

National Directory of Ostomy Associations

AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSN INC.

Second Floor, ACT City Health Centre, 1 Moore St, Canberra City, ACT 2600 Postal Address: GPO Box 1260, Canberra City, ACT 2601 Telephone/Fax: (02) 6205 1055 Website: www.actstoma.net.au Open days: 1st & 2nd week of each month Mon, Tues, Wed. 10.00am -1.00 pm, STN available Wednesday open days 10am-noon Office Manager: Melissa Mason Email: stoma@ACTStoma. onmicrosoft.com Secretary: David Turnbull

NORTHERN TERRITORY

CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House 25 Vanderlin Drive, Casuarina Postal Address: PO Box 42719. Casuarina NT 0811 Mon to Thurs 8.30am - 2.00pm Phone: (08) 8944 1800 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: general manager@waostomy.org.au admin@waostomy.org.au Orders email: orders@waostomy.org.au Operating hours and appliance pickup: Mon, Tues, Thurs 9.00am -1.00 pm

NEW SOUTH WALES

NSW STOMA LIMITED

(formerly Colostomy Assn of NSW) Unit 5, 7-29 Bridge Road, Stanmore 2048 PO Box 164, Camperdown 1450 Operating hours: Mon to Thurs 9.00 am - 4.00 pm and Friday 9.00 am - 2.00 pm Administration and Logistics Controller: Hedy Ferreira Secretary: Peter De Luca Telephone: 1300 OSTOMY or (02) 9565 4315 Fax: (02) 9565 4317 Email: info@NSWstoma.com.au Website: NSWstoma.com.au

OSTOMY NSW LTD

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

QUEENSLAND

GOLD COAST OSTOMY ASSN INC.

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

NTH QLD OSTOMY ASSN INC.

13 Castlemaine St., Kirwan Telephone: (07) 4775 2303 PO Box 173. Thuringowa Central, 4817 Operating hours: Monday 9.00 am - 4.00 pm Thursday 9.00am - 3.00pm Email: admin@ngostomy.org.au Secretary: Gwenda Williams A/H (07) 4775 2303

QLD OSTOMY ASSN INC.

(formerly QLD Colostomy Assn) 22 Beaudesert Rd, Moorooka 4105 PO Box 198 Moorooka 4105 Operating hours: Tues & Thurs 9.00am - 3.30pm Admin (07) 3848 7178 Fax: (07) 3848 0561 Email: admin@qldostomy.org.au Web: www.qldostomy.org

QLD STOMA ASSN INC. Unit 1/10 Valente Close.

Chermside 4032 Telephone: (07) 3359 7570 Fax: (07) 3350 1882 Website: gldstoma.asn.au Operating hours: Mon to Thurs -8.30am - 2.30pm Last Saturday of each month -8.30am - 12.30pm Closed Fridays and Public Holidays Emergency No: (07) 3359 7570 PO Box 370, Chermside 4032 Email: admin@qldstoma.asn.au

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC. Education Centre, Blue Care Garden

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

WIDE BAY OSTOMATES ASSN INC. 88a Crofton Street, Bundaberg West, QLD 4670 Operating hours: 8.30 am - 3.00 pm 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

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: Linda Williams

ILEOSTOMY ASSN OF SA INC.

73 Roebuck St. Mile End. SA 5031 Telephone: (08) 8234 2678 Fax: (08) 8234 2985 Office hours: Mon-Fri 10am - 2pm Distribution times: Tuesdays 10am - 2pm, 1st & 3rd Tuesday evenings 7 pm - 8 pm Secretary: Donna Benge Telephone: (08) 8234 2678 Email: info@ileosa.org.au

TASMANIA

OSTOMY TASMANIA INC

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

VICTORIA

BENDIGO & DISTRICT OSTOMY ASSN INC.

Website: www.ostomytas.com.au

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, 98 Elizabeth St., Block Arcade Lift 3, Melbourne VIC 3000 Phone: (03) 9650 1666 Fax: (03) 9650 4123 Email: info@colovic.org.au Website: www.colovic.org.au Operating hours: Weekdays 9am to 2pm. STN Wednesdays from 9.30am (phone for appointment). AGM: CAV premises, 11am last Saturday every November.

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 9.30 am - 2.30 pm Administrator: Karen McKenzie

OSTOMY ASSN OF MELBOURNE INC.

Burwood Industrial Park Unit 14, 25-37 Huntingdale Rd Burwood, VIC 3125 Telephone: (03) 9888 8523 Fax: (03) 9888 8094 Email: enquiries@oam.org.au Website: www.oam.org.au Operating hours: Mon to Fri 9.00am - 4.00pm STN appointments only Tuesdays and Thursdays, 8.30am-2.15pm.

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

VICTORIAN CHILDREN'S OSTOMY ASSN.

Equipment Distribution Centre, Royal Children's Hospital, Level Basement 2 (green lifts), 50 Flemington Road, Parkville, 3052 Telephone: (03) 9345 5325 Fax: (03) 9345 9499 Email: edc@rch.org.au. Web: www.rch.org.au/edc

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 - 4.00 pm Secretary: Heather Love

Please contact your association for all issues concerning membership, appliance supply or distribution of the Ostomy Australia journal. Contact details are on this page



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Publication of an advertisement in Ostomy Australia does not constitute an endorsement of any products mentioned therein by the journal, ACSA, any stoma association, or any government department connected with the Stoma Appliance Scheme

Readers are strongly advised to obtain appropriate professional advice before using any products advertised.

Privacy: The Australian Council of Stoma Associations Inc. has no control over the use of personal particulars that ostomates provide to companies in response to advertisements contained in Ostoma ustralia. Unless the advertiser states otherwise, a company may use your name and address to contact

If readers do not wish to be contacted further, they are advised to tell the company this. Most companies have said they will comply with such requests. This advice should be taken into account when responding

Complaints: Consumers who are concerned about the way in which stoma appliances are advertised are entitled to lodge a complaint with the Therapeutic Goods Administration. Such complaints should be addressed to the TGA Complaints Resolution Panel, PO Box 764, North Sydney, NSW 2059.

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PRESIDENT'S MESSAGE

In 1992 the Australian Council of Stoma Associations began the publication of a journal by ostomates for ostomates. ACSA is very proud of what *Ostomy Australia* has become and consider that its mix of personal stories, education and supplier advertising makes it a valuable resource for new and old ostomates, along with their families and friends.

Much of this is due to the effort, skill and thoroughness of the journal's editor. It is worthwhile to note that over the past 27 years there have been only five editors. Beginning with inaugural editor Mrs Barbara Callcott (for those of you old enough, you may remember Barbara from the Colgate 'Mrs Marsh' ads in the '70s and '80s), subsequent editors Judy Lopez, Noel Dillion, Kim Lyle and Peter Fuller have each put their own personal stamp on the publication and developed it into the world-class industry journal we have today. This issue marks the final journal by our current editor, Peter Fuller. At the time of preparing this message our new editor has not been selected but I am sure that whoever takes over from Peter will continue his excellent work. He has set a high standard.

On your behalf I would like to thank Peter for his work in editing the

journal over the past three years. His journalism skills and experience in publishing have given us much reading enjoyment. He can now start enjoying the retirement he thought he was getting when he left his communications day job.

Much of what we have today is through the work of those who went before us. This journal was established through the drive and foresight of ACSA in the early 1990s. Similarly, the establishment of the Stoma Appliance Scheme (SAS) by the Australian Government in 1975 was in large part due to the drive and foresight of the early stoma associations. For this ostomates in this country must give thanks. Many countries do not provide any support to ostomates, and those that do often require the ostomate to purchase products and then seek tax credits or refunds through health funds.

Being a government-funded program, the Department of Health has established the

Stoma Appliance Scheme Operational Guidelines for Stoma Associations. These guidelines detail the practices and procedures that a stoma association and its members must follow for the provision of stoma-related products listed on the Stoma Appliance Scheme Schedule. Stoma associations must be conversant with these guidelines and, like them, ostomates should make themselves aware of the guidelines, which can be found on the Department of Health's website, www.health.gov.au/stoma.

There is some misconception that the supply of stoma-related

products is free of charge to registrants Stoma Appliance Scheme. In fact the guidelines state that to receive subsided products through the scheme, registrants must pay an annual Stoma Appliance Scheme access fee. This is a uniform national annual amount, determined by the Department of Health

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in consultation with ACSA, and payable to the stoma association where the member usually obtains their stoma-related products. The fee is compulsory, but associations must make provision for it to be paid by instalments in the case of genuine financial hardship. The

Stoma Appliance Scheme access fee is currently set at \$60, and \$50 for Commonwealth concession card holders. It is payable once per financial year.

The guidelines also permit stoma associations to charge an additional membership fee, separate to the Stoma Appliance Scheme access fee, at the stoma association's discretion. This additional fee is for services the association provides but which are not covered by the scheme, such as support group activities and stomal therapist services. When an association charges an additional membership fee, it has to clearly show that the additional membership fee is separate from and in addition to the Stoma Appliance Scheme access fee, and that the additional membership fee is determined by the stoma association concerned. A member who is not able to pay the additional membership fee because of

financial hardship may apply to the association in writing to have the fee waived.

Like any government-funded program, the Stoma Appliance Scheme's operation is scrutinised by the appropriate department to ensure that the program is operating effectively. It is in the interest of both ostomates and stoma associations that the scheme's operational guidelines are followed.

David Munro PRESIDENT

NORTH QUEENSLAND WEATHERS THE STORM

'Be careful what you wish for...'



At the start of the year, North Queensland Ostomy Association was gearing up to move to new premises in the west of the city. Then the rains came, as NQOA

'Be careful what you wish for, it may just come true!'

Secretary Gwenda Williams

relates.

Hello from a flood-ravaged Townsville. Residents of the city and surrounding areas, including the far west, had been desperate for rain. Our city is sometimes referred to as 'Brownsville' (unkind but true). It seemed the drought was becoming a major concern. Work had commenced on laying a pipeline to bring water to the city from the Burdekin Dam, southwest of Townsville.

Prayers and wishes were answered in late January—in no uncertain terms. On 28 January a slow-moving monsoon trough had formed to the north of Townsville and flooding rains were a risk for areas between Tully to the north and Proserpine to the south.

Townsville residents were eagerly waiting for the rain that was predicted to move down the coast to relieve our situation and get some water into the Ross River dam, the city's water

supply. It had dropped to less than 15 per cent capacity. A concern, because our population is predicted to reach 192,732 by 30 June 2019.

The rain arrived in due course and it was a welcome sight. The monsoon trough moved ever so slowly and then positioned itself over the Ross Dam—and there it stayed. Two solid weeks of intense rain, with Townsville receiving two metres of rain in one week in the catchment area, a record since the 1800s, when rainfall records commenced.

It was a worrying time for authorities. The decision to open the dam floodgates wasn't made lightly and extremely high tides added to the dilemma for the authorities. When the dam rose to 110 per cent capacity on 30 January, the spillway gates were opened to try to manage the situation—little did they know how much more was to come. It was described as a 'catastrophic' event for North Queensland, with Townsville the epicentre of the unprecedented monsoonal downpour. Five suburbs were expected to flood but later in the day, when the dam peaked at 244.8 per cent capacity, a further six suburbs were advised they could also be affected. It was a frightening situation.

It has been, for many residents in Townsville, a disastrous start

to 2019. Many people have lost their homes, cars, caravans and other property to floodwaters Their worldly possessions unceremoniously dumped on footpaths; in many cases everything they own was piled in the streets for the council and army trucks to collect; makeshift dumps were opened across the city. Schools and businesses were not spared. For many there was complete devastation. It wasn't just one suburb or street, it was widespread. Street after street in several suburbs had mountains of residents' possessions piled high and it is hard to comprehend the extent and the emotional toll it has taken on the city.

Many people are still in shock from the devastation, laid out for all to see. Not only have the floodwaters been through homes, cars and belongings, but even the land was contaminated with mud, silt, sewage and other pollutants. The threat to health was great, with residents being warned to be cautious as they cleaned up, as infections such as melioidosis were of great concern. One woman died as a result of this infection and nine others were in hospital one week after the clean-up started. Three deaths that occurred in the region have been attributed to the floods and drowning.

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The Oueensland Government officially recognised Townsville as a disaster area by 1 February. It was heart-warming to see the number of volunteers working beside the SES, the army and council workers, helping in whatever way they could to get residents back into their homes. With the good comes the bad, and looting of homes was added trauma for those already in a fragile state. Price-gouging was also reported. But the generosity of the people and the business community across Australia during disasters such as we have just experienced, is both heart-warming and humbling. May we never lose this compassion for our fellows.

The North Queensland Ostomy Association Inc was not impacted to any great extent, but it was evident on the Thursday, 31 January, that the weather was deteriorating. Local flooding in the streets made it difficult to pass through some suburbs. Residents were being asked to stay off the streets unless absolutely necessary to allow the SES, police and army quick access to all areas. Australia Post drivers were sent home and the association was unable to dispatch the last 25 parcels for our February orders. It was a further week until Australia Post services were back up and running at full strength. Then the parcels were collected and on their way to members. This is the very reason that we keep telling members to build

up a month's supply of appliances, over time, in case of emergencies.

Our office was closed on the Monday and reopened on Wednesday, 6 February. Some stranded travellers from other associations and two members from the evacuation centres that had been set up over the city had called for assistance, but overall it could have been so much worse. Fortunately our stocks were low, having posted most of the orders out at the end of January—as they say, 'timing is everything'. But then the concern was whether the trucks with our stock from Melbourne could make it through. Thankfully all was well, with the stock arriving at the office on 7 February, only a day or two late.

Looking to the future, North Queensland Ostomy Association Inc will be moving to a new address by the end of April. This may be ambitious, given the recent flood event and the amount of work needing to be done to the homes and businesses across the city, including securing telecommunications, but regardless of other priorities, our lease expires on 30 April.

Our new home will need some modifications and we hope there won't be any interruptions to these plans. Unfortunately, we will not be able to keep everyone happy, especially those who have enjoyed the association being in the vicinity of the city

centre and nearby suburb of Pimlico for 40 years.

Our move is to 13 Castlemaine Street, Kirwan, postcode 4817, much to the delight of members on that side of Townsville. We already have a new post office address, PO Box 173, Thuringowa Central 4817. We have been given conflicting reports from Telstra about our phone and fax lines, so at the time of writing our current phone and fax numbers could be subject to change. Redirections will be in place for three months, beginning on 1 April for the post box, phone and fax services. The new Castlemaine Street premises were not affected by the recent floods.

The sun was a welcome sight, but it was followed by heatwave conditions-not so welcome, with heat exhaustion another burden for the exhausted, emotionally drained residents, volunteers and the authorities to endure. As Townsville recovers, our thoughts are with the residents and towns to the west and south west and Gulf regions that had been in drought for nigh-on five years. Virtually overnight, flooding rains almost totally wiped out their livelihood. Queenslanders are resilient and I have no doubt everyone will be working together to see better days ahead. As I said at the beginning of this article, 'be careful what you wish for'. We wish for better days ahead. •



North Queensland Ostomy Association's new premises in Kirwan, in Townsville's western suburbs. The property wasn't affected by the January floods.

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Your say - Letters to the editor

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



Can you produce Ostomy Australia?

Ostomy Australia is looking for an editor. With the current editor retiring in April, the national journal for Australia's ostomates is seeking someone to lead the publication into the future. This is an opportunity to contribute to the enjoyment, knowledge and wellbeing of ostomates around Australia.

There are three parts to the job—accepting and editing contributions from members and regular contributors, liaising with advertisers, and covering the administrative tasks involved with in producing *Ostomy Australia* three times a year, as well as managing its national distribution.

This arrangement could change. ACSA knows the current set-up is complex and would consider appointing extra hands—perhaps an editor who would be responsible for producing the journal and maintaining its quality, and someone with administrative skills to oversee advertising and look after financial and other matters. The division of duties would be determined by negotiation.

Ostomy Australia was first published in 1992 has developed high editorial, design and production standards. Work is concentrated around three production periods (March-April, July-August and October-November).

The editor is a volunteer but receives an honorarium of \$1500 per issue and has relevant expenses reimbursed. The position, as structured, would suit someone with experience in journalism, publishing or public relations. It might also be suitable for someone with a background in administration, teaching, project management or IT.

The editor's role is to ensure that *Ostomy Australia* is produced on time. The person will also maintain the journal's quality and relevance, assess and accept contributions, edit them for clarity, sense, and grammar, plan the journal to allocate appropriate space to editorial material and advertisements, and work with the graphic designer to prepare journal for printing.

The advertising role involves liaising with advertisers and receiving advertisements.

Administrative duties include preparing estimates of annual income and expenditure, reporting to the ACSA executive and national conference, and organising reprints of the booklet *A Beginning not an End.*

Is this a job for you? The answer is 'yes' if you have a sound knowledge of written English, good self-management skills, and the ability to work constructively with advertisers, designers and printers, and associations. A knowledge of print-production processes would be useful.

If you want to make a contribution to Australian ostomy, please contact the ACSA Secretary at acsasec@australianstoma.com.au or iournal@australianstoma.com.au.

DISABILITY TOILETS AVAILABLE TO ALL

Dear Editor.

I read with interest the letter by Maggie Parker (August 2018) about toilet facilities for ostomates and, like her, enjoyed the letter by Val Padley (April 2018) about facilities in Japan. What a great concept it would be for our nation, much better than some 'old world' facilities we are faced with using at times, with even new establishments now having ambulant facilities only. Thankfully there are places that provide serviceable units.

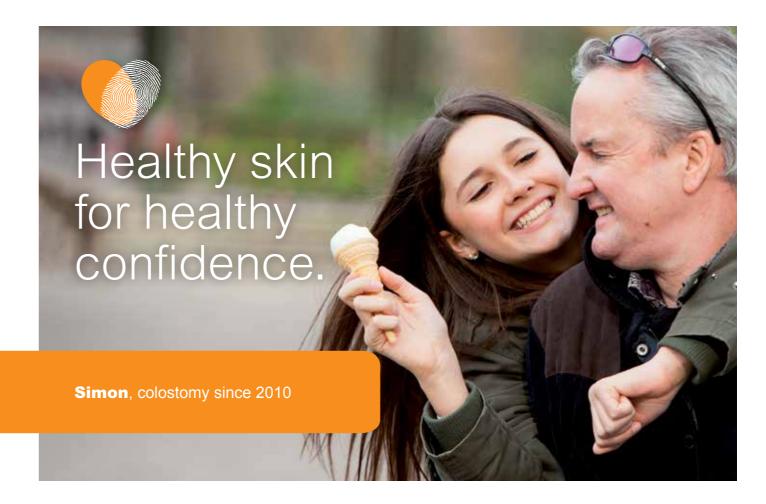
With regards to being challenged on using a disabled toilet, I can relate to this, as it has happened to me more than once, the last time whilst in a public restaurant. I became a little more defensive and reached for the card in my wallet which states that I'm permitted to use such toilets. Then I asked the lady who was objecting if she had permission or a card to approve her using this facility—she had no card, of course. This defused this issue by putting the challenge back on her. Interest from bystanders also helped.

My understanding is that the wheelchair logo is the international symbol for disability/disabled (d/d), not disability only. There appears to me to be a shortfall in the understanding of the difference specifically within the public arena. When asking if disability facilities are available, the response is often 'gah-gah', demonstrating the lack of awareness or perhaps education of these matters.

As an example, I once visited a caravan park in a major River Murray tourist place that had a new \$1.2m toilet block with a d/d shower which had no dry area bench top or seat, no clothes hooks, and a mirror you needed to be seven feet tall to use. Just in case you used a toilet as part of your hygiene routine, it was some meters down the other end of the building, even though it was said to be an approved facility.

However, I made a point of making contact when a council near my home asked for comments on its plans to renovate a toilet block at a lakeside leisure park. I spoke with their community welfare person, who took the time to discuss their plans and the objectives they had to meet, which included the requirements of disability building development acts and regulations. Their focus was to develop a unit suited to people with disabilities and the elderly. The end result I have found to be a very user-friendly facility, suited to many aspects of people with disabilities.

On the subject of awareness, when travelling interstate some time ago we viewed a TV advert sponsored by Crohn's and Colitis Australia. Its feature was awareness for people who, while looking normal, might have health issues and specific needs. We have not seen it since then, but it made for good viewing.



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Footnote: My wife, having had ulcerative colitis for many years, now has Crohn's disease. I had a colostomy following cancer treatment. We like to travel and do day trips, and we also use our small caravan, health permitting. Hence toilet facilities are always part of our outing plans. The disability toilet use card was issued by OstomySA when joining.

Russell Williams, SA

Dear Editor,

A comment on the use of disabled toilets by ostomates (Maggie Parker, August 2018): at the ACSA conference in 2008 or 2009 Mrs Joy Walker from Colostomy Association Victoria proposed that ostomates carry a card stating that the ostomate may need to use a disabled toilet to manage their stoma. One member of her association had been challenged by the security at Crown Casino as she exited the disabled toilet.

Both Victorian colostomy and ileostomy associations produced cards with this information on the face, along with the disabled sign and the ACSA logo. The reverse gave the contact details of the association for the return of the card, if lost and later found. These cards were produced in-house on bought card stock.

The lleostomy Association of Victoria later had a more professional card produced by Mrs Janice Anderson. We issued this to each new ostomate, and these were still in use up to the amalgamation of the ileostomy and colostomy associations in June 2018.

Colostomy Association Victoria dropped the card after the demise of Mrs Walker. I am unsure how many associations produced these cards but I believe that ileostomates who are using foldup closures really need to use a disabled toilet, as I consider this type of closure is far from hygienic and would not pass an OH&S audit.

Terry Carver, VIC

EDITOR'S NOTE

There is nothing to preclude ostomates from using a disability or disabled toilet, even though the principal purpose of the wheelchair symbol, which is used internationally, is to indicate that a toilet has been set up so that people in wheelchairs can use it.

Ostomy Australia asked ACSA's Administration Officer, Kylie McGrory, to explain ostomates' entitlements, and she noted, first, that 'in Australia there are no restrictions on any person using a disability accessible toilet'. She continued: 'Obviously there is a moral responsibility not to use it if there are other vacant facilities available and the person doesn't have a special need, so that the facility is left free for those who do. What is a special need, through? Is it just someone in a wheelchair or on a walker? Or could it be a pregnant

woman with poor bladder control, an ostomate, someone with inflammatory bowel disease or incontinence, a parent with a toilet-training child or a lone shopper who just doesn't want to leave their trolley outside of the door for others to take from?

'It is for this reason that, unlike some countries that do have restrictions on the use of disabled toilets (that is, for the disabled only), official disability toilet cards are not available in Australia—that is, because there is nothing in the Disability Discrimination Act to mandate accessible toilet facilities being exclusively for use by people with disabilities. All associations have access to the template for the unofficial disability toilet card that Terry Carver describes. It is kept within the "associations" menu on the ACSA website (login required).

'Ostomates are also eligible to obtain a MLAK key from a locksmith—this is a master key for disability accessible toilet facilities which are locked after hours. Ostomates just need to get a letter from their doctor or association: http://australianstoma.com.au/resources/mlak/'

Dear Editor.

In 2003 I was diagnosed with bladder cancer and referred to a specialist who treated me for a short time. He informed me in 2004 that he was retiring, and pulled the pin later that year. I found another urologist who quickly discovered the cancer was becoming very aggressive, and after consulting several of his peers decided an operation. A stoma was the only solution.

Bloody hell! I was a healthy farmer, never been sick in my life (69 years old). This was heavy stuff.

But because of the knowledge and expertise of that man, I am alive.

In October 2005, that operation was performed at Albury Hospital and because of the care and professionalism of the hospital staff, I am alive.

I had a stoma nurse who tended and advised me, and because of her input, I am alive.

My wife stayed with me during my stint in hospital and has cared and supported me all the way. Because of her love and support, I am alive.

I am a member of Ostomy Association of Melbourne, and because of the prompt efficient and caring service I receive from the staff and volunteers in this organisation, I am alive.

I write this in response to a letter sent to OAM members by the President regarding abuse and bullying of OAM staff. I would say to any person intending to have a go at OAM personnel, stop and think—because of them, you are alive.

I have had my stoma now for 13 years. I was given a maximum of two years without it.

Continued page 12

Ralph Crain, NSW



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Ostomy Australia April 2019 - 10 -

Dear Editor.

After the vicissitudes of my colostomy had dissipated and my life returned to a normal status I decided to recommence my habit of donating blood. As I live in a more remote part of NSW I had to wait until the Red Cross arrived in a nearby township with their mobile blood bank.

After revealing that I had a colostomy and after a considerable amount of discussion with the Red Cross staff, I was put through to a 'doctor' (via the phone). The 'doctor' stated that as I had a colostomy I may have diarrhoea and this could mean my blood may be infected which rendered it unsuitable for donation. I struggled trying to explain basic human physiology to the 'doctor' but the upshot was that after several hours of my time had been squandered I left, unable to provide a blood donation.

Have I got it all wrong, or does someone need to spend some time with the Red Cross explaining the basics?

Iven Chrebtiw, NSW

EDITOR'S NOTE

Without commenting on Iven's particular situation, it is the case that ostomates are unable to donate blood to the Australia Red Cross Blood Service 'due to increased risks of infection'. The service advises that ostomates may be able to donate blood plasma, but says a number of factors may affect their suitability to do so. The service notes that each individual's situation is unique, and encourages people interested in donating plasma to contact the service's medical team via 13 14 95 for advice.

Dear Editor.

I attended a 'stoma day' at Worrigee Ex-Servicemen's Club (near Nowra) in June 2018. I just wanted to say thank you to NSW Stoma for arranging this very informative day and I hope there will be many more to come.

Initially I wasn't going to attend, but the local stoma nurses were enthusiastic about the event and told me they were very good. So I did go and am so pleased I did. While I have read about and been told about parastomal hernias, I feel I have a better understanding now and am more aware of the importance of wearing support garments. (Thank you again to Stoma NSW which allows five garments per year for the price of your membership). The different suppliers were well represented, too. Requests for support garments with a hole around the stoma have been made to the different suppliers by some customers. I was left with the impression that this was being contemplated by some companies but was discouraged by the stoma nurses, as this would defeat the purpose of using these garments.

Julie Hopkins, NSW

Dear Editor.

This is purely the result of an observation I have made from reading the journal for nearly 15 years since receiving my urostomy. There are very few, in most cases no, contributions made by urostomates. Is this perhaps because there are fewer of us, or maybe because we have fewer medical issues? I have no idea, but it would be lovely to read about other people like me. I have been very lucky with my stoma. I haven't had any problems and have stuck with the same product for most of those 14 years.

I had bladder cancer, which was made evident by blood in the toilet. I had no other symptoms, certainly no pain, and was a very well person. I was referred to a urologist and had a biopsy performed. Several small tumours were detected so I underwent six weeks of insertions of what I believed to be smallpox vaccine—this may be totally wrong, I was a bit too shocked to take everything in. However, I was absolutely sure that all would be well. When I was examined my urologist told me the tumours were still there, so I burst out with 'Oh sh..t', to which he replied 'No, wrong hole!' He then told me that I had stage three cancer and that he recommended that I have my bladder removed. The very day that I received that news I was to go on holiday with my friend. We still went and on the way I rang my boss (I worked in a school and it was the Christmas holidays) to break the news that I would be absent for all of term one. I had the operation on 9 February and also had to have a total hysterectomy. My urologist was confident that all the cancer was contained in the bladder, so that was good news.

Once I left hospital I spent six weeks with my daughter and family to recuperate. Lee, my daughter, was wonderful. When it came to changing my baseplate she sat on the edge of the bath to change it. I had no confidence in the early stages to do it myself. A few times she was nearly squirted in the eye. My goodness it can come out fast! On the other hand, when trying to get a urine sample, it takes forever! I had quite a few leakages to start with but my stomal therapist recomended that I use a convex baseplate, as my stoma was quite flush. I haven't looked back since. Of course I have an occasional leak—this happened to me twice while I was in England recently. I don't quite know why, but after a while it all settled down. It did bruise my confidence a bit but I soon got over it.

I now see my urologist only every two years. He tells me I was very lucky. If I hadn't had the operation when I did, there was every likelihood that the cancer would have invaded the muscle and spread throughout my body.

That's my story, and when I read the next issue of *Ostomy Australia* I hope to hear from one of my fellow urostomates out there.

Vivien Causon, VIC





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Keeping tabs on member entitlements

One of the more common gueries that associations receive concerns the maximum number of a particular item that a member can obtain through the Stoma Appliance Scheme within a given period.

At times this can be a difficult question to answer because of the diverse range of products available through the scheme, the number of products listed on the Stoma Appliance Scheme Schedule (currently around 3,600) and the shared purpose of many of those products. Also relevant is whether the member holds a current and valid Application for Additional Stoma Supplies (PB050) and if the member is eligible for, and has taken advantage of, the two-month ordering cycle allowed under the Stoma Appliance Scheme Operational Guidelines for Stoma Associations.

When determining a maximum allowance, associations must consider the requirements of the guidelines, which state:

6.5.1 Maximum quantity: It is the responsibility of each stoma association to ensure no more than the maximum quantity of any of the stoma related products is provided to members on a monthly or annual basis unless there has been a certificate of authorisation issued for an increase in quantities forwarded to the Department requesting additional

supplies. This certificate must be signed by the members' health practitioner or STN.

6.5.2 Ordering supplies within one sub-group listed on the schedule: When supplies are requested from within one sub-group listed on the schedule, and the products are intended for the same purpose, the supplied amount is restricted to the maximum limit for that type of product.

6.5.3 Ordering supplies from more than one group listed on the schedule: When supplies are requested from two or more different sub-groups listed on the schedule, but for which the products serve the same purpose, the maximum amount supplied from each group must be reduced accordingly (e.g. if the products are supplied equally from two sub-groups then the maximum quantity for each sub-group should be reduced by 50%).

sense is that the maximum quantity of a scheme-funded product that an association can

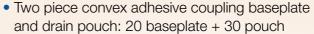
may be affected by other products that serve the same purpose that a member requests within that same period. Consequently, it is not unusual for an association to find it necessary to adjust a member's order to ensure that the product issued does not breach the guidelines. This can result in some very unhappy members at times when they find that they have not received the full order requested!

As a general guide, the following maximum allowances have been set by the Commonwealth Government for commonly used products-monthly unless otherwise

> One piece convex closed pouch: 60

- One piece flat drainable pouch with integrated closure: 30
- One piece convex drainable pouch with integrated closure: 30
- either 40 or 60*
- Two piece flat standard baseplate and closed pouch: 30 baseplate

- and closed pouch:20 baseplate + 90 pouch
- Two piece flat standard baseplate and drainable pouch: 30 baseplate + 60 pouch
- Two piece flat extended wear baseplate and drainable pouch: 20 baseplate + 60 pouch
- Two piece convex baseplate and drainable pouch: 20 baseplate + 60 pouch
- and drainable pouch: 30 baseplate + 30 pouch



• Adhesive remover wipes: either 60 per month

Barrier wipes: either 60 per month or 720 per

Barrier spray: usually 6 per calendar year*

Pouch deodorant: 1 or 2 bottles*

Lubricating deodorant – bottle: 1

• Lubricating deodorant - sachets:

100 per calendar year

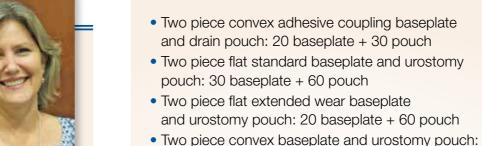
- Pouch belts: 4 per calendar year
- Hernia support belt: 3 per calendar year
- Hernia support boxers/briefs: usually 6 per calendar year*

*depending on product

A risk of oversupply might arise when—for example—a member is using multiple types of pouching systems (such as closed and drainable pouches or one-piece and two-piece appliances), a range of hernia support garments (eg: hernia support belts and hernia support briefs/boxers), or different types of barrier and adhesive remover products (such as spray and wipes). In these situations, the association must take care to ensure an oversupply does not occur. It may need to amend an order, often without having the time to consult the member.

For more information about applicable quantities for specific products and for information about other scheme-listed products not listed above, members can consult their stomal therapy nurse or stoma association.

Kvlie McGrorv



20 baseplate + 60 pouch

or 720 per calendar year*

• Adhesive remover spray: 2

calendar year*

• Flange extenders: 60

• Seals: 30

• Powder: 2

• Paste: 3

Night drainage bags: 5

What this means in a practical issue within a requested period

• One piece stoma cap: 60

It is not

unusual for an

association to

find it necessary

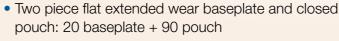
to adjust a

member's order

- One piece flat closed pouch: 90

 - One piece flat urostomy pouch:
 - One piece convex urostomy

 - + 90 pouch



- Two piece convex baseplate and closed pouch: 20 baseplate + 90 pouch
- Two piece flat adhesive coupling baseplate and closed pouch:30 baseplate + 90 pouch
- Two piece convex adhesive coupling baseplate

- Two piece flat adhesive coupling baseplate



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When did you last see your Stomal Therapy Nurse?





The pros and cons of a low-residue diet

By Margaret Allan

As a qualified nutritionist, I have attended many lectures, seminars, conferences and now webinars on diet, and I have examined dietary guidelines and trends from many different perspectives. Some diets can be categorised as trendy fads that promote weight loss, for example, without concern for overall health. Other diets, however, are developed as functional strategies to address and correct unhealthy practices or distressing symptoms and are designed to improve general health.

One diet that I have become very familiar with over the years is a low-residue diet, which is also referred to as a low-fibre diet. This is a diet that is frequently recommended by doctors and dietitians to temporarily address painful and debilitating symptoms as a result of intestinal disease such as inflammatory bowel disease (IBD), diverticulitis or bowel cancer. It is also often prescribed in the initial stages following stomal surgery

What is a low-residue diet?

A low-residue diet is one that creates very little residue, meaning that once digestion is complete there is very little undigested food to be excreted from the intestinal tract. 'Residue' is mainly comprised of fibre that has not been digested in the colon, and which then forms a bowel motion. A low-residue diet contains much less fibre than is recommended in general dietary guidelines.

The average person is encouraged to consume 25–30 g of fibre per day, depending on age and gender. Foods that are higher in fibre include wholegrain products such as breads and cereals made from barley, oats, bran and rye, brown rice, fresh fruits and vegetables with skin, legumes, nuts, seeds and dried fruit.

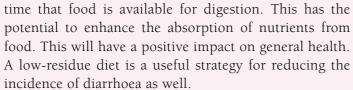
However, a low-residue/low-fibre diet contains less than 10g of fibre per day and focusses on foods that contain very little fibre. These include foods that have been refined, cooked or canned, such as refined cereals and breads. They include white bread, rice and pasta, as well as stewed fruits and well-cooked vegetables without skins or seeds.

The benefits of a low-residue diet

There are several benefits to a low-residue diet that can make it look attractive, especially to ostomates. The first is that, due to the fact that it contains very little fibre and therefore creates very little residue, there is very little stomal output. This can be beneficial for those with an

ileostomy in particular, but may also make life easier for those with a colostomy. The reduced volume of output creates a life with more ease and freedom.

A low-residue diet also slows the transit of food through the intestinal tract, which increases the



In addition, the foods that make up a low-residue diet, such as white bread, white rice, noodles and pasta, are much easier to digest than their wholegrain counterparts. This type of diet is therefore less demanding on the intestinal tract. Digestive capacity can be reduced in those convalescing from surgery or illness and also the elderly, and so a low-residue diet can be easier to assimilate and leave more energy available for other functions or activities.

A low-residue diet can be a worthwhile step to temporarily settle intestinal symptoms such as diarrhoea or pain, a flare-up of IBD or diverticulosis, or after intestinal surgery, including stoma formation or reversal. There is definitely a time and place for consuming low-residue foods; however this does not necessarily make it a viable long term strategy for optimal health.

The drawbacks

A low-residue diet contains foods that are refined and without skin, peel or seeds as well as foods that have been well cooked. It is a diet that contains very little fresh, whole food such as fruits, vegetables, wholegrains and legumes which supply important antioxidants, phytochemicals, vitamins, minerals and other nutrients. And this is where the problems start to arise.

Grains that have been refined have had the parts removed that contain important vitamins and minerals, such as B vitamins and trace minerals. Foods that have been cooked contain fewer nutrients than those that are fresh and raw. Thus, for example, there is less Vitamin C and folic acid, which are important for good health. A low-residue diet can therefore lead to nutrient deficiencies over time which may then have a negative effect on your health status.











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Exorcising the cancer demon

By Fiona Hedges

Gosh! Where to start? After I received the November 2018 issue of Ostomy Australia, I left it on the dining room table to read later. My husband read it from front to back. He got to page 37 and brought it out to me and said I must submit my story for others to read.

ainting the positives at Bondi Beach' (Nov. 2018) was inspiring but I am not at the point that I would ever display my bag in public. But there is still much that ostomates can learn from one another's experiences.

I happily remarried in 2008 and at that time was still working full-time and commuting daily to work 65 kilometres from my home in a small rural town in NSW. In 2011 I retired from that 34-year-long career and took up part-time employment in my town.

In April 2015 I experienced pain while trying to poo, which alternated between runny to extreme thickness. I attended my medical practice and the doctor suggested getting a haemorrhoid treatment and Metamucil from the chemist, which I did. I then noticed some blood residue on the toilet paper, but thought nothing of it.

But in October 2015 I suffered a couple of large blood dumps and went back to my medical practice and saw another doctor, who immediately referred me to a specialist physician an hour away. My colonoscopy detected polyps in the base of my rectum, and on the



eve of my 60th birthday I was told I had bowel cancer. My husband and I were devastated. I could not recall ever receiving a bowel cancer testing kit. A battery of tests ensued, followed by an appointment with a colorectal surgeon in Sydney. I underwent extensive radiation for five days, driving from my home to the cancer centre and returning to work afterwards. I had no side effects whatsoever. When things had started turning pear-shaped I was a healthy 55kg, 173cm tall woman, but I dropped to 47kgs and am slowly clawing my way back up.

I had to have my surgery within seven to 10 days after radiotherapy ceased, so off to Sydney on a Friday in December 2015 and six hours of surgery with a wonderful zipper at the end. Hated that morphine, but not once did I feel nauseous. Hated the physiotherapy—tried to cough and said 'what you get is what I can give', but I persisted with walking up and down the hallway with the pole attached to all the tubes and things. Only clear fluids for nourishment, of course.

On the Monday the stoma therapist came to check and change my new appendage. She forgot something in her bag and I said I would help. So I held the pad over the open stoma while she went to get what she wanted. Everything went well and she gave me instructions about changing the bag in the future. She said she

had never seen anyone deal with the situation as quickly as I did.

My nurse came a couple of days later to do another change, and when we were in the bathroom, she said she was going to do it all for me. I said I wanted to do it, that I had to deal with it, as this was going to be part of the rest of life: if I was doing it wrong, tell me. I was still on clear fluids on Christmas Day and had dutifully ordered my

husband a turkey and ham lunch, which he gleefully ate in front of me. My surgeon came daily, even on Christmas Day.

I was discharged a few days later and came home thankfully. Ironically, the day I got home I got a letter from the National Bowel Cancer Screening Program to say

I should contact them for a new test, I politely said I had just come home from surgery and they could delete me from the register.

Once home, I had daily visits for a while from our wonderful community nurses to tend the wound. They eventually removed 120-odd staples from the zipper.

In early February 2016, I started 'at home' low-dose chemotherapy tablets and returned to my work not long afterwards.

A downside was the fact that I could not resume my normal sexual relationship with my husband. When I felt up to it, I experienced severe pain.

Continued page 22

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The pros and cons of a low-residue diet

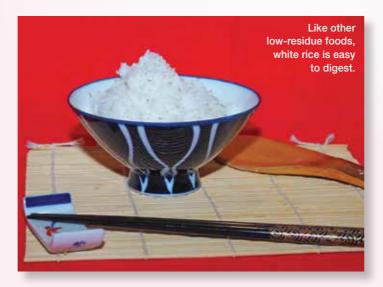
Fibre in food is also a significant source of nutrition for the good bacteria that live in the intestinal tract. These bacteria digest the fibre once it reaches the intestinal tract and then use the nutrients gained for their own health and survival. They perform important functions that support health and wellbeing of humans in general both inside and outside the intestinal tract, and are therefore key factors in attaining or maintaining optimal health. Unfortunately, the bacterial population changes in volume and diversity in response to a low-residue diet, and this can adversely affect health.

When to adopt a low-residue diet

A low-residue diet can reduce stress and alleviate problems for some people, and there is merit in adopting this type of diet in certain circumstances. If you are recovering from stomal surgery or are experiencing a flare-up of intestinal issues, then a low-residue diet can assist with general healing and resolution of symptoms.

For people with an ileostomy or colostomy, there are obvious benefits in terms of reducing both volume of output and possible complications from higher fibre foods. However, this type of diet should only be adopted for a short period of time to alleviate immediate symptoms or complications. Once a condition is settled and stabilised, people should resume a diet that contains as much fibre and nutrition as can be tolerated, as this will reduce the risk of deficiencies in nutrient status or bacterial populations.

For people with a urostomy, however, a low-residue diet provides no nutritional or lifestyle benefit and may even be counterproductive to good health. Nutrient deficiencies may develop and the bacterial population in the colon in particular could be adversely affected. Those with a urostomy will benefit more from adhering



to a higher-fibre, fresh, wholefood diet.

If, for some reason, a low-residue diet needs to be followed longer term, then I recommend supplementation to replace the nutrients that are not readily supplied by this type of diet. If you have been maintaining a lowresidue diet for an extended period of time and feel that your nutritional intake may be lacking as a consequence, or you would like assistance regarding supplementation to fill specific nutritional gaps, a nutritionist can help. You can contact me regarding consultation options.

Wishing you good health and happy days,

Margaret •

Margaret Allan is a nutritionist who advises both ostomates and the general public on diet and health-related matters. She is the director of the consultancy Nutrition For Ostomates. To contact her for a consultation or read more nutrition articles supporting the health of ostomates, go to www.nutritionforostomates.com.au.

Exorcising the cancer demon Continued from page 20

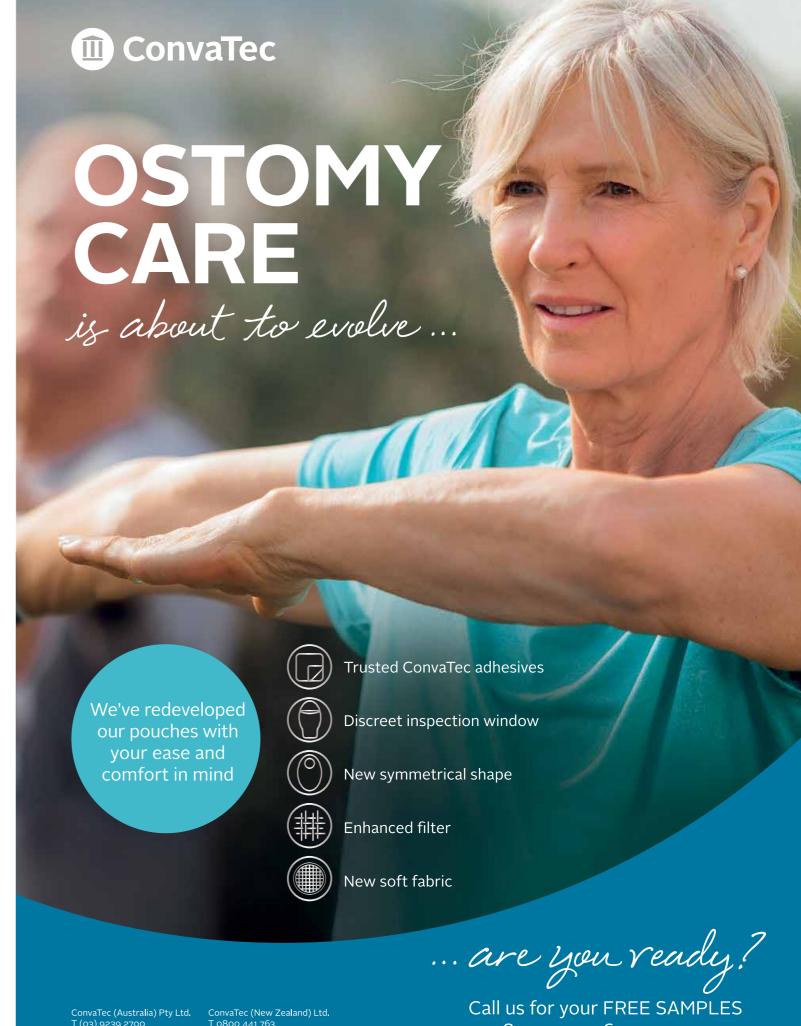
My surgeon suggested a dilatation aid (similar to a dildo) from the Cancer Centre. It sort of worked but things were very tight as a result of the surgery and are still not back to normal. Adapt and overcome.

Of course, all this has been followed up with 'vampiring', colonoscopies and CT scans. So far so good, with nothing

showing and cancer markers

I have recently had to have a revision of the stoma, due to extreme pain from stenosis, which involved chopping off the old and creating a new one. That was done late last year and everyone says I am now looking a lot perkier and nearly back to my normal self.

My take-out message from this experience is—encourage family members to take the bowel cancer screening tests (my husband finally did his and was clear); don't ignore blood in the faeces, and persist if doctors ignore or dismiss your symptoms. Be positive and ask lots of questions.



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Adventures and setbacks

-but life goes on By Craig Wallace

i! Just thought I'd tell my story to let people know that life doesn't have to be boring with a stoma—or two.

I was born in 1965 in a small country town hospital, a healthy little boy except for a major birth defect, epispadias/exstrophy. Basically the lower abdomen wall had not closed and a small bladder was on my outside. I must say I was the first baby with this condition that poor local doctor had ever seen!

There were many operations over 10 years to repair the condition but nothing worked, and I had to wear nappies (cloth ones) and those shocking plastic pilcher pants over the top. I had an ileal conduit performed when I was ten. Thank God! My life started to get some normality. I was hoping the constant teasing and bullying would stop.

Oh boy, was I wrong! It got a little better, but only as I went to high school and left some of the bullies behind in another school. I hooked up with new mates who knew about me but didn't judge me and actually protected me from others. But school wasn't for mebad grades, teasing, and no such thing as counselling in those days: just 'toughen up, buddy'. I dropped out of school at 15 and went to work. Even better, the bullies were

gone now.

I played A grade soccer from the age of eight to 20, was actually a rep goalkeeper, then went on to surf, race dirt bikes, rock climbing, waterskiing and snowboarding. I had girlfriends throughout my teens. I bought a Kombi van and travelled and worked around Australia with a new girlfriend in the late '80s.

Then, when I was 25, I decided I wanted to experience the world. I got a job in an American summer camp as the waterskiing instructor. I had such a good time that I bought a cheap wagon and travelled the States for four years, returning to camp every summer, working my way up the ladder to waterfront director. I also visited the UK and Europe for many months.

The obvious question is—how did I access appliances? My mother would send them in three-month batches to addresses all over the world. And it worked, luckily.

I returned to Oz, moved to Sydney, and started to work properly again, earning decent money for the next stage of my life.

I started full-time work constructing overhead pay-TV cables. But after three years—you guessed it—I was getting bored. I studied tour guiding and got a job as a freelance guide, traveling all over Australia, New Zealand and Fiji. I loved it. I was entertaining large groups of elderly American tourists.

A special event occurred at this time. I met a lovely girl who went on to be my wife. We were both getting older and talk of children popped up. I knew I couldn't have kids naturally, so for many years we went down the IVF path. It was one of the most agonizing times you could imagine. On our very last attempt, as we ran out of money and tears, we struck gold! Pregnant finally! And with some embryos in the freezer.

As we are originally from the country, we decided we didn't want to raise a family in the big smoke, so we moved to

beautiful Jervis Bay—bought land and built a house for less than a

deposit back in Bondi. Then our miracle arrived, a gorgeous baby girl. Life was great. We spent three months touring Cape York when Bella was three years old, and on our return miracle number two happened—a frozen embryo turned into another bouncing little girl.

Jump forward nine years and I found that I was starting to lose control of my bowel movements, a condition to do with my birth defect. It was

very embarrassing and awkward, even for me. After several operations to regain some quality of life, there was no improvement. I'd nearly given up on everything and came to the conclusion that a colostomy was the way to go. It took a while to find a surgeon who was willing to do the operation. I finally found my surgeon when I was admitted to hospital for a bowel obstruction late last year. I had surgery a week later and now have my second stoma. I know for sure it was the way to go—no more running to toilets, going bush all the time, freaking out if there wasn't a public toilet within reach.

I'm looking forward to healing and recovering and on to the next chapter of my life—a year travelling around Oz, leaving in February 2019 in our new van and truck. If you are interested please follow us on 'Cruzin Round' on Facebook and Instagram. All I can say is—live life to the fullest, as we're on Earth for such a short time.



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'ENABLED' BY STRENGTH AND SHARING By Adelle Ingram

became what I like to call an 'unexpected ostomate' on 18 October, 2018. I had never heard of an ileostomy before and had never suffered any bowel or intestinal issues. I was 38 weeks and 5 days pregnant when my husband and I presented to hospital in Werribee to have a planned caesarean section. I had no health reasons for needing a c-section but rather my fear of natural birth blindly convinced me that this was a safe alternative. I had an epidural on the morning of 15 October and our beautiful son, Lincoln

Peter Ingram, was born. There had been no complications—or so

Many women develop 'lazy bowel' after a c-section. The anaesthesia can slow down the muscles and it can take three or four days for the bowel to start working again. Unfortunately, my bowel stopped working altogether. I developed a rare complication called Ogilvie Syndrome, which occurs in less than 0.05 per cent of the population. Ogilvie Syndrome is the acute dilation of the colon in the absence of any mechanical obstruction in severely ill patients. In other words, the body acts as though there is a blockage and over the course of up to a week, in very ill patients, the bowel can perforate.

In the two days that followed the birth of our son, I experienced a pain that I cannot describe. The very thought of it still reduces me to tears. My bowel perforated in less than three days (a record my surgeon tells me!) and no one knew what was wrong with me. I developed sepsis and an emergency operation that saved my life was performed at 12am on the morning of 18 October. My breathing and blood pressure were very unstable due to the infection so I spent three days in ICU before being transferred to

I don't remember the exact moment I realised I had an ileostomy. The early days in recovery were such a blur. My first recollection of seeing 'Steve the Stoma' was my amazing stoma nurse visiting my room and saying 'It's bag change day today! Now, you don't have to do anything, just have a little look'. When the bag was removed, I cried so hard and squeezed my eyes tightly shut. I remember thinking, 'Why is this 'thing' on my body?'

I had to learn to walk again, both due to suffering severe pelvic instability as a result of the pregnancy and also due to my middle having been opened up for the surgery. I was a first-time mother who couldn't breast feed (because I was too unwell) and couldn't look after my own baby for the first two-and-a-half months unaided. At first the trauma was acute but over the weeks and months that followed it has dulled, now manifesting itself in different ways. I have more good days than bad, but even at the best of times it can be difficult to put on a brave face.

To recover from the mental trauma, I started an Instagram page (overnight_ostomate) in January 2019 and reached out to the ostomy community. It was here that I was exposed to the strength and courage of a group that only a few months earlier I didn't even know existed. I learned very quickly that there were other people struggling far worse with their new identities than I was, so I did what many people cannot bring themselves to do and shared a photo of my stoma for everyone to see.

I have never posted revealing photos of my body but ending the stigma that surrounds ostomies is a cause that is bigger than simply my own self-consciousness. Two days after I posted



these photos, 10-year-old Seven Bridges committed suicide in America for being bullied at school over his ostomy. And so the #bagsoutforSeven begun with people all over the globe posting photos of their bodies with their ostomy bags to help to start a conversation about ending the stigma. There is so much work to be done in supporting ostomates in Australia and educating the community about how incredibly enabling ostomies are.

The encouragement and support I have been shown by connecting with other ostomates via social media has given me a renewed strength in myself. You are all warriors! I am in awe of the resilience and strength of my fellow ostomates. I am so proud to be a part of this community, even if it is for a short time, and will give back whatever and however I can. My ostomy has already taught me so much about myself and also about a collective of individuals whom I would have otherwise looked at as having a disability. I understand now that we do not have a disability—it is in fact quite the opposite. We have been enabled. We have been given a second chance, the ability to live our lives to the fullest again. And for this, I am thankful every day.

I have decided that my journey cannot be for nothing and so I am currently working with the hospital where I had my baby to create awareness about the complications that c-sections can have on the bowel, post-surgery. It is important that couples understand that it is still a major operation and not simply a 100 per cent safe alternative way to give birth, as I once believed. There has already been change in the way the staff assess bowel sounds in their patients and they now do not provide solids to patients until the bowel has been deemed 'active'. I am looking forward to becoming an active member of this community: sharing my story in the journal and on my Instagram page is just the beginning #EndTheStigma.



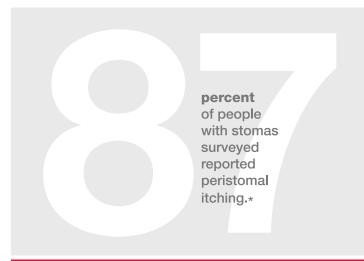
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^{*} Consumer Survey of Pruritus, 2016 Hollister Data on file

^{**}As compared to Hollister non-ceramide skin barriers. Colwell J, Pittman J, Raizman R, Salvadalena G. A Randomized Controlled Trial Determining Variances in Ostomy Skin Conditions and the Economic Impact (ADVOCATE Trial), J Wound Ostomy Continence Nurse, 2018;45(1):37-42

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Patient or prisoner?

Jodie Nelson is an Accredited Life Coach, mindset specialist, motivational speaker and executive leadership coach who specialises in chronic disease management and effective communication strategies for patients, medical professionals and supporters.

Towards the end of last year I was fortunate enough to have the opportunity to deliver a keynote speech at The Focus on Pain Group conference held at The Princess Alexandra Hospital in Brisbane.

I was asked to give an honest account of life as a regular hospital guest—or, a carelessly thrown-around term, a 'frequent flier'.

After careful consideration and many discussions with other ostomates and nursing staff, I decided to deliver a speech that delved into the core of what makes us either a patient or a prisoner when we step through the doors of a hospital.

These words can literally define the roles and identities we take on throughout our hospital journey. Could we really be a guest? Or are we a patient? What about a prisoner? Maybe a victim? Sometimes a victimizer? Very rarely a victor.

You see, the identity or role we take on depends on what part of the journey we are on.

Here's an example. You present to hospital through the front door: you are now a patient.

You are taken through to acute care, where you are still a patient.

You are given a gown to change into and an identification band is placed on your wrist. Now you have become a prisoner.

You are asked to explain what brought you to hospital that day and now you move over to being a victim.

The doctor walks away with your information and doesn't tell you what the

next course of action is. Now you are both a patient and a prisoner.

You will most likely become anxious at this point. Why?

You have no control over what happens next.

You have no certainty, nor do you feel safe.

Often you will take that anxiety, turn it into aggression, point it at the nearest person to you, and fire. Generally this will be the nursing staff, not the doctor who failed to communicate in the first instance. Before you know it, you have become the victimizer.

Once you reach this level your brain goes into protection mode, which is referred to as the fight or flight response.

Most people will fight, as they know they need to receive the medical attention the hospital provides in order to get well. This is where it gets really interesting.

The fight and flight response tells your adrenals to kick in and that magic hormone, cortisol, releases into your system. Now combine that with some adrenalin and guess what? You are now a walking Mount Vesuvius and you are ready to explode at any given moment.

It's often at this point that medical intervention will start, so it may take a little longer for medication to take effect.

While this is occurring you may move between being a patient, a prisoner, a victim and a victimizer. How toxic and exhausting!

I urge you to think about this for a minute: how often are people stuck in this vicious cycle?

Do most people have the emotional capacity to actually register when they are in this cycle?

Do they take ownership or responsibility for their own actions?

The answers to these questions are—60 per cent of people are too caught up in their own dramas or creating other

mind over matter



dramas to know there is another way of dealing with their journey. Everyone else is to blame, not them.

Thirty per cent of the population recognise there is a problem but don't know how to express it resourcefully; nor are they able to completely resolve the problem, but the good thing is they are trying.

The scary part is, only 10 per cent of the population are happy to be exactly where they are.

They are able to explain their problems and resolve issues as they arise. These people have very few dramas and are grateful to be alive. These people recognise the part they play in their own journey.

Be honest and ask yourself—are you part of the 10 per cent?

If you are, congratulations, I applaud you. If you are not, why not?

You can change this straight away, if you really want to. To start off, all you need to do is change one thing at a time. What could that be?

Which single change would benefit you best on your personal road to recovery or treatment?

Act on your decision straight away.

Make no excuses and see how different
your journey will look going forward.

If you fail at first, try again and you will eventually succeed.

Remember always to fail going forward, not backwards, and enjoy every moment you have on Earth.



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A farm day to savour By Peter Ralph



Late last year Northern Tasmania Ostomy Support Group was invited to participate in a friendly barbeque lunch at the Ivy Lawn Farm property of Don and Barbara Pitt near Greens Beach in Northern Tasmania.

Ivy Lawn Farm is situated at a most picturesque location on the western side of the entrance of the Tamar River estuary.

On a beautiful warm spring day at about 11am we arrived to be met by Barbara and Don. They introduced us to several early starters from the North West Coast Ostomy Group who had made the trip from the Burnie-Devonport area to share the day with us Northerners. Barbara and Don had a lovely array of tempting morning tea titbits and drinks at the ready. The BBQ was already warming up, with enticing aromas of things to come.

By midday the group had grown to around 30 souls. Old acquaintances were being re-made, friends welcomed and stories were being told or re-told.

At this stage Barbara called us all to attention and we were escorted into her large entertaining and dining room, where we were introduced to our guest speaker, local historian Greg Squires, who the gave us a pocket history of Ivy Lawn Farm, with a detailed account of the property and the area going back to times before white settlement. For 40 minutes we were treated to tales going back before the 1820s, from shipwrecks and people living in tents and hessian huts, to financial ruin in the Great Depression. The property has been used for orcharding, potato farming, and raising cattle and sheep. Stands of timber have been planted that are still being used today.

After Greg's presentation, it was time for lunch. There was no shortage of food. Various meats were available, including wallaby rissoles, possibly made from game procured on the property. The BBQ delights were amply supplemented by an array of

salads and breads. Then, just when one thought there was no room left, desserts! Fruits, cake and pavlova, biscuits and scones, cordials, tea and coffee. What a spread!

After the feast, those feeling able were invited to see Don's saw-milling operation. Huge logs of macrocarpa cyprus pine were being broken down into planks and boards. The operation can be handled by one man, though two obviously can do it more easily. Much of this timber was planted many years ago and is still producing an income today, 50 to 100 years later. Every aspect of Ivy Lawn Farm is in pristine condition and a delight to behold.

Well into the afternoon, our appetites sated, it was time to say goodbye and head for home. A great day was had by all. Thanks to Adrian Kok for his organising skills and dedication to ostomates in Tasmania, and to Barbara and Don Pitt. Without their invitation, this wonderful event wouldn't have happened.

National Directory of Ostomy Support Groups

NEW SOUTH WALES

ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00 am 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: Tarndra (08) 8080 1333

CENTRAL COAST

Meet: 1.30 pm to 3.30 pm 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 2016 meeting dates to be advised. Venue: Sawtell RSL Club, First Avenue, Sawtell.

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

GRAFTON & DISTRICT

Meets first Thursday of each month from 9.00 am to 11.30 am 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 at 10 am to 12 noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec. Inquiries: Neil 0427 856 630 or Glennie 0410 637 060

ILLAWARRA

Meets 10am to noon, April June, October and December (Christmas Party). Venue: Figtree Private Hospital, 1 Suttor Place, Figtree 2525. For further information contact Helen Richards CNC STN (Wollongong Private Hospital) (02) 4286 1109 or Julia Kittscha CNC STN (Wollongong Hospital) 0414 421 021

MANNING/GREAT LAKES Meet: 10.00 am to 12 noon on first

Wednesday in Feb - Apr - Jun - Aug -Oct - Dec. Venue: Skills for Life Building, 5-9 Elizabeth Ave. Taree NSW

5-9 Elizabeth Ave. Taree NSW (wheelchair accessible)
Website: www.mglostomy.co.cc
Contact: Karla MacTaggart on (02) 6592 9469

NEWCASTLE DISTRICT

Meet at 1.30 pm on the last Saturday in Feb - May - Aug (AGM) - Nov. Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton. Enquiries: Geoff (02) 4981 1799 or Lynda 0425 209 030 or Maree (02) 4971 4351

ORANGE & DISTRICT

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

SHOALHAVEN

Meet: Meets Feb, May, June, August, Nov 2019 at 2pm. Venue: Nowra Community Health

Centre, 5-7 Lawrence Ave, Nowra. Contact: Brenda on (02) 4424 6300

SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets: Thursdays from 1.00 pm to 3.00 pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden)

For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SYDNEY - PENRITH AREA

Nepean Educational Support Group meets 2pm-3.30pm, 10 May, 26 July, 27 September, 29 November.. Venue: Sydney Medical School, Clinical School Building, 62 Derby St., Kingswood. Family and friends welcome,

afternoon tea supplied.
Enquiries: Naomi Houston (stomal therapist) (02) 4734 1245

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

TWEED-BYRON

Meets 3rd Tuesday of March, June, Sept., 2nd Tuesday in Dec., noon to 2pm. Venue: South Tweed Sports Club, 4 Minjungbal Dr., Tweed Heads South. Contact: Lisa Clare STN (07) 5506 7540.

WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00 am to 11:00 am. Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga Enquiries: David (02) 6971 3346 or 0428 116 084 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

BALLARAT & DISTRICT OSTOMY SUPPORT GROUP

Meets: 2pm 2nd Wednesday of each month Venue: Barkly Restaurant, cnr Barkly St and Main Road. Contact: Graeme on 0400 979 742 or David Nestor on (03) 5339 4054 Emails: david.nestor2@bigpond.com or graob44@gmail.com

BENALLA / WANGARATTA

Meets 2.00 pm on the third Monday of each second month. Venues: Wangaratta: North-East Health. 4-12 Clarke St., Wangaratta.

Health, 4-12 Clarke St., Wangaratta, April, Aug., Dec. Benalla Community Health, 45 Coster St., Benalla, Feb, June, Oct.Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943. Email: mgpwang@gmail.com

BURWOOD

Meets third Saturday each month except Dec. and Jan. 9.30am - new members' orientation; 10.30 - established members' meeting. Venue: OAM Distribution Centre, Burwood Industrial Park, Unit 14, 25-37 Huntingdale Road, Burwood, VIC 3125.
Phone (03) 9888.8523
Email: enquiries@oam.org.au

MELBOURNE

Colostomy Association of Victoria.
Meets 11.30am - 1.30pm, second
Wednesday of each month from
February to December.
Venue: Australian Prostate Centre,
Level 8, 14-20 Blackwood Street,
North Melbourne.
Website: www.colovic.org.au
Contact: Colin Hunter 0437 070 657
Tues. and Wed.

MILDURA

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

SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on 0447 942 406 for more information

SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre Enquiries: Norma Murphy 0409 252 545

WARRNAMBOOL & DISTRICT

Meets at 10.30am on the second Friday of the month in Feb - Apr - Jun -Aug - Oct - Dec.

Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093 Warrnambool Ostomy rooms (Fridays)

WESTERN AUSTRALIA

ALBANY

(03) 5563 1446

Meets at Albany Hospice conference room, 9.30 am to 11 am on the first Friday every three months. For details, contact Terry (08) 9847 4701 or 0428 502 530

PERTH (WAOA)

Venue: 15 Guildford Road, Mt Lawley. New members support orientation session: Second Saturday of every month, 12 noon-1pm. Weekend general support group: Second Saturday of every month,

QUEENSLAND

BEENLEIGH

1pm-3pm.

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: Logan Hospital Stomatherapy Unit, (07) 329 9107

BOWEN

Meets the first Wednesday of each month at Bowen Hospital, 10.30am. Contact: Natasha Leaver (07) 4786 8222 or

Valerie McDonald 0407 691 160.

BRISBANE

Brisbane Ostomate Support Visitors Service (BOSVS) is a new ostomate visitor service operating in the Greater Brisbane Area. Phone: (07) 3359 6500. Website: qldstoma.asn.au/bosvs.htm Operating Hours: 7 days, 8am to 8pm. Operated by Qld Stoma Assn and Qld

LOGAN

Ostomy Assn.

Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre Corner Wembly & Ewing Roads Contact: Logan Hospital Stomatherapy Unit, (07) 3299 9107

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MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan -Mar - May - Jul - Sep - Nov). Venue: Meeting Room, Mackay Mater Hospital.

Contact: Graham Stabler for further information on 0428 776 258 or email:

grahamstabler@bigpond.com

SOUTH BURNETT

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

SUNSHINE COAST

Sunshine Coast Stoma Support Group meets at Maroochy RSL Events Centre, Memorial Avenue (off First Avenue), Maroochydore, second Monday of every month, commencing 10am. **Enquiries:**

Laurie Grimwade: (07) 5445 9008 sid.and.laurie@gmail.com Janelle Robinson: 0409 762 457 candirobinson@bigpond.com Kathy Himstedt: (07) 5445 9270 greg.kath1@bigpond.com

TOOWOOMBA

Insideout Toowoomba Stoma Support. These stoma mates would love to hear from you: ring for a chat or send an email. Margaret Brabrook (07) 4635 1697, embv1936@gmail.com: Leanne Wilshire (07) 4630 0629, leanne.wilshire@bigpond.com; Margaret Lavery 0407 375 417, mslavery80@me.com; Laurel Czynski, 0413 805 809

WIDE BAY

Meets from 1.00 pm to 3.00 pm 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'

Meets in Hobart on the third Friday of every month from 2pm to 4pm. **Enquiries: Renata, Cancer Council** Tasmania, (03) 6169 1900.

NORTH & NORTH-WEST

North: Meets at Cancer Support Centre, Howick St., Launceston, on first Monday of March, June, Sept and Dec.

North-West: Meets Ulverstone Senior Citizens' Club, King Edward Street, Ulverstone, 10am-noon, on the second Wednesday of March, June, Sept and Dec. New and present members welcome.

Contact: Adrian Kok on 0498 196 059

SOUTHERN TASMANIA

Meet at Glenorchy RSL Club, Main Road, Glenorchy, 10am-noon on first Wednesday of March, June, Sept, Dec. New and existing members welcome. Further information: Adrian Kok: 0498 196 059

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: (08) 8234 2678

FLEURIEU

Meet: 10.00 am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbour. 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

NORTHERN TERRITORY

DARWIN

Meet: 5.00-6.00pm on the first Tuesday of every month. Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810 Contact: Marg Lavery: (08) 8944 1800

YOUNG OSTOMATES **UNITED (YOU)**

Tel: Helen (03) 9796 6623 Web: www.youinc.org.au Email: helshae@hotmail.com Facebook:

Young Ostomates United

BOWEL GROUP FOR KIDS INC

Tel: (02) 4659 6067 or 0431 857 188

Email: enquiries@bgk.org.au Web: www.bgk.org.au

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Email: au.care@coloplast.com Website: www.coloplast.com.au

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

Sutherland Medical



PO Box 1194, Huntingdale, Victoria 3166

Phone: 1300 664 027 Fax: 1300 664 028

Website: www.sutherlandmedical.com.au

Future Environmental Services



PO Box 319, Blairgowrie, Victoria 3942 Phone: +61 3 5985 2828

Email: health@futenv.com.au Website: www.futenv.com.au

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Nice Pak Products

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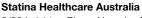
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