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Correspondence/Contributions to:

The Editor, *Ostomy AUSTRALIA*
PO Box 195, Frenchs Forest, NSW, 1640
Phone: (02) 8011 3535
Email: Journal@AustralianStoma.com.au
These contact details apply only to matters directly associated with *Ostomy AUSTRALIA*. Only Email, Word or PDF documents, and hard copy submissions accepted.

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Patron:

His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd)
Governor-General of the Commonwealth of Australia

Executive Members:

Geoff Rhodes - President
P.O. Box 152, Wanniasa ACT 2903
Email: acsapres@australianstoma.com.au

David Munro - Vice President
PO Box 370, Chermerside South QLD 4032
Email: acsavp@australianstoma.com.au

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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Gum trees around a billabong in the Pilbara region of the Western Australian outback.

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

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

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

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

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

Have you ever considered how miraculous, even magical, a stoma is? How else could you describe something that is able to free people from the grip of sometimes life-threatening diseases, severe debilitating pain or the endless consumption of large quantities of extremely strong medication?

For Ostomates this “magic” is not an illusion and as with all great magic, there must also be great magicians. For an Ostomate it is the GP, surgeon, oncologist, Stomal Therapy Nurse and, in fact, all the medical staff we come in contact with during our chemotherapy and stay(s) in hospital.

Faith is also a major factor for many and we should not underestimate the importance that support from family and friends provides us during our treatments and recovery.

We are also blessed with the modern Ostomy appliances, which were “magically” developed by some very clever scientists and which are now freely available to us via Australia’s unique Stoma Appliance Scheme.

Another “magic trick” is that a stoma often delivers a new lease on life to a new Ostomate, enabling them to do things they were unable to do before their ostomy operation. Unfortunately the “magic” of a stoma isn’t quite strong enough to let us play A-Grade cricket or a piano concerto if we didn’t have sufficient ability before the operation.

Of course we all would prefer not to have a stoma, and yes, there are a lot of negatives; the occasional leakage, skin problems, inappropriate load noises at inappropriate times, etc. It sometimes seems to be an almost endless and ever changing list of issues we endure. However, I think for many the alternative to a stoma could have been very much worse!

In our first article, “*Life is Magical*”, Luke Escombe tells of how he is now Crohn’s and medication free thanks to ileostomy surgery. Luke takes a very positive and somewhat light-hearted approach to his new and very close companion, while his young son is sometimes just a bit too fascinated with Luke’s ostomy bag.

Similarly, PT describes in “*Life is There to be Lived*”, her battle with endometrial tumours, which required the creation of an ileostomy mid-2013. She eventually gathered the strength to resume her beloved scuba diving, and as an Ostomate did her milestone 200th dive. Six months post reversal she was also able to celebrate her 250th dive.

Margaret Sanft in “*One Day at a Time*”, Annette Shears in “*A New Life*”, Emma Kilpatrick in “*To Hell and Back*” and Rachel in “*I Really Can’t Eat Popcorn After All*”, also give their perspectives on their own personal battles and recoveries, and how they go about staying positive.

These and our other contributions reflect this new found freedom and positive approach – and yes, perhaps a little bit of magic – which has helped with their recovery and acceptance of a stoma.

In this issue’s “*Nutrition for Ostomates*” article, Margaret Allan discusses dietary solutions to prevent Urinary Tract Infections. Margaret advises us to drink ample hydrating fluids, avoid excessive intake of sugar and refined carbohydrates, and consume foods that help to boost the immune system.

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.

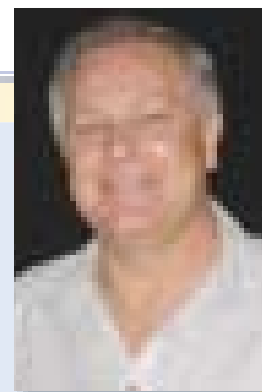
Kim Lyell EDITOR

“You can never cross the ocean until you have the courage to lose sight of the shore.”

CHRISTOPHER COLUMBUS

Help!

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



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

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

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

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

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

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

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



Like to be on the front cover of this journal?

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

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

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

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

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

President's Message

This is my first President's Message and I wish to thank Peter McQueen for his support and encouragement of me as Vice President over the last four years. I also take this opportunity to congratulate Peter on his inauguration as a Life Member of ACSA. It is a fitting tribute for Peter's seventeen years of service on the ACSA Executive and the outstanding contribution he has made to the development and success of ACSA over that period.

I am also extremely pleased to welcome David Munro onto the Executive team as Vice President. I have worked closely with David over the past few years while setting up and operating the Computer Committee, and know he will make a significant contribution to ACSA as Vice President.

The 2014 Conference addressed several issues which will influence the way in which Stoma Associations, and therefore ACSA, evolves over the next few years. The three primary issues considered were:

1. The relationship between associations and suppliers within the Stoma Appliance Scheme environment.

This was considered as part of a workshop conducted at the Conference, with the following factors being identified as critical to a successful association/supplier relationship:

- Recognition by both parties that there should be a give and take process to agree on new processes;
- Communication about operational effectiveness (feedback);
- Open discussion about process failures and prompt remediation of those failures; and
- Education of workers, suppliers, STN's, members and associations about the importance of embracing continual change.

2. The development and introduction of a National Stoma Appliance Scheme Management System.

The Meeting accepted a proposal put by the Computer Committee for ACSA to buy the TOMAS system (developed by Ostomy NSW Limited) and to develop it as the National Stoma Appliance Scheme Management System. A total budget of \$250,000 was approved for the acquisition, development and implementation of the system. It will be provided at no cost to member associations who will be provided with training and support during the implementation period.

The benefits that will accrue from introducing a national computer-based management system include:

- Inbuilt backup with secure data and disaster recovery;
- Automatic update of schedules and other changes;
- Reduced effort for staff and volunteers issuing supplies;
- Formal national support arrangements;
- Automated processes available if required;
- Capacity to provide automatic links to suppliers;
- Capacity to provide links to Department of Health

and Department of Human Services;

- Capacity to develop and provide on-line (Web based) member ordering if required;
- Demonstrable professional system for management of government expenditure; and
- Auditability by Government.

In order to manage the acquisition and implementation, the meeting approved the establishment of three subcommittees. I am pleased to announce that the positions in those subcommittees have been filled by volunteers as follows:

Configuration Control Committee

David Munro	Queensland Stoma Association
Bob Newman	Ostomy NSW Ltd
Ian Draper	Ileostomy Association of SA

System Implementation Committee

Geoff Rhodes	ACT and Districts Stoma Association
Sue Hoyle	Ostomy Tasmania
Ian Samuel	Ostomy Association of Melbourne

A third subcommittee, the **Strategic Directions Committee**, will be formed from members of the other two Committees and will set the system objectives. All three Committees will report to the ACSA Executive and are authorised to invite others to join the Committee for specialist advice as required.

The objective is to have the system defined and ready for implementation within twelve months and to have all associations wishing to adopt the system fully operational within two years after the first implementation.

I believe this initiative will ensure that the Stoma Appliance Scheme can continue to be run efficiently and effectively by our stoma associations, which are best able to understand and meet the needs of fellow Ostomates. A new National System will provide a computer infrastructure that supports associations' ongoing capacity to manage the Scheme.

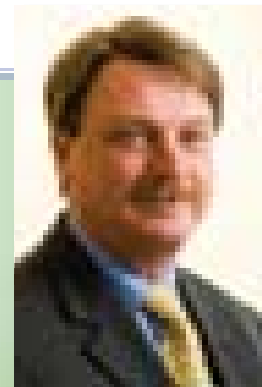
3. The primary issues which will shape the future of stoma associations in the coming decades.

The following issues were considered by three groups and I will elaborate on the outcome of those discussions in the next President's Report:

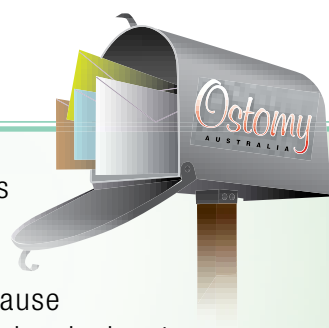
- Management of an \$80M+ annual business under the current structure;
- Access to Volunteers; and
- Maintenance of Personal Support Services.

In conclusion, I look forward to serving the ostomy community in this role and working with all of you to address whatever opportunities and challenges we face in the future.

Geoff Rhodes PRESIDENT



Letters to the Editor



Dear Editor

It takes courage to go on flights with a colostomy, what with the fear of leakage, uncomprehending air stewards and startled security officers when they decide to "pat you down".

Information (multilingual) was in the past available from some associations but the type face was too small for the crew to read. Hollister brought out a very small "certificate" but it is barely legible as its type face is also tiny. However, they had the right idea.

Could someone please tackle this issue and produce an information brochure for those of us who travel, especially overseas?

Katherine Kingsbury, VIC

Dear Editor

Thank you once again for an informative journal.

In reply to the letter written by Shoshanna Monk regarding paper towels and cloth-type wipes [*"Your Say / In Your Own Write"* - August 2014 issue], I have been meaning to write exactly what Shoshanna wrote. Whenever I change my pouch, I put a wet paper towel over my stoma to catch the output (if any) and have been doing this for a long time now. I also only use the 'toughest when wet' brand as no other compares for what we use it for.

Thanks Shoshanna for your letter - this is a most useful tip.

Nancye Turner, QLD

Dear Editor

At seventy-five years of age and nearing the fortieth anniversary of my ileostomy for ulcerative colitis, I set my aim to train and join the 2014 City to Surf Fun Run in Sydney for the first time. The motto on my medal was "I did it for Clancy" (of the overflow) and all the other Ostomates.

Ben Selinger, NSW

Dear Editor

The article submitted by Katrina Roads [*Life With A Stoma, The Gory Details* in the August 2014 issue], set my mind to thinking that it all depends on one's situation whether a particular moment could be funny or grim.

I named my colostomy "Winsome" but when I introduced him to my close friends they thought the name was absolutely awful. They asked how I could be so

insensitive as to call it a girl's name. Indignantly I told them I had never heard of such a name. I just made it up because sometimes I would win some when he burst his banks, and other times there would be such a horrid unmentionable mess that I would lose everything. Hence "Winsome" - WIN SOME, LOSE SOME!

I also chose it to be masculine as it could also be very unpredictable. One Sunday, all was quiet in the church as the cleric was offering prayers, when Winsome got it into his head to fervently join in. I opened my eyes and looked around just as all the other people were doing. I was lucky there was no smell to give me away and no one was aware that I was a Colostomate. There are plenty of other incidences that could also make you laugh or cry.

Isn't it marvellous that our great surgeons have been able to make our lives so bearable. We should all be forever grateful.

C.S., NSW

Dear Editor

Recent letters express difficulties with having adequate supplies. While everyone's situation is different, what comes to my mind is whether or not some people might find drainable bags to be more useful. I average two drainable bags per week and empty these about four times a day. A quick squirt from a recycled plastic sauce bottle which I fill with warm water keeps them fresh between changes.

Maybe there is a limitation of drainable bags which I am not aware of but I certainly vouch for them.

Isobel Davie, VIC

Dear Editor

In regards to the lack of spare supplies raised by Kerri and L.B. in the August 2014 issue [*"Letters"*], as in the case of Kerri my monthly supply arrives around the fifth of each month.

I use a one piece drainable appliance, hence thirty per box per month and I currently have two month's supply as spares. The way this was achieved was quite simple, I wear a bag for two days instead of just one day. It doesn't leak and doesn't deteriorate if it gets wet in the shower, so perhaps you may also not need to change your bag daily.

I only had to do this a number of times and soon had an adequate buffer supply of spares.

Graeme Mitchell, QLD



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My Own 'Gator' Tips

Submitted by **Peter Fitzsimmons, QLD**

In reference to the interesting submission by Kerry Kimbrey on becoming a 'Gator', I offer some more thoughts on stoma irrigation as there really isn't much hands-on literature around.

Hooks - When travelling it is generally difficult to have toilets with a method for hanging the water bag at a height which encourages complete irrigation. I calculate the correct height for me is to have the bottom of the bag - not the hose or cone - level with the top of my shoulder. So, whenever I plan any overnight stopover away from home, I always carry 'Command removable adhesive hooks' which are readily available from most hardware outlets and has always supported my water bag. You can get a hook that fits through the top of your bag and easily attaches to a wall above the toilet, is able to hold up to 2.2kg, easily detaches when you are leaving and does not leave any marks on the wall. You only need one hook and can buy large adhesive strips separately.

Yes, I have often forgotten them when travelling and many housekeepers around Europe must wonder about these wall hooks.

Hygiene - It is not always easy to be near a tap to provide clean-up water for the cone and plate so I always carry "Thick Baby Cleaning Wipes" with me. These are large, very moist and ideal for cleaning plastic surfaces as well as hands. They are available with a fragrance which assists in keeping down any odours. I always watch out for 'specials' so don't find the financial outlay too draining.

I always carry plenty of "Skin Lotion Tissue" to clean the stoma area when I travel. These are preferable to baby wipes as they don't leave any residue from additives such as Aloe Vera which tends to interfere with skin adhesion.

I also find that adhesive from the sleeve can build up on the plate holding the sleeve and causes discoloration. This is easily removed by the use of "Adhesive Removal Wipes/Spray" to keep your equipment looking perfectly clean.

Of course I find "Nappy Sacks" are the optimum disposal bag. Most have some fragrance so you are not so concerned about bad odour build-up.

Transport - Also, when away from home travelling by car, I carry all of my ostomy supplies in those very handy chiller/cooler blue bags that can be purchased very cheaply from most supermarkets. These are easy to keep clean, provide some protection against the effect of heat on appliance adhesive and quickly identify your ostomy supplies within a carload of luggage.

Odour Control - On these trips I also carry one of the bathroom/toilet spray trigger-packs that are available from supermarkets. These ensure that I leave the toilet clean and disinfected. I also carry a spray pressure pack to remove any odours. When combined with baby wipes, you can be confident that you will leave the toilet sparkling and free of odours.

I hope that this might add to the 'Gator's' travelling kit.

Jeremiah was a Bullfrog

Submitted by **Valerie Jack, NSW**

I really enjoyed reading the personal stories of other Ostomates in the August 2014 edition of *Ostomy AUSTRALIA* and I admire the way they deal with the problems associated with their stomas. One thing that is obvious to me is their great sense of humour. I just adore the "Tummy Bum" and many other imaginative and amusing names people have given to their stoma.

When my stoma first arrived it made noises which sounded to me like a bullfrog so I named him "Jeremiah". Jerry celebrates his birthday each year with a cake decorated with candles and a stoma made of icing! This reminds me that he saved my life.

Belts and Braces going through an Airport

Submitted by **John, WA**

Having a stoma since the end of June this year, I had a problem with my stoma being on my belt line so bought a pair of braces from Carba-Tec in Perth which work great. They freed up my trousers and jeans around my waistline and did not restrict my stoma.

Last week I went to visit my daughter in Sydney and decided to wear my braces. I didn't encounter much problem with the metal on the braces when going through airport security. I was put through the scanners at Perth and Sydney, had to remove my shoes and was then scanned with a hand held scanner, which I did not mind as it was for security reasons.

As I'm travelling overseas soon and will be travelling through a number of airports, I thought there must be something more airport-friendly. Perhaps something similar to how they replace the steel toe-caps in safety boots with a hard non-metal composite material.

An internet search found airport-friendly braces called "No-Buzz" which have composite clips and adjusters. These are USA-made and are available in Australia from Executive Accessories (PO Box 340 Greenwith South Australia 5125) - they also have a website.

You can also try a USA website (www.suspenderstore.com) which has a big selection of braces for US \$19.95 plus postage. They also have an Under Garment pair made of soft material which can be worn next to your skin for US \$15.95 plus postage.

My Tips for Managing an Ileostomy

Submitted by **P.B., QLD**

Initially I used a pouch with a viewing window (convex drainable cut to fit) and used small curved scissors to cut the wafer to fit, but now use a drainable pre-cut pouch as the size of

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REFERENCES: 1. Black P. Peristomal skin care: an overview of available products. British Journal of Nursing. Vol 16. No 17. 2007. Page 1054 2. Trio Protocol: PMS 002. December, 2007. Data on file. ConvaTec, Inc. 3. In Vitro: Trio Products 110099. Test Report AC-0170. July, 2012. Data on file, ConvaTec, Inc. 4. TR-PMS-013 Product Evaluation - Niltac Medical Adhesive Remover Spray & Wipe.

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my stoma has become more stable following surgery.

When changing I first cover the seat in the bathroom with an old folded towel and a large plastic bag. After using the toilet, I remove the old pouch and place it in a large plastic bag in a waste basket (for later removal to the dustbin), clean the stoma area with an adhesive remover and soothe the area surrounding the stoma with a special cream.

When showering I use a bland soap. Once dry, I sprinkle stoma powder around the skin next to the stoma then gently blow off the excess.

As I have a dip in the area around my stoma, I also prepare a very thin slice of curved thick seal which I first roll between my fingers and then, while standing facing the mirror and holding my stomach in, carefully fill the indentation with it. This helps to prevent leaks but it does take some practise.

With one hand I lift the fold of skin above the stoma, place a whole seal around the stoma (I use a thin seal, but this may vary according to a person's shape), then place a small roll of toilet paper in the pouch before pressing it in place.

Finally I place two side seals to completely surround the pouch, then place four pre-cut lengths of stretch tape over each side of the seal, under and above the pouch.

Although this is not infallible, it is certainly worth trying to overcome leakage difficulties and achieve some peace of mind.

Living Comfortably with my Stoma

Submitted by **John Samphier, VIC**

On 18th October 2014 it was fourteen years since I received my stoma and I quickly developed some easy processes to live comfortably with it. These simple procedures have helped me to eliminate skin problems around my stoma, reduce odours, aid digestion and makes living with my stoma very manageable.

1. I try not to eat any slow to digest foods after 6.30pm. Hence, almost all my food will have been digested and passed into the pouch by morning.
2. When showering each morning, I first empty the pouch but don't remove it until after entering the shower cubicle. I then wipe around the stoma with adhesive remover.
3. As I'm a fairly hairy male, every second morning I also very carefully shave the area where the pouch adheres. The pouch will stick better to shaven skin.
4. I then wash the stoma and surrounding area during normal showering.
5. Finally, after drying myself down to below the stoma, I use adhesive wipes before attaching a new pouch.

I hope this is helpful for anyone having difficulties. Once into a regular routine it is only an extra couple of minutes under the shower and you are in a position to easily clean up if the stoma decides to misbehave.

Early Detection can Save Your Life

Submitted by **Lynn Pearce, NSW**

My story started when, at the age of fifty-five years, I received a National Bowel Cancer Screening Program Kit. The test results reported some blood had been detected in my faeces and I should see my GP, who in turn said that I should have a colonoscopy. At the time I didn't know what a colonoscopy was, so he told me what was going to happen.

I tried to remain calm while waiting for the results after the colonoscopy. The doctor finally told me he had found a few polyps which had been removed but I also had rectal cancer and would need twelve weeks of chemotherapy. That was in May 2011. Then the fun really began!

I had to travel to a place called "Daffodil Cottage" in Bathurst to have my chemotherapy but thankfully it is a wonderful place with great staff. They really look after you!

So after I got through the chemotherapy, I had another colonoscopy to see if the chemo had worked. Unfortunately, the cancer was still active in my bowel and I had to see a surgeon to remove the cancer. That was also when I first met my Stomal Therapy Nurse who told me what was going to happen. It was all a bit scary.

I went into a great hospital for my bowel surgery, which went well and there was also a lot to learn about my new stoma. However, two days after surgery I was in so much pain and had to have an emergency repair for a twisted bowel. Then my biopsy results returned with poor news, showing that my bowel cancer had escaped.

After a lot of X-rays and CT-scans the doctor finally found the cancer happily living in my left lung. I then had to see yet another surgeon to have my lung cancer removed and went to another great hospital where all of the staff and the food were just wonderful. My surgery went well, but it did take a while for me to get better.

Now I have a CT-scan every six months as well as blood tests before seeing my chemotherapy doctor at "Daffodil Cottage". I still see the wonderful nurses there, who are now a part of my life. I also had my wonderful husband, my girls, family and friends supporting me all of the time that I was sick.

So if you get a National Bowel Cancer Screening Program Kit, please make sure that you do the test. It can save your life if a cancer is found early enough.

I love reading the articles and letters in our journal, and I have learnt a lot from them. Some of the stories can make you cry, while others make you smile.

The "Meet and Greet" and Regional NSW UOA Ostomy Information Days are also great. You learn so much and it helps you understand the new products on the Scheme, meet some wonderful people and of course, those great Stomal Therapy Nurses. So don't be shy, you are not on your own.

PS: If you see someone without a smile, give them one of yours.

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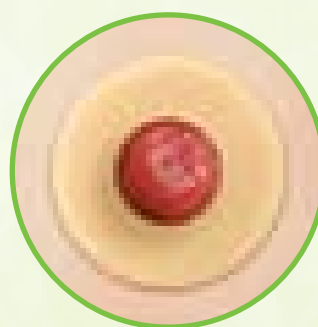
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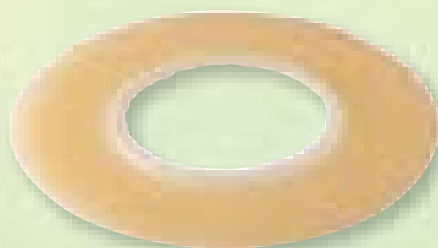
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LIFE IS MAGICAL

Submitted by: **Luke Escombe, SA**

.....

My fifteen-month-old son Harry is fascinated by my ostomy bag. He crawls across to me while I'm eating, reading or otherwise relaxing, grins impishly and whips up my T-shirt like a magician unveiling a trick: Ta Da!

He still doesn't quite know what to make of it. His eyes fill with wonder and then look up at me as if to say "what is this thing Dad and when am I going to get one?"

I'm happy to let him prod it for a while - after all it's nothing to be ashamed of - but as soon as he starts trying to rip it off I politely shoo him away and draw my shirt back down. Seconds later, with a shriek and a cackle, he is back at it.

Up. Down. Up. Down. It never ceases to amuse him.

Now he has discovered the location of my ostomy bag stash and his new favourite activity is methodically scooping up all my pouches and seals with his tiny pink pincers and plunking them on to the floor like discarded potato peelings. I pretend to be exasperated by this mischief, which only delights him further.

The truth is I am even more delighted than him. What a transformation has taken place in my life in the last eighteen months! To see this object - once the stuff of my worst nightmares - now turned into a source of childish fun is cause for unbridled celebration.

I was diagnosed with Crohn's Disease at the age of fourteen and suffered with it for twenty years without once giving serious thought to a surgical solution. I tried every medication available, and many more that had no scientific backing. I saw naturopaths and homeopaths plus possible sociopaths and psychopaths, and gave money to them all. I endured hospitalisations, abscesses, fistulae, months and months of bleeding and severe weight loss, being housebound for years at a time, things so bad I still can't quite bring myself to talk about them ... and yet whenever a surgeon suggested to me that all my misery could end if I just had my rotten intestine removed from my body I closed my ears and sang the same old protest song. Surgery? No way! The bag? Not in a million years!

The worst period of all also ended up being one of the most life-changing. In early 2009 I spent eleven nights in a hospital ward at St Vincent's in Sydney sharing a



.....

room with three old men with noisy bowel conditions. I'd been very sick for the last three months and had lost more than thirty kilograms. I looked like a skeleton with a moustache. Things were desperate.

The irony about hospitals is that one of the most crucial things you need to feel better is sleep, and yet hospitals seem to go out of their way to stop you getting it. All through the night there are lights blinking, alarms going off, people waking you up to take your blood pressure or

put tubes in your ear. Every morning at 6.00am, just as I was finally dozing off, the nurses would come in, fling the curtains wide and drain thirteen vials of my blood out of my arm with no explanation whatsoever. What did they do with the blood? No-one told me. But after ten days of this happening they told me I was low on blood and needed a transfusion. As I watched it trickling into me I wondered: "Is that mine?"

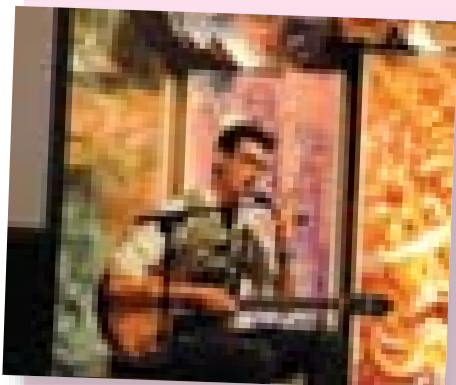
My wife, Kamilla, was an angel throughout this ordeal. I'm sure there are many of you reading this who could say the same about your own partner, at least I hope you can. To be loved in these circumstances is a miraculous and beautiful thing, more precious than anything in the world.

We'd married early, at the age of twenty-two, and our love had been severely tested just a year later. My initial Crohn's flare at age fourteen had been nothing compared to the first relapse in my early twenties. It's no surprise to hear that the guy who wrote that unforgettable dinner scene in the Alien movie had Crohn's (arm yourself with a sick bucket and YouTube it if you don't know what I'm talking about). It's like there is a monster living inside you, eating you from the inside out. The illness takes over your whole mind and becomes your whole world. Only an experimental and very expensive regime of heavy antibiotics saved me that time. It took three years until I was ready to face the world again. Kamilla stood by me throughout, albeit with some tough love towards the end



to lift me up off the sofa and march me out to face the world again. I'm so thankful she did.

The eleven nights in hospital in 2009 happened just months after the release of my first album. I'd been all set to go and live out my rock and roll dreams in Europe and the United States. Instead I spent night after night on my knees on a hospital toilet floor wrestling with a rectal prolapse. That's a letdown, in anyone's language.



A few months later I started writing songs again. Guitar is usually my instrument but I was too weak to hold one so I started messing

around with drum loops and keyboards instead. Soon I found myself with a whole new repertoire of quirky tunes, written in a style somewhere between funk, pop, comedy and hip-hop. I called it "Flip Flop".

In early 2011, I unveiled these songs at the Melbourne Comedy Festival in a show called "Chronic". I'd never performed comedy before and was terrified, but the fear was also good for keeping the Crohn's at bay. By now I was on an injectable medication called Humira that was also helping. I'd written a lot of "jokes" into the show that were mostly greeted with awkward silences, but one night I started talking about my hospital experiences and found that people were laughing. I was encouraged. The show got some good reviews and I was able to take it to the Edinburgh Fringe and then all around Australia. By the end of the year I was telling my story to a room full of teary-eyed politicians at Parliament House.

In early 2012, with my Crohn's just about under control, my wife and I started trying for our first child. It was also around this time that my gastroenterologist sat me down and told me I had a stricture in my bowel that could only be removed by surgery. Although she had always respected my decision not to consider it, she informed me that the benefits of surgery now far outweighed the risks. I could have a tumour hiding somewhere beyond that stricture and they wouldn't find it until it was too late.

A few weeks later Kamilla and I met with the colorectal surgeon. His recommendation was exactly what we didn't want to hear: ileostomy surgery with a

permanent ostomy bag. I bargained and pleaded for another option but to no avail.

In my comedy show, to make it easier to talk about the bag, I referred to it as the "iPad" (you know, it comes with a range of accessories and allows you to do your business on the go). I asked him if it would affect our chances of making babies? He said it might. That was all the reason I needed to delay the operation.

Not long after that I went for my first fertility test. It was a lot more fun than a colonoscopy.

Unfortunately, despite decades of practice, I flunked it, and so we now found ourselves plunging headlong into three bleak months of IVF consultations and treatments. Both of us fell under a heavy cloud of depression as we contemplated the very real possibility that, after all we'd been through together, we would not be able to have children.

When we got the news that only one of our embryos had survived the first cycle we were not hopeful, but our spirits were lifted when we saw our lone survivor on the TV screen in the implantation chamber. The cells had barely begun to divide in this tiny speck of life but already we began imagining its possible future – birthdays, first dates, high school formals and graduations. Two weeks later came the momentous news: we were pregnant.

When I woke up from the anaesthetic and saw my stoma for the first time I thought it was the most adorable thing I'd ever seen. Instantly I gave it the name "SpongeBob". Whether it was the relief of knowing that my rotten colon was now gone, the euphoria of taking such a positive step for our future, or (more likely) just the incredible amount of morphine and ketamine rampaging around my body, I felt delirious with happiness. My wife was sitting in a chair beside my bed, her belly swollen with our baby boy.

On 24th April last year Harry arrived into the world, early and urgent, and spent the first few weeks of his life with tubes up his nose and surrounded by beeping machines. This time it was me who was the strong, capable one, looking after him and his mother. Crohn's free and medication free for the first time in a decade, heavier, healthier and happier than I've ever been.

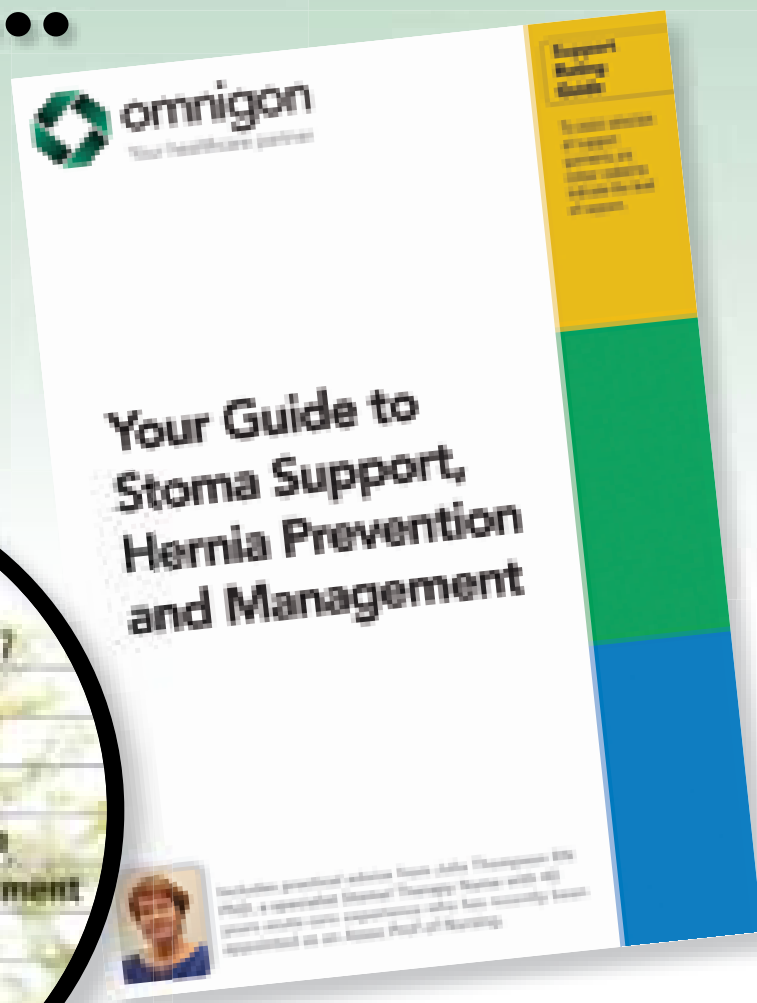


Harry, you truly are a magician. One day, I hope you will understand what a gift you have given me. Until then, play on you little rascal, your daddy plans to be around for a long while yet. ★

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

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

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

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A New Life

Submitted by: **Annette Shears**

"Hanna" was two years old early in October 2014 and I turned seventy years old in March. Without "Hanna" I wouldn't be alive to tell this tale.

In June 2012, I was diagnosed with bladder cancer. I was in shock. I had never smoked, but was always sensitive to the cigarette smoke of others smoking around me. I had recently retired from teaching English to speakers from non-English speaking backgrounds. I was otherwise very healthy, walked every day and was enjoying some voluntary work. My GP, who discovered the tumour, sent me to a wonderful surgeon who sent me to a wonderful oncologist. Although the surgeon had explained everything very clearly to me, it was only when I was with the oncologist as he outlined the chemotherapy prior to the operation that I seemed to go into shock. I could hardly walk out of the room unaided.

There was also one small problem - I was to be a delegate at a conference in Newfoundland Canada in September 2012. By the end of May, all the bookings for the conference, extra travel and travel insurance for me and my companions had already been paid, and with this diagnosis coming in June I thought I would have to find a replacement delegate.

I explained my problem to both the surgeon and to the oncologist, and the surgeon said that there was a 'window' between the end of chemotherapy and when the surgery was to be done but I had to be back by the first week of October. If I was feeling well after the chemotherapy then I could go, as it would probably do me good. The oncologist was also encouraging. Our scheduled arrival home was 2nd October and my surgery was set for 9th October.

Well, off I went with my array of head scarves and hats. Leaving Seoul airport I was asked by one of the staff to remove my scarf to which I said "No." So she felt around my head and decided that I was not hiding any weapons there and it was alright for me to board the plane. After that I wore a soft hat over my scarf and was only asked to remove my hat from then on.

Everything was wonderful - the three day trip over the Rocky Mountains, staying in Newfoundland, the conference and the trip to Niagara Falls. It only took a few days for me to get over my jet-lag, and for the last few days before my surgery I felt so fit and healthy that I wanted to call the whole thing off.

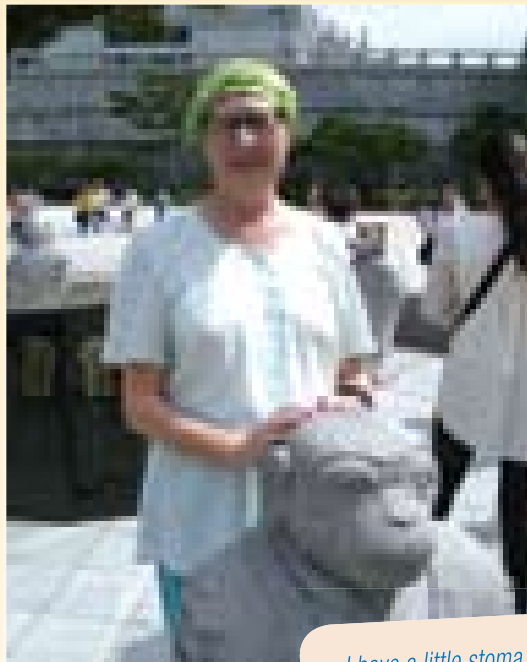
After surgery it took me some time to get used to having a bag and changing it under supervision. I often worried that I might hurt the stoma. I couldn't cope when they said it was

time for me to leave hospital and was allowed a few extra days before going home. After leaving hospital I was still very unsure of my ability to care for the stoma. For the first three weeks at home I set my alarm for 2.00am to empty the night bag, as I was afraid it would be full before I woke the next morning. Occasionally, it almost was!

I was gradually getting used to things, when in December, about two months after the operation, I became very depressed about the whole situation. I resented having the stoma, the extra time it now took to shower, change the bag, wash the night bag, clean up, etc every morning. I felt so bad, but thought "I don't want to be a grump for the rest of my life, but what can I do?" After a few days I got an idea that I should give my stoma a name. The name "Hanna" popped into my head and has made all the difference since then.

Over time I gradually got into a routine. However, I was still quite sensitive, imagining that people could see where the hernia poked out, so I bought some blouses that were big enough to hang out over my skirts and slacks. Now I don't care as I realise that people can't tell.

When the summer temperatures in Brisbane soared, I developed a red, itchy rash on my skin under the wafer that sticks the bag to the skin. Then the leaks started. I first tried cutting off the edges of some now-too-small pouches to plug the leaks. Then I contacted my Stomal Therapy Nurse and went to see her once a week for four weeks until we found a pouch with a base plate that was kinder to my skin and a cream that cleared the rash. Sometimes after removing the pouch so the nurse could check my skin, "Hanna" relished the new



*I have a little stoma, I call her 'Hanna dear'
She wees all day, through the night and right throughout the year.
Mornings when I change her pouch she's sometimes quiet and sombre
But then she does projectile 'wees' that sometimes hits the mirror.
I made for her pouch a little dress - I really hope she likes it.
It keeps my skin from getting itchy and makes Hanna look so pretty.
Hanna's now my lifelong friend, she's always there for me.
Her caring and devotion are wonderful to see.*

freedom and 'weed' everywhere - on the floor, down the wall, into the sink, all over my leg and foot. Just as well I always carry a clean pair of undies!

The problems gradually sorted themselves, except for the area where the new pouches came in contact with my skin,



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I Really Can't Eat Popcorn After All

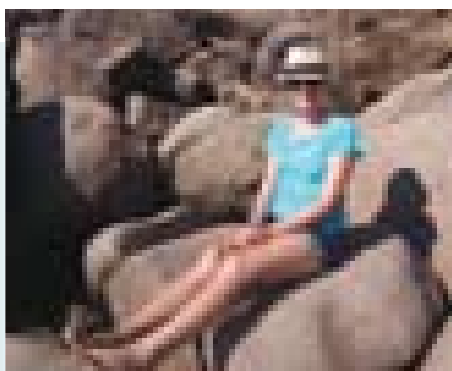
Submitted by: **Rachel, QLD**

My permanent ileostomy was created in Melbourne in November 2004, following a horrendous six-month battle with Ulcerative Colitis that stopped me studying, working, seeing friends, and being a normal twenty-year-old girl. In 2003 I had spent time in hospital with a potentially fatal lung condition and was well and truly sick of being sick.

Following surgery it took me a long time to get back to normal life, because I'd been unwell for so long. I slowly got used to eating normally again and returned to studying four months later. Most of my hair fell out, then grew back in ringlets, and then returned to normal.

My twenty-first birthday was six months after surgery and I was still pale but, as my uncle said at the time, I had the sparkle back in my eyes. Many of my friends and family members worked in health care, and easily took the news of my stoma in their stride.

In 2008 I finished my undergraduate studies in counselling and started working with vulnerable young people. I played netball, travelled to Bali (by myself!) and performed in amateur theatre shows. I finished postgraduate studies in youth mental health in 2012 and continued living my life to the fullest extent I could imagine. My father and I travelled around central Australia in a motorhome during October 2012 and had a sensational time, before I started my Master's degree in 2013 whilst working full-time. I am still



working with young people who have experienced trauma and abuse.

I dated a few people when I'd recovered from surgery, but didn't have any serious relationships. I had a particularly bad experience with a healthcare worker who told me that he didn't want to see me anymore when he learned about my stoma - very disappointing!

In January 2013 I met Ben and it was love at first sight. I agonised over when to tell him about my stoma, and decided to do so when our relationship was clearly going to become intimate. His reaction was remarkable - he was very accepting, and researched stomas when he got home. I'd invited him to ask any questions that he wanted to ask, but it appears that Google had already done that for me. In July 2013 Ben, who is an Australian Defence Force employee, was informed that he was being posted to Townsville. He came home and asked me to marry him - and of course I said Yes! We were married on August 31st 2013 in Melbourne, and began the long

drive to Townsville five days later.

I adore the tropical lifestyle in North Queensland where the year round warm weather suits me very nicely! I play netball twice a week, and Ben and I often go exploring in the great outdoors. My stoma does not inhibit me in any way - I swim, hike, take our dogs to the beach, spend time with my friends, travel, and enjoy every opportunity that comes my way.

Whilst I've had my share of leakages and explosions I've now found an appliance that suits my body, and I've learned (the hard way) that I really can't eat popcorn after all ... but if that's the worst thing, then I'll take a stoma over Ulcerative Colitis any day! ♥



Continued from page 16

which now became red and itchy. I solved that problem by making small cotton bags that slip over the pouch and make sure that there is no part of the pouch rubbing against my skin. It was quite a feat working out a design to accomplish this.

Occasionally I still get a leak. Sometimes it is due to a faulty pouch, which is far worse than one where the wee just makes its way to the edge of the wafer and escapes (these are fairly easily solved by using 'wings').

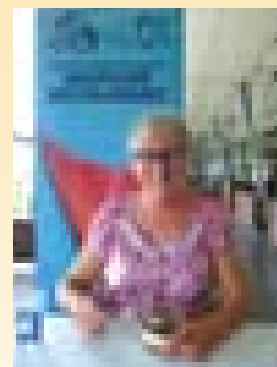
Being diagnosed almost a year ago with Diabetes Type 2 (which is being controlled by diet) has also complicated some aspects of my life.

It is now just over two years since "Hanna" and I became acquainted. Although early in the year I had a difficult prolapse operation, I am now back to walking each day and in May I took up my voluntary work again - helping migrants and

refugees with their English and adapting to life in Australia.

I have also managed a two week trip to Cairns - up by train and back by plane. I'm not into scuba diving but I did enjoy the trip in the glass-bottomed boat over the reef and the Skyway up to Kuranda. I was able to find a toilet every two hours so the trip went very well.

I have been very lucky with my GP, surgeon, oncologist, Stomal Therapy Nurse and, in fact, all the medical staff I came in contact with during my stays in hospital and during chemotherapy. And, of course I am grateful to "Hanna", because it is she who has kept me living. ●



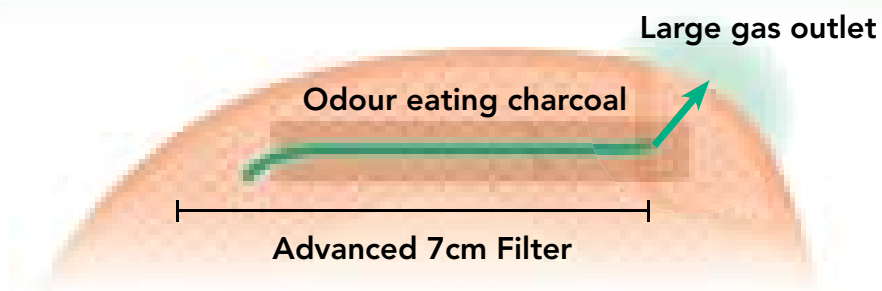
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LIFE IS THERE TO BE LIVED

Submitted by: **PT, Vic**

Six days after major surgery in May 2013 to remove the largest of four recurrent endometrial tumours (two and a half years post-hysterectomy), I was rushed into emergency surgery to repair a sudden bowel rupture. This was my second major surgery in less than a week, and I awoke from the anaesthesia to discover that I now had an ileostomy.

I will not lie to you. On top of having cancer and an enormous midline wound with forty-eight staples and gaping, infected wounds that would not heal, the ileostomy was more than I felt I could cope with. I struggled enormously, and unfortunately my experiences with the original Stomal Therapy Nurse were just not as positive or as supportive as I would have hoped. Sometimes life simply does not deal a fair hand, and I found myself traumatised by the new circumstances that I was now forced to face.

After three weeks in hospital, I returned home wondering whether I would ever adjust. My stoma was highly problematic, being located so close to the wounds along my midline; these needed packing and dressing almost every day for five months. Thankfully, my new Stomal Therapy Nurse at the local public hospital who took over care of my wounds was an angel and gave me all the information and support that I felt I had been missing up to that point. My beautiful neighbour, Pat, is also an Ostomate and was a tremendous support to me through this extremely difficult period of my life. I was deeply encouraged and inspired by her acceptance of her colostomy and the positive approach she always took to living an active and busy life full of purpose, fun and adventure.

I genuinely struggled to change my appliance, but I quickly discovered that playing one particularly soothing instrumental song on an iPod in the bathroom while I changed my bag helped me to relax and get the job done.



I also found that organising everything I needed into paper bag kits ahead of time when my supplies arrived helped me to be more relaxed and efficient when routine or emergency changes were needed.

My stoma leaked regularly and my skin was often raw, but I discovered products that would help me to manage the daily challenges with increasing confidence. I slowly began to heal enough to live more actively and even returned to work part-time. Because I struggled to accept my ostomy, only my husband, best friend, father and boss knew that I was an Ostomate. I wore long jackets at work which hid my bag-bulge, and mostly found ways to function in my job as normally as I could.

Yes, there were times that I needed to leave meetings part-way through to attend to unexpected leaks, but I found for the most part that I was able to manage my condition discretely. Each day confirmed that if I remained positive - sometimes even finding the humour in my situation - I could slowly begin to accept that things had changed, and that life could be lived more fully than I could have imagined, one day at a time.

Of everything that had been put on hold during my recovery, the thing I definitely missed the most was scuba diving. Eventually, I gathered the strength and courage to try diving with my ostomy, and I am proud to say that I did dive numbers 198, 199 and my milestone dive number 200 as an Ostomate!

I even found a little bit of courage that I never had before, allowing my husband and his friends to take me for a snow skiing lesson for the first time in my life! Within minutes I fell flat on my face - and on my stomach. But instead of panicking at the idea that my spectacular fall may have resulted in a conspicuous mountain-top appliance emergency, I laughed so hard that I could barely get up to try skiing down the little kiddy slope again.

Six and a half months after my emergency surgery, I was given the opportunity to have my stoma closed. Although I was desperate to have this operation, my internet research almost convinced me that a reversal might be scarier than living with the bag permanently. However, because I had never had radiation on my bowel, I decided to go through with the surgery. I fully anticipated the worst case scenario, that my bowel might never again work as it had previously, and that I might spend the next several years trying to adjust to a difficult 'new normal'. This frightened me enormously, but in the end, it was a risk that I was willing to take.

I cried with relief when I awoke from surgery to be told that the operation had gone well and I was amazed when my bowel remembered how to function properly just forty-eight hours after the surgery. I have never once had any sort of post-reversal 'accident'. Despite my initial fears, I was so glad that I had gone through with the operation, and



I am pleased to report that, just six months post reversal, I was able to celebrate my 250th dive last weekend.

Although my time as an Ostomate was challenging - and in fact I honestly consider it one of the most difficult experiences of my life - I learned that the human spirit can adapt to almost anything, and that by maintaining a positive attitude, we can find within ourselves the ability to rise above the things we fear the most. Yes, things are different with an ostomy, but life will go on if we allow it to. Whether we have a strong personal support

network or need to dig deeper into our own personal reserve of courage and strength, we absolutely can live a satisfying, adventurous life - stoma and all.

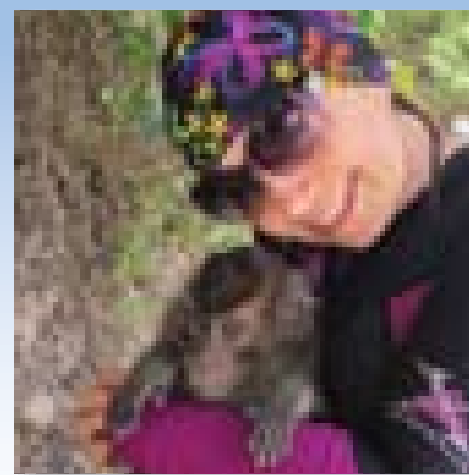
Whether you are just beginning your journey as an Ostomate, are living with a permanent ostomy or are in a position to consider a reversal, three things are true. Firstly, each one of us has a unique story and a unique set of experiences, and these should be understood and accepted, rather than feared. Secondly, some days are tough, and some days are tougher. But eventually, life just begins to feel a bit more like life again, and soon we may even find ourselves laughing harder than we ever have before, because now we understand the joys and challenges of life within its fullest spectrum.

Finally, when we remember not to let a little thing like a stoma define who we are, we can begin to reclaim our lives and live them in such a way as to discover, or rediscover, what brings us bliss and satisfaction. I am the same person post-reversal as I was pre-ostomy - and during my nearly seven months as an Ostomate. Now I spend much of my time

encouraging people through my blog - **www.pinktankscuba.com** - to rise above their circumstances and to live and celebrate their lives as fully as they can, regardless of their circumstances.

Even though I still navigate my personal cancer challenge on a daily basis, I believe that my time as an Ostomate has made me stronger, more determined and more appreciative of life while it is mine. My thoughts are with all Ostomates, whatever stage of your journey you may be on.

Remain positive. Seek help and support when you need it. And above all, embrace and live your life as fully as you can. It is there to be lived! ●



AASTN Patient Education Pamphlets

Submitted by: **Genevieve Cahir**, Stomal Therapy Nurse
AASTN Education and Professional Development Subcommittee

The Australian Association of Stomal Therapy Nurses' (AASTN) Education and Professional Development Subcommittee have over recent years developed a series of **Patient Education Pamphlets** for use by Stomal Therapy Nurses and as a resource for people with a stoma. They may be of benefit to many, such as, a person about to undergo surgery resulting in a stoma, for parents of a child with a stoma, or a person with an established stoma.

Please ask your Stomal Therapy Nurse for any pamphlet or you can access them online at the AASTN website (stomaltherapy.com) under the subheading 'Education'.

The Subcommittee would also value any feedback on pamphlets, which can be directed via email to fiona.bolton@calvarycare.org.au

These pamphlets are reviewed regularly by the Subcommittee and we would welcome any suggestions for future pamphlet development.

Pamphlets available are:

- Anal discharge following stomal formation
- Antegrade Continence Enema (A.C.E)
- Mitrofanoff Stoma Management
- Caring for your child's stoma
- Caring for your colostomy
- Caring for your ileostomy
- Caring for your stoma – a guide for teens
- Caring for your urostomy
- Eating and drinking for the person with a colostomy
- Eating and drinking for the person with an ileostomy
- Food, fluid and electrolyte balance for the person with an ileostomy
- Handy hints for the person with a stoma
- Perianal skin care
- A guide to preventing constipation.
- What is a Stomal Therapy Nurse?
- Healthy bowel habits for all
- Managing your stoma supplies
- Prevention and management of a parastomal hernia

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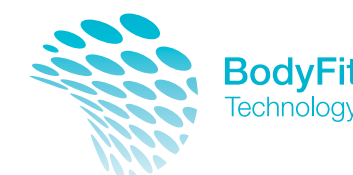
Amy, ostomate

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Report on the 2014 ACSA Annual Conference

The 2014 Conference of the Australian Council of Stoma Associations (ACSA) embracing the 14th Annual General Meeting and 45th General Meeting was held at the Hotel Grand Chancellor in Surfers Paradise on 10th and 11th October, followed by a social day on Sunday 12th. Delegates and observers from nineteen of the twenty-two national ostomy associations attended.



Norm Kelly with Councillor Margaret Grummitt

The Conference was officially opened on Friday morning by **Councillor Margaret Grummitt** of Gold Coast City Council. Councillor Grummitt addressed delegates and told them how important organisations such as ACSA were in bringing people together in a support capacity and thanked all associations for their dedication.

ACSA President **Peter McQueen** opened the Conference with information on the ACSA Executive activities over the past year and asked delegates to remember those that had passed away and to keep in their thoughts those former delegates currently experiencing health issues.

Lynda Hurley of the Department of Health spoke on the Stoma Appliance Scheme (SAS) and advised that eighty-five million dollars had been spent during the 2013/2014 tax year, with over 40,000 people accessing the SAS which covers 420 products and 2,000+ variants of these products.

The Computer Systems Review Committee, who were tasked at the 2013 Conference to identify computer software able to support the current and future requirements of Associations, reported that they had

identified the TOMAS computer software as suitable. This software has been purpose built over the past few years by a third-party software company for Ostomy NSW Ltd. The Committee's proposal for ACSA to purchase the TOMAS system was approved by Conference Delegates and is to be implemented at Associations over a two year period once its purchase has been finalised.

Our first guest speaker, **Sheryl Waye STN**, (principal Stomal Therapy Nurse at the Gold Coast University Hospital) shared some of her interesting experiences when assisting in a Nurse Training Team that visited Kenya earlier this year.

Another of our guest speakers, **Dianne Jones OAM** (Nurse Unit Manager of the Endoscopy Unit at Logan Hospital in Queensland), took us on an Endoscopy Technology journey starting from the very basic equipment available over a century ago, through to the modern miniaturised and robotic technology available today, and then onto the next generation of technology which is just around the corner.

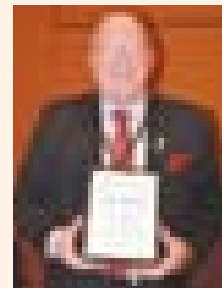
Mrs **Janet Yaki**, Founder and Interim President of the Papua New Guinea Stoma Association, also provided a very interesting talk on the daily struggles of Ostomates within Papua New Guinea. Lack of ostomy appliances generally mean that most must cope as best they can and many are ostracised from their communities. Thankfully, the Gold Coast Ostomy Association has been able to provide some support by sending surplus ostomy products which Janet carefully distributes to those most in need. Though nowhere near enough supplies for all, it is a vast improvement for those lucky recipients.

Representatives from each of the major ostomy product supply companies were involved in panel discussions covering issues such as delivery chain and back-order problems, the imminent change to their delivery freight costs, and other opportunities for service improvement.

The final stage of the Conference saw **Geoff Rhodes** (ACT and Districts Stoma Association) elected as our new ACSA President and **David Munro** (Queensland

Stoma Association) as the new ACSA Vice President. Current officeholders were reappointed to the remaining Executive positions.

The Conference concluded with the presentation of an ACSA Life Membership award to **Peter McQueen** (former ACSA President) for his outstanding contribution to the welfare of Ostomates and his service on the ACSA Executive Committee for over eighteen years.



Peter McQueen



L to R: David and Annette Munro with Carol and Geoff Rhodes

In closing the Conference, newly elected President **Geoff Rhodes** thanked all of the Ostomy Associations within Queensland for hosting the Conference, and all Delegates and Observers for their contributions.

Interspersed across the Conference's business agenda, several enjoyable social activities 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 new-comers to the annual ACSA event. The traditional Saturday evening Conference Dinner Dance provided a great meal and many enjoyed dancing well into the night. Sunday saw many of us cruise up the beautiful Broadwater on a tall ship to McLaren's Landing and were then treated to a sumptuous lunch within the beautiful surroundings. After a slow trip back to Surfers Paradise it was time for our final farewells until next year.

The next AGM and General Meeting of Council, to be co-hosted by South Australia's two ostomy associations, will be held on 16th and 17th October 2015 at the Stamford Grand Adelaide Hotel at Glenelg. ●

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Diagnosed with anal cancer in May 2007, I am pleased to say that even though I had no private medical insurance, my case received the utmost speed and assistance. I had three specialist doctors - an oncologist, a radiation doctor and a surgeon. After the initial surprise of the diagnosis I then suffered the additional shock of discovering that I was to have a colostomy. I, like many others, imagined that this would be much worse than it in fact turned out to be. I hope that any readers faced with this challenge will feel more able to cope after reading this.

My operation, under general anaesthesia, was pain free and I was in hospital for only four days. I then went on to have both chemotherapy and radiation, running concurrently. All the professionals on my case were absolutely amazing in every way.

I have heard others say that having cancer changed the way they look at life. Now I know what they mean. I was ready to do whatever was required in order to survive, facing up to whatever I had to do in the spirit of understanding what would be happening and why. I had complete trust in my doctors and it was not misplaced. Though the radiation was daunting, I was happy to find that there was no pain accompanying the actual treatment. As the weeks progressed I had quite a bit of discomfort in the region of my anus and associated areas. A lovely occupational therapist made me a special cushion which helped a lot. During the period of intense treatments I adopted a "one day at a time" attitude which served me very well. I used to say to myself "Today is alright, yesterday has gone, and tomorrow is not here yet". I also made it a rule not to fight against things I could not change. That way I was able to give time to the things that I had to do.

One thing that I did not hear people talking about was how to keep your partner's spirits up as well as your own. My partner, Peter, has an aversion to all things medical which was a worry as I spent lots of time in hospital and he even found that visiting me was a trial for him. However, he managed very well to overcome his problems and I attribute that to the attitude I maintained during that time. On the plus side, it really helped me to get through because I was too busy keeping his spirits up to worry about myself.

Initially I had to get over my feelings of being a "broken thing". I honestly felt broken! I had also worried about my partner's attitude towards me but that did not become a problem. I am so lucky to have a partner that loves me unconditionally, and that includes the fact that I now have an ostomy bag.

His acceptance made me feel whole again.

In between everything else I was learning to cope with a very retracted stoma. I have never come across much help and have read little about coping with a retracted stoma, so for the most part, I have worked out my own strategies. I do not know the percentage of Ostomates with retracted stomas and I would be interested to find out.

As most readers will know, at first it is very much a case of trial and error. I am a proactive person so I quickly contacted the various ostomy appliance manufacturers and their help in sending samples was invaluable. I have to use a concave bag, which is just as discreet as the flat ones. I also use mouldable seals which are a godsend. I have to mould them very specifically as my stoma is misshapen and, following surgery three years ago, has a deep scar line to one side.

Like everybody else, I had my share of accidents to deal with in the early weeks but I soon learnt to be ready for anything and not to take any chances. I always carry two changes in my handbag and nowadays rarely need to change when out and about, but there will always be the unfortunate case when you need both of them.

There is also the problem of output consistency, which in my case can vary from hard little lumps to very runny, and sometimes all in the one day. During constipated times I am often in danger of "pancaking", while during times of a loose bowel I get "ballooning". Somewhere between these two I have a halcyon few days when all goes well.

Despite all these problems I lead a very active life. I have managed bag changes in the confined spaces of aeroplane toilets, once on a toilet at the back of a bus, and in public toilets here and there. The public toilets are the most challenging as they have nowhere to put things down, are often badly lit and do not offer the means to wash one's hands properly. It is so easy at home because Peter has put lovely shelves in our own toilet.

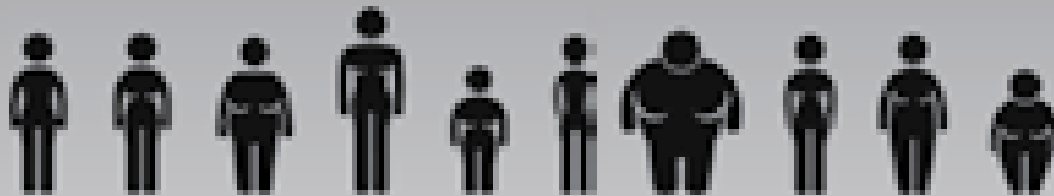
So, seven years into my stoma adventure, I am fairly confident and can spot a problem before it becomes really dreadful. I regularly direct plays for our local theatre group, am a volunteer driver for our elderly support services and a member of the Red Hat Ladies. I also won a prize at a Red Hat Ladies meeting for having the most unusual

item in my bag; I bet you can guess what it was!

Good luck to all you Ostomates! Isn't it lovely that our description includes the word "mates", because that is what we truly are. ●



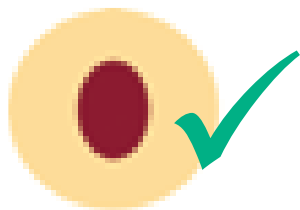
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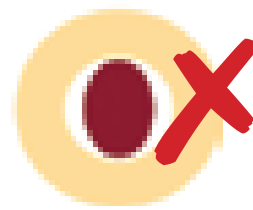
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1. *I am planning on travelling overseas early next year and am a little worried about my ostomy being picked up during a full body scan. As an Ostomate, can I ask to be excluded from the screening requirements?*

Unfortunately, no. Having a stoma does not exclude an Ostomate from having to participate in the body scanning process.

When leaving Australia by air, you may be selected to undergo a body scan as part of the security screening process. Fortunately, the Australian Government does have procedures in place when dealing with ostomy patients to ensure that the privacy of those patients is respected. According to the Government's TravelSECURE website, if you are selected to participate in a body scan, a screening officer will ask you to enter the scanner. You will then be asked to stand with your legs a shoulder-width apart and with your hands raised above your head. You will be required to hold this position for approximately two seconds while the scan takes place.

You will then be asked to exit the body scanner. The screening officer will show you the results of your scan on the body scanner control panel. The control panel will display a generic human outline with a box overlayed on the area of the body where your stoma is located. The screening officer will ask you if you know what the body scanner has detected. If you wish you can ask the screening officer for this conversation to take place in a private room with a screening officer of the same gender. The screening officer may also use a hand held metal detector and/or explosive trace detection test to clear the ostomy pouch. You will never be asked to show your stoma or ostomy pouch, and a screening officer will never touch these items.

Obviously this process only applies to departure through an Australian airport and you may find that procedures are quite different in other international airports. When travelling internationally, it's wise to carry with you a "Travel Card" which is a pocket sized card explaining your condition in several different languages. Travel cards can be obtained by request to the association of which you are a member.

2. *My ageing Italian father recently had stoma surgery and I am seeking any information that I can give him to help him to understand about living with a stoma. Are there any information sheets translated in Italian? He cannot read or speak English.*

The Royal District Nursing Service (RDNS) website has a series of stoma care fact sheets available which have been translated into Italian, Greek, Macedonian, and Vietnamese. Subjects covered include the role of the Stomal Therapy Nurse, a guide to eating and drinking with a stoma, caring for a stoma and hints for patients with a stoma.

Fact sheets can be downloaded from **www.rdns.com.au/services-we-provide/information-in-other-languages/translations**

3. *I have developed quite a large hernia and my specialist has recommended that I wear a hernia belt to help stop the hernia from getting any worse. He told me that I should be eligible to receive a hernia belt through the Stoma Appliance Scheme but when I placed a request for a belt with my association my request was denied. The reason they gave was that I have already received six pairs of support pants this year. A hernia support belt is completely different to pants so why are they treated as the same thing?*

The maximum entitlement of support garments that a member can obtain through the Stoma Appliance Scheme is three (3) full units of support garments per calendar year.

Support garments include all hernia support belts, waistbands and support pants. The unit weighting of support garments does differ depending on the garment type, which means that you may be able to obtain more of one style of garment per year than another.

For example, one Omnigon hernia belt or one pair of Statina Healthcare Corsinel is equal to one full unit of support garments whereas one pair of Omnigon or Ainscorp support boxers or pants is equivalent to a half (0.5) unit of support garments. Members can choose to obtain a combination of support garments as long as the total unit weight received during a calendar year does not exceed three (3) full units.

As you have had six (6) pairs of support pants this year, you have received your full entitlement of support garments for the current calendar year (ie. 6 pants x 0.5 unit weighting = 3.0 full units). Your entitlement will reset in January 2015 at which point you will be able to order your hernia support belt.

If you need the belt before January, you do have the option of purchasing a garment through your association. ●

Please send your "Ask Kylie" questions via email to feedback@australianstoma.com.au
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New Bowel Cancer Support Group

Concord Hospital, Sydney

Submitted by: **Sonia Khatri** Colorectal Cancer Nurse

A Bowel Cancer Support Group has recently been started at Concord Hospital. There are limited support groups specifically for individuals who have been diagnosed with bowel cancer in Sydney despite this cancer being the second most common cancer affecting people in Australia.

The group is open to individuals who have recently been diagnosed with bowel cancer, currently having treatment or have finished treatment and feel life is not the same. The group encourages all carers and partners to attend.

It is a free service held monthly on campus providing professional support and advice.

Benefits of joining a support group are:

- Knowing you are not alone – a sense of belonging
- Share feelings and experience with other people
- Obtain up to date information from health professionals
- Learn coping skills in a non-judgmental and safe atmosphere

David has been attending the support group for the past few months.

"Having the opportunity to be part of a bowel cancer support group has allowed me to see that people from all walks of life

are affected by bowel cancer" David says. *"There are people of different ages, interests and personalities, all brought together by*

a common struggle. Yet we are able to encourage each other and be encouraged by each other. And that is invaluable. We hear from medical experts with insights that will help us lead healthier lives. And we share our own experiences, support each other, and learn together."

The group is co-facilitated by a Colorectal Cancer Nurse, a Stomal Therapist and a Clinical Psychologist. The meeting format includes open discussions and information sessions with a range of health professionals.

Meets: Thursdays 11am to 12 noon

Venue: Level 7, Medical Centre, Concord Hospital, Hospital Road, Concord

Meeting Dates for the remainder of 2014:

- 20th November
- 11th December

Contact: **Sonia Khatri** (Colorectal Cancer Nurse)

Phone: **(02) 9767 5943**



From left to right - Ian Whiteley (Stomal Therapy Nurse), Sonia Khatri (Colorectal Cancer Nurse) and Sue Butler (Clinical Psychologist)

Bulletin Board

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Full particulars and Seminar registration details are on page 39.

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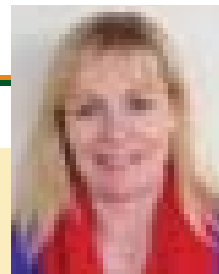
North: Meets 10.00 am on the first Monday of Mar - Jun - Sep - Dec at the Cancer Support Centre, 69 Howick Street, Launceston.

North-West: Meets 10.00 am on the second Monday of Mar - Jun - Sep - Dec at the Ulverstone Senior Citizens Club, 16 Edwards Street.

Please contact **Adrian Kok** for further information on **(03) 6326 4664**

AASTN President's Report

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



As you read this summer will have arrived, which is a welcome change to winter for myself and my family. A less hectic time and an opportunity to enjoy all that the mountains and lakes provide in the summer months.

Many of the AASTN Executive have travelled extensively this year, taking in conferences and the sites that the host cities have to offer. I had the opportunity to meet the lovely Mary Gordon from Eakin in Belfast. The Eakin factory is located in a field (or paddock as we would say here) about half an hour drive from Belfast. It's a quiet country town, quite unassuming for such a large worldwide business. My husband and I had a grand tour of the Eakin factory and their just completed new premises. It was truly fascinating to see how the products are made. Of particular interest was the quality control that goes into each of the seals and fistula appliances. Each individual piece is checked by a person, then boxed and sent throughout the world. The company remains family owned, and it was quite evident that they look after their staff, with many living close to the factory in the little hamlet. Seeing their factory plus beautiful Belfast and the Antrim Coast was certainly one of the highlights of my trip.

In the last six months I have enjoyed the opportunity of a couple of different roles. One of these was as a Lead Nurse Educator with the Sister Alison Bush Mobile Simulation Unit, a NSW Health-owned asset that travels to rural, remote and regional areas, providing education through simulation to the nurses and medical staff in those areas. I travelled around my Local Health District for three months providing educational sessions to all levels of staff, NSW Ambulance and Justice Health. It was a great opportunity for me to see how other sites are managed and to work with other components of the NSW Health system. You may have seen their very colourful truck at your site or driven behind it with its two emus watching you as you drive!

Simulation is the future of nursing and medicine. It provides for realism to situations,

clear learning intentions, and allows for peer work, involvement and discussion/debrief about the tasks. Stoma Therapy Nurses are very much about simulation to provide the best possible outcomes for you, the Ostomate.

I'd like to take this opportunity to wish you a Merry Christmas and a Happy New Year. If you are travelling on the roads, please take it easy. Till next year, Kirsti. ●

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Emma's Story **TO HELL AND BACK!**

Submitted by: **Emma Kilpatrick**, VIC

My story began when I changed doctors due to a misdiagnosis of IBS, after I had been suffering bouts of gastro for over a year. My new doctor sent me to a gastroenterologist for an MRI and colonoscopy, and I was finally diagnosed with Crohn's Disease in April 2005. However, by then I was in constant pain and had a hard mass in my abdomen. I couldn't even eat soup on some days without a reaction and had diarrhoea daily. I was put on steroids and tried a couple of different drugs but nothing seemed to reduce my pain or the symptoms.

In early August 2005, I awoke with immense pain. My gastroenterologist admitted me to St Vincent's Private Hospital in Melbourne where I had my first bowel resection, after which my bowel stopped working. I was in hospital for eight long days and nights and it took me a good year to get over that operation. I was left angry and confused and did not really understand the disease at that stage. I thought that cutting it out would be the end of it.

I didn't have any major flare-ups for around two years, but I also didn't stop working two jobs and doing my music. Working two jobs allowed me to fund my music and I was very good at pushing the limits, but living on adrenalin only lasts for so long. I would have bouts of diarrhoea, take my medications and then stop them when I felt better. Though mild it still disrupted what I ate and my everyday life. It appeared 'normal' to me, as I had lived with diarrhoea for years.

After marrying in March 2009, I started a new retail job but had a boss who I found to be very difficult. Through the year I started getting sick and pain developed in my rectum. By the end of the year I



was hospitalised with the pain and could barely sit or walk. After a colonoscopy my surgeon advised me I had severe rectal Crohn's. However, I still didn't quite understand what 'severe' meant. It took me a few years to actually live through severe Crohn's to realise that was what I was experiencing. I wasn't even taking any pain relief at that point, just endured the constant pain and discomfort. I would literally cry in pain every time I went to the toilet.

In 2010, I was working full time in a government contract role but had to reduce my hours through the year. During this time I started losing control of my bowel and my weight dropped ten kilograms. By March 2011, I was so ill that I was in and out of the hospital every couple of months having scopes to keep an eye on the rectal area. The ulceration in my rectum was damaging my sphincter and other upper bowel muscles.

I also had a brother battling melanoma cancer at the time and managed to fly back to New Zealand in early May to sit with him until his last breath. I flew back to Melbourne the next day for admission for yet another scope. As they wheeled me into theatre that Monday morning I cried so much and was filled with grief. I had seen my brother only four months earlier at Christmas and the shock of his skeletal frame and

death was just too much for me to handle.

My surgeon performed a flexible sigmoidoscopy (which is a scope of the lower region of the large colon/rectum) and suggested that I needed an ileostomy to give my bowel and rectum a rest. A Stomal Therapist visited but I was not in the right headspace for it. I just didn't want to know about my Crohn's and certainly not about getting a bag.

The next few months were a real struggle. I was dealing with grief as well as constantly racing to the bathroom. I couldn't venture far from home nor eat much. I changed my diet several times but the Crohn's just got worse and spread. I tried cutting back on gluten, dairy, alcohol, sugar and caffeine but the disease went rampant instead of improving. I tried hard to find something that would ease the symptoms but nothing worked. I spent thousands of dollars on alternative therapies too (homeopath, herbalist and naturopath) and learnt to look after my immune system and what the disease was actually doing to my body. No matter what I tried, the Crohn's spread in my ileum and sigmoid, as well as leaving the inside of my rectum red raw. I was having accidents up to five or six times a day and was constantly rushing to the bathroom. The pain and smell were awful but it was now part of my daily life. I constantly had to wear thick pads and have spare underpants handy.

In November 2012, I was hospitalised again in unbearable pain. My gastroenterologist changed my injection drug to the last option - 'Infliximab'. Both my specialist and surgeon warned that if this didn't work I would need to get a bag.

I had three good months over

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TO HELL AND BACK!

the Christmas period on the new infusion drug and hadn't felt this good in over two years. I was able to go out and see friends without worrying, and started swimming for the first time in years. My doctors had warned me that as my colon healed it may close up due to scarring, so waste couldn't push through easily. Sure enough, it did. I would go days without shifting my bowel but had mucous leaking constantly followed by a horrid session convulsing over the toilet emptying my bowel.

I finished my government contract at the end of March 2012, hoping for a good rest but in early May was instead hospitalised for three nights as I was turning yellow, was very weak and dehydrated. I spent a week in bed vomiting and having convulsions when I went to the toilet. The Crohn's was now throwing off secondary inflammations too and I was getting arthritis in my legs and body sores all over me. I also had four dermatologists inspect my body who confirmed it was all autoimmune related. My surgeon and gastroenterologist then performed a flexible sigmoidoscopy and both suggested I needed a stoma. At this point I was begging for it and had known for a few weeks that this was inevitable.

I had my ileostomy operation on 9th May 2012 and was in hospital for thirteen days. I had a nasogastric tube down my throat as my bowel had stopped working. Until my stoma started working, bile and gas built up inside while the tube drained my stomach. I had a four day Icy Pole diet along with constant hot water bottles and lots of morphine for the pain.

I'll never forget my surgeon visiting me a week after my operation. I was in tears with that tube down my throat and the wind pain, but he told me I had turned the corner and to just hold on a bit longer. My stoma started working



that night. In the meantime, I was still emptying via my colon so my bottom was very sore. I remember one morning I struggled to go to the bathroom with my ostomy bag, drip bag, nasogastric tube/bag and one other bag hanging off me. I collapsed on the toilet in tears and rang for the nurse. It was all just too much.

When I did get home, I recovered well from my ileostomy and adjusting to it took a few months. I also developed a rare condition called 'pyoderma gangrenosum' which ulcerated the skin around my stoma. It was awful pain and the ulcers wept so I had to change my bag daily and was taking painkillers around the clock at this point.

Six months after my operation I finally got some part time work as things settled down.

Unfortunately the ulcer in my rectum caused my colon to start closing up and I was getting a build-up of mucous and bloating. I put on way too much weight despite going to the gym and swimming. After a number of dilations and scopes my surgeon booked me in for a proctocolectomy and I had my large colon and rectum removed on 25th July 2013. The operation took four hours and thankfully was a success. It was nowhere near as painful as when I had my ileostomy or bowel resection. I was in hospital for a week and my bowel didn't go to sleep this time, which was a huge relief.

About a month after, my rectal wound opened right up and I was readmitted to have a vacuum dressing installed, which is one of the most painful experiences ever. I had the vacuum dressing in for over five or six weeks including two weeks in hospital and then home nurse visits after this. I had to be readmitted at one point as my rectal wound bridged over, which was opened again under sedation and I spent another nine days in hospital with a vacuum dressing reinstalled. Then I had problems with homecare and was readmitted a third time. I reached my limit that day and couldn't stop crying for hours. I spent another four days in hospital before I went home vacuum-less and received home nursing for a further few weeks.

But it wasn't over just yet! Six months after my proctocolectomy an infection started leaking from my umbilical wound and I spent a couple of days in hospital. A CT-scan showed that I had an infected tract under my skin. As I had a USA trip planned for March 2014, my surgeon asked me to manage this with antibiotics and steroids for three months, and would see me after my trip. After the surgeon cleared the infection it wouldn't heal so he did a wound debridement on 1st May 2014. He also confirmed he had checked my stoma and small bowel and there was no sign of Crohn's. My blood tests had been clear for a few months, which was a huge relief.

I was discharged with a pack dressing and home nursing was again organised. That next morning I woke with a bad pain between my stoma and umbilical wound, and was in horrible pain by the time we got to Emergency. My husband held my hand for over seven hours as I cried and hyperventilated from so much pain. They kept giving me morphine shots but this didn't help much as my tolerance to pain and the drugs was high. After four very painful days I had further surgery, then had

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TO HELL AND BACK!

a vacuum dressing installed on my umbilical wound and was given strong antibiotics that caused a red rash all over my face and collapsed my veins.

I was sent home after ten days in hospital. The hospital organised wound specialists to visit and assess me and my Mum flew over from New Zealand to look after me. But I was home barely twenty-four hours before I again woke in pain and we rushed back to Emergency at 4.30am. Nothing was found with a first CT-scan but I asked them to scan again with me on my side, which allowed the radiologist to push the contrast dye further into my abdomen and find the connection between my stoma and the umbilical infection. My surgeon explained that he suspected a pyoderma had attacked my umbilical wound shortly after my proctocolectomy and the solution was to sew the base of the stoma and block off this connection.

So on 16th May I had my fourth surgery within five weeks. My surgeon debrided my umbilical wound and where the infection had started. I also had stitches around my stoma. I spent another ten days in hospital and went home

with a pack dressing. The hospital organised wound specialists for homecare and I had another vacuum dressing for nearly three weeks. I was able to go to work but for limited hours with my vacuum dressing in a shoulder bag. It was frustrating and embarrassing but my workmates were accommodating. At least I wasn't in hospital anymore!

Slow healing and wound breakdown are all Crohn's related. Even though I now didn't have active Crohn's, it had still affected my white cells and immune system. I kept up with my supplements to help but time was really the answer.

I spent fifty-seven nights in hospital over ten months. At times I didn't want to go on and the only thing that kept me going was the fact that I was Crohn's free for the first time in over a decade. My whole spirit has been tested and it has taken every bit of strength inside me to keep going. I still break down and cry at times but just allow for these moments. I am blessed to have such a loving family and friends. Support is especially important for recovering in those dark days.

While in hospital I wrote a song called 'The Dark', and released it online in September 2013 to help

raise awareness. I had kept video blogs since the day of my ileostomy, mainly for my own therapy but since making them public last year it has been incredible receiving response from people – many cry when they watch them. I don't want sympathy, just empathy and understanding. Being sick is tough but so is the surgery. My video blogs are raw and honest and some contain coarse language but they might just help a person that suffers from an IBD and/or has had surgery.

Despite this rocky road, I now love being an Ostomate and wouldn't want to live any other way. I will never forget the pain and just how debilitating this disease is. I may have been to hell and back a couple of times over the last few years but the end result is far better than when I was sick. I can now live without fear. I can live at ease and I can finally have some kind of quality of life.

I am now hoping to get involved at my hospital and/or get qualified in the medical field to use my experience to educate and help others. I feel that it's now my turn to help others and raise awareness of Crohn's Disease and living with an ostomy. ●

Smile A'While

English is a Crazy Language! Something to think about...

There is no egg in eggplant, nor ham in hamburger, and neither apple nor pine in pineapple. English muffins weren't invented in England nor French-fries in France.

It is a language of many paradoxes: quicksand can work slowly, boxing rings are square and a guinea pig is neither from Guinea nor is it a pig.

In what other tongue do people recite at a play and play at a recital? Ship items by truck and send cargo

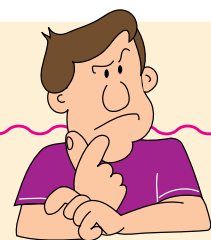
by ship? Have noses that run and feet that smell?

How can a slim chance and a fat chance be the same, while a wise man and a wise guy are opposites?

How can your house burn up as it burns down?

Why do you fill in a form by filling it out and how does an alarm go off by going on?

Why is it that when the stars are out they are visible, but when the lights are out, they are invisible? ☺



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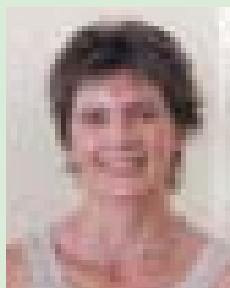


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Nutrition for Ostomates

Submitted by: **Margaret Allan**, VIC



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

Margaret is based in Melbourne and is available for clinical and telephone consultations by

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



In this article Margaret discusses dietary solutions to prevent Urinary Tract Infections.

Urinary tract infections (UTI's) are one of the most common bacterial infections and can result in a person feeling very unwell with substantial suffering if the infection is severe. The prevention of urinary tract infections is important for Ostomates and non-Ostomates alike to prevent damage and scarring to the kidneys. Poor management of and recurrent UTI's can lead to chronic progressive renal damage, renal failure and the development of hypertension.

The urinary system is comprised of several muscles, organs, and nerves which collect, store, and release urine. The kidneys form urine by filtering waste and extra water from the bloodstream. The urine is carried through the ureters to the bladder, and the bladder stores urine until you are ready to empty it. The bladder opens into the urethra, the tube which allows urine to pass outside the body. Sphincter muscles, which are circular muscles at the end of the urethra, close tightly to keep urine from leaking inappropriately. When you are ready to urinate, the brain signals the sphincter muscles to relax and, at the same time, the brain signals the bladder muscles to tighten, squeezing urine out of the bladder and creating a strong urinary flow.

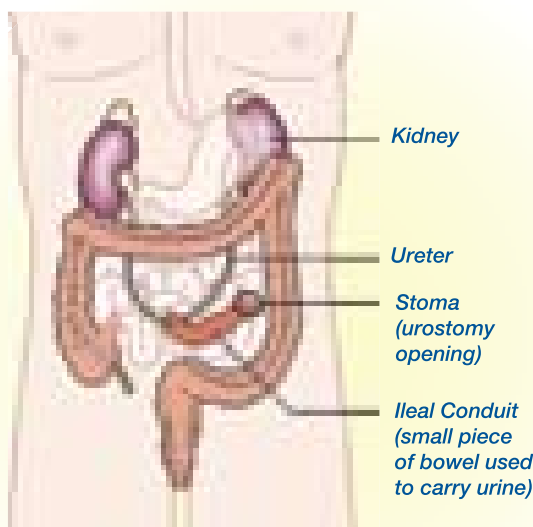
A UTI can occur when there are an excessive number of bacteria in the urine; usually more than 100,000 per ml. Infection arises from bacterial proliferation (growth), usually of E.coli, within the otherwise sterile urinary tract. Not all bacteria in the urine will cause a UTI, and some people do not experience illness when they have bacteria in the urine. Most UTI's have an ascending route of action, meaning that once the bacteria have established themselves in the urinary tract, they tend to travel in an upward route towards the kidneys, which places them at risk of infection, damage and scarring.

In the case of urostomates, the bladder has been removed and a segment of bowel tissue is used to create a conduit between the kidneys and the stoma on the skin. The muscles that assist in storing and releasing urine from the bladder are also removed. A lack of muscles that usually assist with urine flow means that urine output is not controlled and therefore constantly 'dribbles' through the conduit as it is produced by the kidneys.

A strong urinary flow from the bladder usually assists in preventing UTI's by washing away any bacteria. However this functionality is no longer available for urostomates, which may create a greater opportunity for pathogenic bacteria to attach to the walls of the urinary tract. Bacteria are also commonly found in the urine of urostomates because bowel tissue is used to create the conduit for the passage of urine.

A variety of antibiotics are commonly used for the prevention and treatment of UTI's, however antibiotic resistance may develop so it is important to look at other options to reduce the incidence.

Drinking additional fluids increases the amount of urine produced by the kidneys on a daily basis. With increased urine production, the urinary tract is flushed out more thoroughly. This can impede the adherence of pathogenic bacteria to the urinary tract walls and also flush out mucous that is produced by the intestinal tissue that was used to make the urinary conduit. Water, herbal teas and fresh vegetable juices are all appropriate fluids to consume. Aim to drink at least 30ml per kilogram of body weight each day, but check with your doctor if fluid balance is an issue or concern. Sugar can encourage habitation of the urinary system by undesirable bacteria, so soft drinks, alcohol and concentrated fruit juices and drinks should be reduced or avoided.



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Urinary irritants such as caffeinated beverages (coffee, tea, cola, cocoa), alcohol and spicy foods can also upset the harmony of the urinary system and should also be reduced or avoided. Signs and symptoms of inadequate fluid intake include thirst, dry mouth, dry lips and dry skin, as well as headaches, fatigue, irritability, poor concentration and constipation. Urine may also appear dark and cloudy in colour.

Refined carbohydrates found in white bread, white rice, and white flour products such as cakes, muffins, biscuits, etc can have the effect of suppressing the function of the immune system, making it less able to fight infection. A diet that incorporates whole grains, complex carbohydrates, fibre, fruits, vegetables, garlic, onions, cold pressed oils, fermented dairy products (such as yoghurt and kefir) and good sources of protein is more supportive of a strong immune system.

What is "Kefir"?

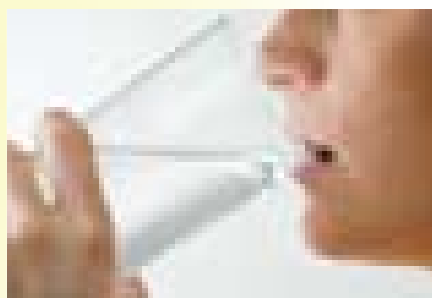
Kefir is a fermented milk drink made with kefir "grains" (a yeast/bacterial fermentation starter) and has its origins in the north Caucasus Mountains. It is prepared by inoculating cow, goat, or sheep milk with kefir grains.

Drinking cranberry juice has long been thought to prevent and treat UTI's because it appears to prevent the adherence of bacteria (specifically E.coli) to the walls of the urinary tract. Cranberry has also been shown to inhibit binding of E.coli to intestinal mucosa. However, most forms of cranberry juice on the market contain one third cranberry juice mixed with sugar and water. As sugar is also detrimental to the immune system, the use of sweetened cranberry juice is not recommended.

The high sugar content of commercially prepared cranberry juice could also be problematic for diabetics. It is very important for diabetics to keep their blood sugar levels under control, as high levels of blood sugar can cause glucose to spill into the urine via the kidneys. This provides an excellent food source for any bacteria in the urinary tract and enables bacteria to rapidly multiply, which increases the risk of UTI. Chronically elevated blood sugar can also suppress the immune system and therefore increase the risk of UTI.

Fresh cranberry juice (unsweetened or sweetened with apple or grape juice) is preferred. Based on the research, positive effects from cranberry juice are achieved via daily ingestion of 250-300 ml at least three times daily, and overall evidence suggests no significant alteration to urinary pH at doses less than 330 ml per day. At a dose of one or two glasses of cranberry juice per day, it takes about four to eight weeks of continual use before benefit is noticed.

Another option is to purchase cranberry supplementation in a concentrated pill form. Cranberry tablets have been proven to be clinically effective and economical with faster results. The tablets need to be taken twice daily.



Please note that cranberry may increase the INR (International Normalised Ratio; used to determine the clotting tendency of blood) in patients on Warfarin, so patients taking Warfarin and cranberry regularly should have their INR closely monitored.

Fermented milk products containing probiotic bacteria (such as kefir) have also been associated with a decreased risk of recurrent UTIs.

To provide benefit the kefir must be consumed at least three times per week.



Another strategy to combat UTI's is to acidify the urine, therefore creating an unfriendly environment for bacteria to multiply and grow.

Urinary pH usually varies between 4.0 and 8.0 depending on food intake and metabolic processes in the body. Foods that are considered to promote urinary acidity are meat, fish, cheese and grain products. However it should be noted that maintaining urine in an acidic state over long periods (at a pH of 5.5 or less in particular) may predispose the individual to either kidney stones or gout, due to high levels of uric acid. It is easy to self-test urinary pH via a pH Test Kit that can be bought at health foods stores. Generally speaking, urine that smells fruity is too alkaline.

Urinary acidification may also be achieved by means of Vitamin C supplementation; however very high doses are required which may loosen bowels and cause diarrhoea. Supplemental Vitamin C can also affect the results of numerous laboratory tests, including blood and urine tests, and should be stopped prior to any medical investigations.

It is common to experience fever and chills when a person has a UTI, however elderly people may not experience these symptoms and they cannot therefore be relied upon as an indicator of infection. Mental confusion may be evident instead. Urine that is dark and cloudy with a very strong odour may also indicate an infection.

To summarise, my dietary recommendations for reducing the occurrence of UTI's are as follows:

- Drink ample hydrating fluids for your body weight to flush mucous and bacteria out of the conduit. Check with your doctor the appropriate amount if fluid balance is an issue for you.
- Avoid excessive intake of sugar and refined carbohydrates.
- Consume foods that boost the immune system.
- Consider unsweetened cranberry juice or tablets.

Overall it appears that drinking ample hydrating fluids to flush the urinary system and keeping the immune system strong with a healthy diet are, in my opinion, the safest ways to prevent UTI's.

Wishing you good health and happy days, Margaret. ●

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National Directory of Ostomy Support Groups

NEW SOUTH WALES

ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec.
Venue: Hilltop Accommodation Centre,
600 Keene Street, East Albury NSW
Contact: Alex Watson 0428 578 385

BATHURST

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

BROKEN HILL

Meet: Every 3rd month or as required.
Venue: Broken Hill Hospital Conference Room.
Contact: Tandra (08) 8080 1333

CENTRAL COAST

Meet: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting.
For further information, phone the Stomal Therapy Service on
(02) 4320 3323

COFFS HARBOUR

Meets 2:00pm to 3:30pm
12 Feb - 9 Apr - 11 Jun - 13 Aug - 8 Oct - 10 Dec
Venue: Club Coffs, West High Street, Coffs Harbour.
Ostomates & friends welcome.
Contact Mandy Hawkins STN on
(02) 6656 7804

EUROBODALLA REGION

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

FAR NORTH COAST

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

FAR SOUTH COAST

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

GRAFTON & DISTRICT

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

GRIFFITH & DISTRICT

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

HASTINGS MACLEAY

Meet: The Old Hospital in Room 4 at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries: Jennifer (02) 6586 0270

ILLAWARRA

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

MANNING/GREAT LAKES

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

NEWCASTLE DISTRICT

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

ORANGE & DISTRICT

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

SHOALHAVEN

Meet: 2.00pm on 2 Feb - 11 May -17 Aug - 16 Nov
Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra.
Contact: Margaret or Tracey on
(02) 4424 6300

SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).
2015 meeting dates to be advised.
For further information, please contact: Diane or Lu (STNs) on
(02) 8738 4308

SYDNEY - PENRITH AREA

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

SYDNEY - SOUTH-WEST AREA

Meet: Saturdays 3pm - 5pm on 2 May - 22 Aug and 5:30pm - 6:00pm on 21 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

Meets 2.00pm on the third Monday of each second month.
Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug - Dec and Benalla Community Health Service, 45 Coster Street, Benalla in Feb - Jun - Oct.
Contact: Rex Nankervis
(03) 5762 2080
Email: rexmarn@bigpond.com

OSTWEST

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

MILDURA

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

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

MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month

(Jan - Mar - May - Jul - Sep - Nov).
Venue: Gordon White Library on Phillip Street, Mt Pleasant.
Contact: Graham Stabler for further information on 0428 776 258 or email grahamstabler@bigpond.com

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GOLD COAST

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

REDCLIFFE

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

ROCKHAMPTON

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

SOUTH BURNETT

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

SUNSHINE COAST

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

WIDE BAY

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

TASMANIA

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

NORTH & NORTH-WEST

North: Meets 10.00 am on the first Monday of Mar - Jun - Sep - Dec at the Cancer Support Centre, 69 Howick Street, Launceston.
North-West: Meets 10.00 am on the second Monday of Mar - Jun - Sep - Dec at the Ulverstone Senior Citizens Club, 16 Edwards Street.
Contact: Adrian Kok (03) 6326 4664

SOUTH AUSTRALIA

CENTRAL

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

FLEURIEU

2015 meeting dates to be advised.
Meet: 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor.
Please contact Sue McKay STN for further information on 0412 692 418

SOUTHERN

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

YOUTH GROUP

Doris Steyer,
Telephone: (02) 4296 5354

YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623 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

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