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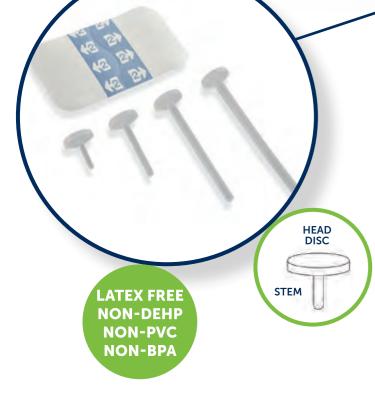
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## **PRESIDENT'S MESSAGE**

#### Greetings to you all.

I would like to begin my first President's Message by thanking outgoing President Geoff Rhodes for his tireless efforts as part of the Australian Council of Stoma Associations (ACSA) Executive over the past eight years, the last four as President. I have appreciated the support and encouragement he has given me in my role as Vice President during these four years. In the last edition of *Ostomy Australia*, Geoff recounted some of the challenges that have been faced within the last few years. It is a testament to his leadership that ACSA has met these challenges and continues to guide the delivery of support through a world-leading ostomy appliance program.

I am very pleased to welcome Erin Goodwin to the ACSA Executive as Vice-President. For several years Erin has been a dynamic advocate for ostomates both in Australia and internationally through her blog, website and Facebook page, Inside Out Ostomy Life. I know she will make a significant contribution to ACSA as Vice President. I take this opportunity to also thank the continuing committee members, Rosemary Quick (Secretary) and Robert Barsing (Treasurer) who, along with our Administration Officer, Kylie McGrory, form the ACSA Executive team.

The theme of the recent 2018 ACSA Conference was 'Youth Inclusiveness' and it was heartening to hear the message of hope and perseverance that Kristy Ross and Hally Chapman, two 'younger' ostomates, delivered. Their stories invoked many memories for me, both good and bad, of when I received my stoma at the age of 17 after a severe episode of Crohn's disease and the struggles I had recovering from surgery and learning to live with an ileostomy. We also heard from Jenna Brook, who undertook 'Running for Bums', a run from Tasmania to Cape York. Jenna ran an incredible 4,500 kilometres to raise money for and awareness of bowel cancer. These three ladies were truly inspirational.

Some of you, especially those of you who may be reading this journal for the first time, may be wondering exactly what ACSA is and what it has to do with your stoma association. ACSA represents, at a national level, the interests of the 21 stoma associations across Australia. Through its Executive Committee, it acts as a liaison for associations between the two government departments responsible for the Stoma Appliance Scheme (SAS) and the suppliers of products listed under the scheme. It also provides advocacy for people living with a stoma in Australia, and publishes this journal and the national publication for new ostomates, *A Beginning Not an End*.

In addition, the Department of Health has also delegated to ACSA the role of monitoring the continuing compliance by stoma associations of the *Stoma Appliance Scheme Operational Guidelines for Stoma Associations*. The operational guidelines

dictate the practice and procedures that associations must follow when issuing stoma-related products to their members through the SAS. The issuing of scheme products by associations is an extension of their primary purpose, which is to assist the wellbeing of people living with a stoma



by providing stoma-related support, information and encouragement.

While all stoma associations in Australia continue to be not-forprofit organisations, many have grown beyond the capabilities of being volunteer organisations. As such, they operate through a blend of paid employees and volunteer workers under the control and management of a volunteer management committee. If you are available, I would strongly recommend that you consider volunteering at your association. The benefits associated with being able to interact with others sharing a similar condition are well documented.

One query regularly raised with associations is why members cannot obtain some stoma-related products 'for free' through their association. By way of explanation, only those stoma-related products that are listed in the SAS Schedule are subsidised by the Australian Government. Stoma-related products that are not listed in the schedule are not subsidised and will need to be purchased either through an association or elsewhere.

To have a new stoma-related product added to the SAS Schedule, the supplier of the product must make application to the Department of Health. Each application is reviewed by an independent technical advice panel appointed by the Department of Health and known as the Stoma Products Assessment Panel (SPAP). After the product has been reviewed, the SPAP makes a recommendation to government and, if the recommendation is favourable, the product should eventually become available through the scheme if the government accepts the recommendation.

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.

David Munro PRESIDENT

# Painting the positives at Bondi beach



When people hear that someone has a stoma, sometimes their reaction is to think: 'Oh my god, your life is over.' But it's not like that at all, says Sydney artist Maryjane Boaretto Pureza—MJ in her professional persona. Her own experience proves it, and she's painted her conviction in bold colours for everyone to see.

MJ's positive statement is spread across a four-by-three metre mural on the beachfront wall at Bondi—down from the Pavilion, just to the right of the Bondi Beach Lifeguard Tower as you face the ocean. Bathers, surfers and sunlovers disport themselves against a brilliant yellow beach. Three of them have their stoma bags in unselfconscious display. You'd say they look, well, normal.

And that's the point. More young people now have ostomy bags, says MJ, and art is a good starting point to talk about their new situation. 'The purpose behind the artwork is to make a positive impact,' she says. It intends to reduce the stigma about life with a stoma and start positive conversations about it.'

Like many good things, the mural owes something to chance. A friend who lives at Bondi saw that the local municipality, Waverley Council, advertised for artists to submit ideas for work to adorn the wall. The council would choose from the submissions it received—'and if there's a story behind it, which in this case there was for me, that's something that they were really interested in,' MJ says.

The story behind the mural is ostomy awareness, and it evolved out of work that MJ began to do after her ostomy surgery in July 2017. 'I did a lot of ostomy art that I put on my Instagram account,' she says. 'It was more about looking at the positive side, and looking at the benefits of having an ostomy bag.'

Those positives came after MJ went through the ordeal of ulcerative colitis, diagnosed when she was 17. She explored all the pharmaceutical treatments, which brought a range of complications and undesirable side-effects. Finally, when dysplasia cells seemed to be developing, she agreed to the doctors' suggestion of a total colectomy and having an ileostomy.

'If I'd known how much my life would improve, I would have had it, like, five years ago. Or maybe earlier.'

Waverley Council's positive response owed something to the municipality's art curator feeling that MJ's proposal was 'quite special', influenced perhaps by her own father being an ostomate.

The council provided the space but not the materials, so MJ went looking for sponsors. She approached several stoma organisations before Omnigon stepped forward. 'Omnigon said, look we'd love to do it, but we want to be exclusive,' she recalls. 'I said—that's fine by me.' This too had a personal dimension, because Omnigon director Len Collins is a painter and an art aficionado—'so when this project came up, he was really interested in backing it. It seemed like a wonderful opportunity for both of us.'

The council was good to deal with. 'They were really understanding,' she says. 'I was supposed to do my artwork starting in January but I broke my collarbone—my painting arm—so I said, I'm so sorry, can we push this back? And they said, yes, that's fine.'

When the injury had healed, she went to Bondi to start work. 'They allocate you a spot, and there's an existing artwork there. If it's a very dark artwork you have to paint over it—you just use grey paint to cover the dark paint. We were quite lucky, we had a light piece to paint over, and my husband helped out with the initial

## Painting the positives at Bondi beach

Continued from page 5

stages-he's not very arty, so he just did the undercoat.

'My friend from Bondi, who initially encouraged me to submit my artwork, came to help me paint. My mum also helped out. I did all the drawings and I'm like, OK, you can start painting that bit yellow, you paint that bit green. It was nice to have a bit of help and both mum and my friend agreed that painting felt like a therapeutic experience.'

MJ and her team used external acrylic house paints to withstand the wear-andtear of sun, wind, and rain. 'Because it's such an exposed wall anyway, it's never going to be perfect—it's a rough surface. l've been down and already dirt and things have built up on it. But it's the place where the art is, out in the elements, so it's to be expected '

She finished the mural in July, after four days of intensive effort. 'And it was freezing cold! It was really windy, the temperature must have been 10 degrees, maximum. I had to start early, at about seven, and I'd finish about four. One day it was so cold, I had to go and get a hot chocolate and sit in my car just to warm my hands up before I could keep painting.

'It was really nice to have the painting actually finished on the one-year anniversary of having my stoma—I called it 'stomaversary' on Instagram. There was no way I could have done something like that while I had ulcerative colitis.'

MJ's active use of social media played into the mural project. Some Instagram friends made a point of visiting the mural and taking selfies, sometimes with their bags on display. There are plans for half a dozen young Sydney ostomates to pose for a #getyourbellyout photo in front of the mural before the year is out. 'We're hoping to get the photo into the media and get some more awareness out there,' MJ says.

She notes that social media support for ostomates has 'really taken off in the last couple of years'. People know they will get excellent medical advice from doctors and stoma nurses, but social media offers



the chance to connect 'with other likeminded souls'. 'You're able to see you're not alone, you're able to get support and advice from people who know what you've been through. It's just so great to be able to talk with someone who's actually experienced the same things." Her own ostomy illustrations are at www. instagram.com/emjayuc.

However, an unexpected and immediate bonus while MJ was painting was feedback 'from people who were walking past, people who actually knew someone with an ostomy bag, or had heard of people with Crohn's or colitis or that sort of thing. It was more of a talking point than I realised it would be.'

MJ studied graphic design and later taught herself web design, but has always been interested in art and illustration. She has created a couple of murals when visiting South America with her Brazilian husband, but nothing of the scale of the Bondi work. Although she will be illustrating a children's book for the next few months, she will look at mural

opportunities when she next goes to Brazil. A viewer at Bondi might detect the inspiration of Brazil, where the colours are 'so bright and positive'.

Waverley Council updates artwork at Bondi every three to six months, so the mural's life is limited. Still, some artwork has been there for more than a year. Longevity seems to depend on a work's popularity. MJ thinks it would be great if her work remains for summer.

And will it encourage people to go on to the beach with their appliances on display? 'I really hope so! I know some people do,' she says. 'I have, but Sydney water is too cold for me to swim, so I'd just rather sit on the sand—but it's something not to be ashamed of. Everyone is a different shape and size. Some people talk about their ostomy bag and wish they didn't have something there. My approach is-it's just there, and that's how I live now. You just have to keep living your life and not worry about these things.'

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## NATIONAL CONFERENCE **ACSA will tackle SAS funding squeeze**

The Australian Council of Stoma Associations will approach the federal Department of Health to explore ways to ensure the continuing financial viability of Australia's 21 stoma associations.

The decision was taken at the 2018 ACSA conference, held in Sydney on 19 and 20 October, after delegates were told that associations faced a squeeze because of the widening gap between costs and revenue under existing Stoma Appliance Scheme arrangements. Data presented by ACSA's Administration Officer, Kylie McGrory, showed that most associations were operating below break-even point under current SAS arrangements. Consequently, SAS revenue alone was not sufficient to ensure the longer-term viability of associations.

Kylie identified several factors contributing to the shortfall affecting many associations. First, the implementation of the new pricing structure between 2010 and 2012 after the SAS review in 2010 had led to a net decrease in the handling fee as a proportion of products distributed. The benchmark price of some products had fallen as a result of the review, and even with the 2.75 per cent handling fee introduced after 2012, returns in some cases had fallen by more than 30 per cent. The difference on a one-piece urostomy product was a deficit of 39 per cent.

Secondly, members' usage had changed over the past decade, with a move towards one-piece appliances. The 2.75 per cent handling fee increase had been designed to compensate associations for reductions in the rebate they received, since the review had adjusted downwards the price of some products-notably one-piece convex items. But the product mix that existed in 2012 had shifted, and the increased demand for one-piece products had amplified the effects of the unit price reduction, Kylie told delegates. The total number of onepiece systems issued had increased by almost one million units between 2012-13 and 2017-18, whereas the issue of two-piece systems had fallen by around 300,000 units.



The Lord Mayor of Sydney, Clover Moore, officially opening the 2018 national conference. She praised ACSA for its work in serving its members around Australia.

The removal of 'price premiums' on some products in April 2013 had also reduced the listed prices of products and, consequently, the return to associations. Annual indexation of prices had been suspended in 2010, ostensibly as a temporary measure. The suspension was made permanent in May 2012, but the promised periodic pricing reviews had never been held, she said.

As well, the number of products listed had increased by more than 80 per cent since 2011, forcing associations to keep less stock on hand but increasing the cost of stock management, and driving up administration costs associated with ordering, invoicing and assessing requests. This came at a time when the minimum wage had risen by 16.7 per cent.

To break even, Kylie said, associations needed an average handling fee set at 3.5 per cent of product cost. Options to tackle the problem included setting the handling fee at a level to reflect the true cost of running the SAS, increasing the SAS fee, reviewing product prices, rationalising the number of products listed, and setting up a stakeholder

group to review current scheme arrangements. Yet even if SAS schedule prices rose by 5 per cent, the handling fee to 3.5 per cent and the access fee to \$70, a few associations still would not break even. Thus there was an argument for rationalising association resources, including reducing the number of associations.

During subsequent debate, there was general agreement that revenue earned through the SAS was not sufficient to sustain associations in the longer term, though one speaker argued that bigger associations were not necessarily better, because they tended to lose money as membership increased. Another cautioned that mergers would not always be beneficial.

However, delegates heard that some associations were eating into their reserves to sustain their operations, and some were using other sources of income-such as raising postage costs-to cover outlays. Retiring vice-president David Munro was one of several speakers who believed that associations needed to take stock of their operations and see what they could do to reduce their expenses.

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There was support for approaching the government to increase the rebate or access fee. Retiring president Geoff Rhodes told delegates that although the Department of Health seemed to have no specific information on the matter, it recognized that associations were under pressure.

Conference resolved to approach the department with a view to working together to find solutions that would ensure that associations remained financially viable, and that the integrity of the scheme was maintained.

Conference decided to reassess the roll-out of the Stoma Appliance Management System (SAMS), following delays in having the dedicated national computer application installed around Australia.

The development of a single national computer system to replace the different systems being used by associations was approved in 2014, when conference agreed to purchase the rights to Ostomy NSW's system and develop it into a single application that could be used nationally. Retiring ACSA president Geoff Rhodes said the implementation committee, which he chaired, had hoped to have all associations using SAMS by the end of 2018, but by October only three associations were using the new system. 'This is not where we expected to be,' he said.

Associations adopting SAMS had been able to migrate data successfully from their old systems, but delays had been caused in some instances by the need to understand each association's operating environment. Most associations used outside providers to run their IT systems, each of which had its own ideas on managing installation and operation.

Geoff Rhodes told delegates the original idea had been to have a centralised environment using the cloud, which would have reduced costs and been more efficient, but that an earlier conference had overruled this.

Delegates expressed frustration at the delays and ongoing cost of the roll-out, including what they saw as a lack of responsiveness by the company developing SAMS. Several motions and

amendments were put before delegates approved the motion by Ian Scholes (Colostomy Victoria) to expand the implementation committee from four members to five, and to report on developing SAMS into a cloud-based system. The report is to include details of benefits and costs, the means for moving SAMS to a cloud base, and a timeline for doing so.

The report is to be circulated to all associations within three months for an electronic vote, if required. The fifth member of the committee will be Ian Murray of NSW Stoma Association.

David Munro was elected president for a two-year term. He had been vicepresident since 2016. Erin Goodwin of Western Australian Ostomy Association was elected vice-president. Rosemary Quick was returned as secretary and Robert Barsing as treasurer.

In his final report, outgoing president Geoff Rhodes said the major focus of the executive had been management of the Stoma Appliance Scheme, to which end it had continued to liaise and consult with the Department of Health. Members of the executive and the national officers had provided a high level of operational and planning outcomes. He thanked associations for their support, friendship and cooperation.

An amended budget with a projected operating deficit of \$40,118 for the 2018-19 financial year was approved. Delegates rejected a recommendation to increase the capitation fee-the per-member affiliation fee that associations pay to ACSA-by 40 cents, from \$1.80 to \$2.20. In recommending the increase, treasurer Robert Barsing anticipated that without the adjustment, ACSA's operating cheque account and term deposits would fall by at least \$80,000. However, the consensus was to leave the fee unchanged.

Under the amended budget, income from affiliation fees, publishing and other sources is anticipated to reach \$105,282. Major expenses include the national computer program (\$50,000), accommodation (\$10,000) and honoraria (\$14,500).



Warren Ravment

National conference conferred life membership on the past president of the Gold Coast Ostomy Association, Warren Rayment, in recognition of his contribution to the development of the ostomy community in Australia and internationally.

Warren has been an ostomate for more than 50 years and in that time helped to found the lleostomy Association of NSW, of which he was president for almost two decades. He is a past president of ACSA, and was president of the South Pacific Ostomy Association and vice-president of the International Ostomy Association in the 1990s. In recent years he has been active in ostomy education at Queensland universities.

**Conference** decided to begin a two-year process to set up formal contractual arrangements between ACSA, associations and supplier companies, including servicelevel agreements or terms-of-trade compacts.

The 2017 annual conference set up a working party to investigate the feasibility of developing these arrangements. The group presented a summary of its deliberations and prompted delegates to specify what the arrangements might include. The meeting agreed to press on with work, with a view to having agreements in place by October 2021. 

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Hally Chapman, Kristy Ross and Jenna Brook: social media an essential tool for young ostomates.

## Focus on youth: support, resilience, communication

Custaining relationships, the need for personal support, the role Uthat social media can play in adjustment and emotional health and the importance of resilience and seeing the positives were among the themes highlighted by three guest speakers during the 'focus on youth' presentation at the ACSA national conference in Sydney.

The trio agreed that having a stoma could be traumatic, but it could also have beneficial outcomes. 'There are challenges,' Kristy Ross told her audience, 'but it doesn't have to be a limitation in the long term. It has given me a second chance at a life that is worth living.

The conference organisers scheduled the session to give younger ostomates an opportunity to talk about their experiences and needs, and for delegates to learn and to consider how associations might better meet the requirements and preferences of younger members. It was also designed to raise younger ostomates' sense of involvement with the stoma community generally.

Each speaker brought different experiences and perspectives to the session. Kristy Ross was diagnosed with ulcerative colitis in her early 30s. The condition did not respond to treatment and she had ileostomy surgery in January 2018. She discussed how she dealt with the challenges she has faced since surgery 'to shed some light on some of the areas that young people might struggle with'. 'It is important that young people with stomas know that there's highs and lows and everything in between,' she said-the 'in between' indicating that life was returning to normal.

Hally Chapman had managed a range of conditions, including ulcerative colitis, for almost two decades before becoming an ostomate in 2014 after being diagnosed with bowel cancer. Along the way she won numerous rowing titles, culminating in the world junior single scull title in Lithuania in 2002. She had married, had two children, and was studying nursing. She was now an elite coach for NSW and the University of Technology, Sydney. Knowing from her teenage years that a stoma was likely meant that she had been able 'to plan her options with that in mind'.

Jenna Brook is not an ostomate but her family history of bowel cancer prompted her to undertake 'a little trundle from one end of Australia to another' in 2018-in all, 4529 kilometres from southern Tasmania to the tip of Cape York. She launched her Running for Bums project after a routine colonoscopy indicated that without the examination, she had a 50 per cent chance of having bowel cancer by age 30. Jenna was able to talk candidly to her doctor, but she recognized that many young people didn't have that luxury: 'That's something that Running for Bums was trying to get across: that we need to be empowered to ask more questions as young people where there's a history of bowel cancer or if you're experiencing symptoms.'

Each speaker dealt with the importance of ostomates having support from those close to them, though the experience of each was different and in Jenna's case the situation was reversed, with her taking a supporter's role with her father and grandfather.

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Her family 'had an open dialogue about bowel cancer,' she said. 'We'd make jokes about it, because our family is like that. It was very strange to me that most families aren't like that. It's a taboo subject in a lot of instances, and it is a real shame.' On her trek, she said, 'I spent a lot of time talking to people about bowel cancer, trying to get them to understand that it's not something that needs to be a taboo subject.'

Kristy and Hally spoke warmly of the support they received from family and friends, and how they had benefited from having strong relationships. Kristy's husband told her that getting her well again was all that mattered, though her new situation had been a lot for her children to deal with, and they had reacted differently. It was important to let them take their own time: 'I suppose that the most important thing for them is that they see me coping, and happier and healthier.'

Hally and husband Tom had long known of the health challenges she faced, and he hadn't treated her any differently since surgery

'other than to gently remind me not to do things like lifting washing machines'. Her friends had been 'nothing but supportive'. 'They knew I'd had a lot of health problems over the years, so they're really glad to see me back out and getting into things.'

Kristy also was lucky to have close friends who were 'very supportive and helpful' early on. Yet though she was very close to them, she had not relied on them

for emotional support-partly because she did not want to explain the intricacies of her situation, and because she was concerned that 'they might think differently about me'. Instead she found the emotional support she needed through social media. 'Social media accounts have been absolutely instrumental in my capacity to adjust, and to connect with other young people with stomas,' she said. 'That's been really helpful for me-just connecting through organisations and making sure that I'm feeling that I'm part of that community. That has filled the gap that I wasn't able to do with my friends at that time.'

Hally's reaction to her cancer diagnosis was to put the news on Facebook, which she uses to reach close family and friends. When she posted the diagnosis, she encouraged people to make sure they had regular checks—and as a result, her mother's best friend from childhood days was diagnosed with cancer at a stage where she could be treated effectively. Jenna learned about young people with bowel cancer through Instagram, 'because you don't really hear about it unless you're engaged in social media'.

Kristy and Hally expanded on their comments during the subsequent question-and-answer session. Kristy recalled finding other young people on Instagram who had had the same experience, and on her worst days she would read their entries: 'It provided me with reassurance that I was going to get through it.' 'There is a message out there on Instagram about getting back into your life again-about it not having to take over your life, that you can adjust to it very well. It can be life-giving."

Hally had joined a Facebook ostomy group whose members posted news of their activities, put up information about the products they used for different situations, and posted when they were having good or bad days. 'Just going through and reading that regularly sometimes it answers stuff that is relevant to me, or I can ask questions,' she said. 'Because it's on Facebook, it reaches people from all over the world. If you post something, you can have an answer within minutes, from the other side of the world.

The speakers agreed that young people often struggled with body image and confidence, and that being an ostomate often compounded those feelings. Clothes could be an important part of someone's identity and self-expression, especially among the young, but Kristy found it 'reassuring that I didn't have to change my wardrobe too much'. As a rowing coach and competitor, Hally spends a lot of time in Lycra on the water, but she has found that her fellows aren't conscious of a changed appearance.

> Kristy thought that her experience had made her better at her profession. 'I have become a better psychologist-more empathetic, more patient—as a result of experiencing having a stoma. It has definitely changed my passion for psychology and the directions I want to head in. I'm very passionate about mental health in managing the effects of chronic illness for those living with stomas, and so having an ileostomy has added a new dimension to my career.'

Hally recalled her mother's admonition to have the serenity to accept the things she could not change, the courage to change the things she could, and the wisdom to know the difference. 'I refuse to see myself as a chronically ill person or in any way disabled,' she said. 'I have one life, and this is the one I'm given and I'll continue to focus on what I can do and not what I can't.' Without the threat of bowel cancer, she had returned to competition. 'It's such a nice way to reinforce myself, how lucky I am to have an operation like that and get back to the things that I love, even if it is on a modified level.

Jenna emphasized the importance of persistence and facing up to challenges—something she learned on her run to Cape York. 'We need to learn to embrace anything that comes along,' she said. 'Any challenges in life, anything that we find ourselves in, any goals that we're trying to achieve, there are going to be challenges, there are going to be holes in the ground, there are going to be people sideswiping you, there's going to be yourself getting in the way of yourself achieving things, because you don't believe you can do it.

'If there is one thing I'd like you to take away, it's to go home and think about those things you are scared to think about, because you think-oh I couldn't do that, or what if it doesn't work out, or I can't guit my job because I need the money ... Think about it and just start. It is pure fear that holds us back. It is the fear of failure that so many of us spend our lives trying to fight. Instead, just let it go. All you have to do is start.'

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pH is the measure of how acidic or alkaline something is. If you were to guess though if most stoma output was acidic or alkaline, you might guess acidic. Surprisingly, this is not the case. Digestion starts in the stomach, which is an acidic environment. Once it leaves the stomach, the enzymes required to break down the food that you eat (proteins and fats) into absorbable nutrients work in a near neutral to alkaline environment.<sup>1</sup> For enzymes to be effective, they need this neutral to alkaline environment to work.

Additionally, for people with a urostomy, they would find their urine may be alkaline.<sup>2</sup> Normally, urine is acidic. When a urostomy is formed, a portion of the small intestine is typically used and this can contribute to an alkaline environment. Medications and other challenges such as infection can also change naturally acidic urine to alkaline.<sup>2</sup>

Here is the tricky part – your skin surface is naturally acidic.<sup>3</sup> Often called the 'acid mantle' the skin

performs best in a slightly acidic environment. Your skin is made up of fats and proteins and your enzymes don't know the difference. Once the stoma output gets into contact with the skin, it will start the process of digestion or changing the skins' natural environment.

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"TRE technology is an exciting new technology that creates an environment that is friendly to the skin yet unfriendly to digestive enzymes."

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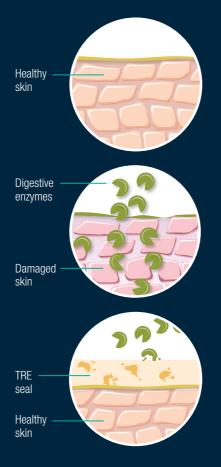
References: 1. Evans et al., 'Measurement of gastrointestinal pH profiles in normal ambulant human subjects', Gut 1988, vol. 29, pp.1035-1041 2. Walsh, BA, 1992, 'Urostomy and urinary pH', Journal of ET Nursing, vol.19, no.4, pp.110-113. 3. Saba, M, Yosipovitch A&G, 'Skin pH: From Basic Science to Basic Skin Care', Acta Derm Vener, 2013, 93, pp.261-267.

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## John O'Neill: service above self

Barry Maughan recounts the work and achievements of John O'Neill, a New Zealander who had a significant impact on ostomy worldwide.

**T**ohn Edmond O'Neill was born in Whanganui, New Zealand, on 22 November 1926 and, apart from schooling and early working life, lived in the area up till his death on 17 September at the age of 91.

John became an ileostomate in 1966 and during the next half-century gave significant service to ostomates in New Zealand, Australia, Asia and worldwide.

John qualified as an accountant in 1948 while working as a stock agent after leaving school and in 1953 became the firm's accountant at Whangarei's new branch. In 1956, as his father needed him, he returned to the family farm near Whanganui and until 1989, when he could no longer drive, travelled to the farm weekly. John married Jan in 1970 and had two daughters, Caroline and Teresa. His close family fully supported John's work for ostomates worldwide and his local community activity.

John founded the Whanganui Ostomy Society in 1975, becoming their first president and served on their committee as treasurer until his passing.

In 1980 he was elected to the

Federation of New Zealand Ostomy Societies (FNZOS), and was president from 1982-1994 and treasurer from 1995–2007, finally serving as patron for four years, 2009-2012.

John travelled to the Anaheim International Ostomy Association (IOA) Congress, California, in 1985. He was appointed as the South Pacific representative and was elected to the IOA Board at the 1988 Congress. In 1991 he was elected IOA treasurer and served in this role for 14 years until 2004.

As Australia was not an IOA member, John spoke at the ACSA 1991 Conference in Perth and encouraged ACSA to join IOA. He met then ACSA secretary Fred Cooper there and in 1994 the IOA World Congress was held in Adelaide, with Australia now a full member of IOA. The South Pacific Ostomy Association (SPOA) was formed in the following years, with John, Warren Rayment, Gerry Barry and Frances Butler as first officers.

John worked closely with John Cardosa from Malaysia to form the Asian Ostomy Association region and expand the number of member countries. He was part of the IOA team that restructured the organisation in 2010 when Asia and the South Pacific regions joined to form ASPOA.

His years as IOA treasurer meant safe stewardship of IOA finances: he was the glue in the IOA during those 14 years. At



John O'Neill with his Vinitsky award.

this time IOA developed the International Stoma Advocacy Programme (ISCAP) and the Ostomy Visitor Training program that is translated into many languages.

As well as significant work for ostomates, John was a member of the Whanganui County Council (Shire) for 18 years, retiring as deputy chairman. In 1995 he was awarded the Queen's Service Medal for his service to the community and ostomates in New Zealand.

At the IOA Congress in 2007 in Puerto Rico, John was awarded the prestigious IOA Archie Vinitsky award for his outstanding service to ostomates worldwide. This recognised his great attributes of humility and dedication, and putting service above self.



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 with their treating doctors prior to embarking on any course of treatment.

#### Dear Editor.

In relation to the letter by Maggie Parker of Queensland (Ostomy Australia August 2018), noting her bad experience whilst using a disabled toilet in Brisbane—some years ago my local association issued me with a card that had been provided by ACSA.

This card, the size of a business card and easily put into a purse or wallet, has a disabled sign on the right top corner with TOILET written underneath and the following words: 'The holder of this card has a disability of a stoma, and may be required to use a disabled toilet for the management of his/her condition. This may be confirmed by contacting The lleostomy Association (Vic) Inc., Phone (03) 9650 9040.' On the back it states that anyone finding the card should return it to the address given.

Now I don't know if this card is still available in an updated version, but feel this would benefit many of our members who find themselves in similar situations, and especially when travelling overseas. I for one would be happy to have an updated version if available. I have not had occasion to use it but feel confident I would should the need arise.

#### Loraine Potter. VIC

EDITOR'S NOTE: The card mentioned was developed by Ostomy Association of South Australia and a template sent to associations for their use. IA Vic, which recently merged with Colostomy Association of Victoria, was among those issuing cards.

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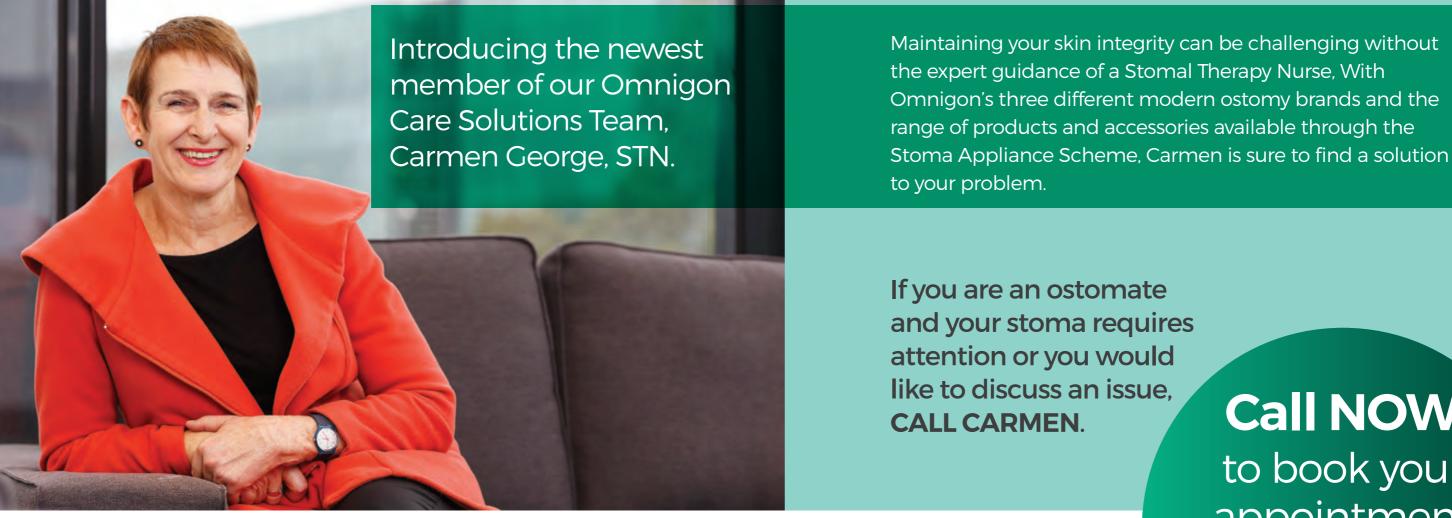
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## Are you eating mindfully?

or an ostomate, there are many factors to consider that can contribute to your sense of wellbeing. Being confident in managing your stoma on a daily basis, using an appliance that suits your lifestyle and activities, and keeping on top of your emotional state are several components of a successful life after stomal surgery.

As an ostomate, the manner in which you eat your food may also be a good area to examine, because it can have a significant impact on how well and how extensively you absorb and use the nutrients in the foods being consumed. This in turn can have a significant impact on your health and the level of ease and comfort you enjoy with your stoma.

The topic of eating style is commonly discussed during my nutritional consultations with ostomates, as it has a significant bearing on the health and wellbeing of the individual. If you have been reading the articles published in the Ostomy Australia journal over the years or have attended a nutritional presentation that I have given, you will know that my mantra to ostomates is

always chew food really well

(I am using bold letters to emphasise the importance of this statement and how strongly I feel about it!). The reason I focus on this so frequently and emphatically is mainly to reduce the likelihood of a blockage. However, the benefits for ostomates of chewing food thoroughly can extend far beyond this.

There's no denying that, compared with times gone by, life is much more fast-paced today. Everyone rushes here and there whilst juggling many

things at once with minimal rest and relaxation. There is very little time to stop and smell the roses! As part of this fast-paced lifestyle, meals are often quick, rushed affairs, or food is grabbed while we're on the run. In the city I often see people walking and eating at the same time, not even allowing themselves the luxury of sitting down to consume their food.

Unfortunately, this way of living is not good for health or for digestion, and is especially detrimental for ostomates. Many ostomates experience dietary restrictions or reduced food intake, so it is important to maximise

the absorption of the nutrients in foods that are able to be consumed for greatest benefit. Digestion starts well before food reaches the stomach, and there are many lifestyle strategies that can support and even enhance the digestive process, and that will enhance nutrient absorption and overall health. These include mindful eating.



#### What is mindful eating?

Mindful eating is more about the way that you eat than the food you are eating. It is about removing distractions and focusing more fully on the single task of consuming food. Eating slowly and mindfully brings you more in touch with the process, so you are more in tune with what your body is experiencing and desiring.

> My top tips for mindful eating are:

- Select food that is fresh, nourishing, appealing and appropriate for your stoma.
- Prepare the food attentively and lovingly.
- Set the dinner table with nice cutlery and crockery.
- Turn off any devices that will create distraction during the meal.
- Play some pleasant background music that will enhance the enjoyment of the meal.
- Once food is on the table, take
- a minute to pause and reflect on the

beauty and abundance in front of you and give thanks if you feel it is appropriate.

- Look at the colours and smell the aromas of the food on your plate.
- Eat slowly and chew every mouthful fully, enjoying the tastes and sensations in your mouth.
- Put down your knife and fork and pause every now and then so that you can breathe and relax during the meal.
- Only eat as much as you desire, and stop eating when you feel full.

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It takes time for the brain to catch up with the body and register the fact that you have eaten, so mindful eating can have benefits beyond just a more relaxed meal environment.

#### What are the benefits of mindful eating?

In the case of ileostomates and colostomates, mindful eating can certainly reduce the likelihood or risk of a blockage, but all ostomates can benefit from mindful eating. Many ostomates experience compromised digestive function as a result of their surgery, which can reduce nutrient absorption. Mindful eating enables the

digestive 'juices' to flow more freely before and during a meal, which facilitates more complete digestion of individual nutrients in food. This can help to support and enhance digestion so that some of that function is regained. This can lead to greater health and therefore benefit from the food being consumed.

It also increases the enjoyment you get from food, because you have a direct experience of eating a meal that lingers in your mind and body and increases your feelings of appreciation and satisfaction. This can help you to achieve or maintain appropriate weight levels. If lack of appetite and weight are a concern after stomal surgery, mindful eating can stimulate the senses which in

turn can stimulate appetite. Visually focusing on food while preparing and eating it may encourage saliva to flow in the mouth, which may increase hunger signals and appetite.

On the other hand, if excess weight is causing problems with your stoma, then mindful eating can help by reducing the amount of food being consumed. Drenching the senses with the sight, smell, aroma and taste of food registers more completely in the brain that food is being consumed, which satisfies the body more fully. Many people who wish to reduce their weight are often hesitant to engage more completely with food because they feel it will increase their total food consumption. However, the opposite tends to be true. Eating mindfully results in greater enjoyment and satisfaction from a smaller quantity of food so that, over time, someone will consume more appropriate amounts and types of food for the body's needs.

> Mindful eating is more about how you eat than what you eat. It is about savouring food so that your mind and body can benefit. So take time with your meals. Set up an environment in which there is no rush. Engage your senses and enjoy the luxury of tasting your food fully and completely. Your body and your stoma may benefit in ways you did not expect.

> Wishing you good health and happy days,

#### Margaret •

Margaret Allan advises both ostomates and the public on diet and health-related matters. She is the director of the consultancy Nutrition For Ostomates. To

contact her or read more nutrition articles supporting the health of ostomates, go to www.nutritionforostomates.com.au.

## It's important to keep things moving ...

Censible eating and avoiding the risks of Obowel obstruction and restricted bowel movements have been the focus of advice to members of the Benalla-Wangaratta Ostomates Group.

Nutritionist Margaret Allan attended the group's August meeting and discussed foods that might affect ostomates, including those who had had a stoma reversed. Group facilitator Graeme Pitts followed up with more information about ileus-that is, the inability of the bowel to function normally and remove bodily waste.

The mid-year newsletter told members that

there was a risk of the bowel not working properly immediately after surgery. This was because of a delay in the return of peristalsis—the involuntary contractions that move material through the bowel. The condition is sometimes caused by the bowel having been handled during surgery. It could take a few days before bowel movements occurred normally again and a patient could start to pass both wind and stool.

If lack of

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If an ileus or bowel obstruction occurred and bowels temporarily stopped working, a person might experience bloating, abdominal pain, nausea and vomiting

Sometimes this would need medical intervention. Temporary ileus could be managed by stopping or reducing food intake and allowing the bowel to rest. Keeping mobile and chewing gum would help prevention. People could return to an expanded diet once their bowels began working again, and they were able to eat and drink without abdominal bloating, nausea or vomiting.

The Benalla-Wangaratta group plans to hold a suppliers' day on 30 March 2019, from 10am until 4pm, with time set aside for presentations by each supplier. The venue is yet to be announced.



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# Fishing with a bag limit By Frank Prokop



#### This is not your stock-standard I fishing story, although it is about the joy of fishing. It's not full of the usual one-that-got-away tales—though in this case the one that got away is actually me.

It's more about what fishing can provide for someone while they struggle to come to terms with living with cancer and one of the most obvious reminders of that cancer, a permanent colostomy. It's about how one person has dealt with adversity and remained focused on coming out the other side to return to highly prized activities.

I have always loved fishing and like to think that I'm pretty good at it. It has been my passion and my job for more than three decades.

And then I got cancer. At first it was just a small hernia that my wife insisted I get checked out. It was to be simple surgery—a couple of days off work, a bit of man-flu milking of the situation and then back to my job.

It didn't quite work out as it was supposed to. The doctor came the next morning and held my hand and asked the kids to leave the room. It was eerily like in the soap operas. And then it came; with sympathy and lots of really big words. But all I heard was blah, blah, blah CANCER, blah, blah lose organs, blah, blah prognosis pretty good.

It was not just any sort of cancer—I got cancer of the one organ they don't really know has a function. I got cancer of the appendix, also known as jelly belly cancer. And the treatment is straight from a script of Alien-they remove all this jelly slime, tumour and bits that hopefully you don't really need, and replace it with heated-up chemo. They parboil you for a while and then use you as a milkshake by putting new chemo in your belly for the next five days.

Before the surgery, they paint those ominous two black dots on your belly in case they have to take out so

much intestine that you have to have a colostomy. And that-as much as any of the surgery and chemo and other complications—really scared me. I did not want to become a bag man!

So the very first thing I did when I woke after surgery was lift the blankets to see if the black dots were still there. Whew! Back to the tough job of beating this thing.

Well, the good news with this form of cancer is that the prognosis is pretty good. The bad news is that it frequently returns. And mine did-five more times. And for the first four, those black dots were reassuringly still painted on my belly when I returned from surgery. Back to concentrating on fighting this thing.

The sixth lot of surgery had a different sort of discussion. The surgeons were saying there was a good chance that I would lose my bladder—not good. There was a very

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## Fishing with a bag limit

good chance that I would have a bag, but they might be able to reverse it. There was a tumour the size of a softball in my lower abdomen and it had to go-they just hoped that it hadn't compromised anything important ...

Yep—woke up this time and no black dots. Instead an ugly fleshcoloured bag was in its place. No opportunity to really worry about it at the time—there were also holes in my ureters, the tubes that run from your kidneys to your bladder. This also was not very good, so I became a medical pincushion for the next couple of months while I slowly got back some strength and energy. I had the procedure in Sydney and finally flew home to Perth with no fewer than five bags attached to my person. I needed a bag to carry all my bags!

And I had to come to terms with the fact that I was a bag man. OK-I'd got to have an excuse for making fart sounds in mixed company, but most men, me included, do not react well to this set of events. And for me, most importantly, would I be able to keep fishing?

I pinned a whole lot of hope on having the procedure reversedgetting back to some form of 'normal' and putting the whole sorry episode down to experience and getting on with living.

But it wasn't to be. The rectal stump had deteriorated and couldn't be reattached. I was a bag man for life. And since I wasn't going to give up, it became a matter of making the best I could of the situation.

During the dark days of morphine dreams and chemo I concentrated on being able to go fishing again. I was determined to get back to what I loved, and my doctors were very encouraging.

So slowly, first with bait fishing for bream from my small boat, and then gradually with longer and more challenging trips, I went fishing. And it was wonderful!

One of my favourite activities is redfin fishing in the south-west of



Western Australia. It's tiger country and not for the faint-hearted. There is no mobile phone coverage and a fisherman has to lift and carry a canoe over massive jarrah and karri logs during the day.

You also have to unsnag about a hundred logs, because if you aren't in the gnarly stuff, you aren't catching fish. So my good mate Murray Joseph and I ventured into tiger country. Ironically, Murray is also a bag man-an ileostomate-a brave and wonderful inspiration to me to get up and get out there.

So here we are, two bag men, dragging this Scanoe from snag to snag and having an amazing time. Redfin are so good to eat that they go into the Esky-which of course gets heavier, and the logs seem to get higher—so your stamina is well and truly tested.

When we stopped for lunch Murray finished his sandwich and was munching on a peeled apple. I was eating mine like a man, when Murray pointed out that apple peel might not be so good for someone in my condition. C'mon Murray-no worries. And on we went.

Until I started to get twinges. Not good twinges. Which gradually became cramps that had become very painful by the time we got to the exit point. Ultimately, I ended up in Pemberton Hospital with a bowel obstruction and about 9/10 on my pain scale. I spent three days in what is a lovely hospital—and hope never to need it ever again. Needless to say, apple peel is off the menu!

Continued from page 26

But my favourite place to fish, and relax, and enjoy, is New Zealand. I get there as often as I can, and love everything about the place, from no snakes to Speight's beer, to better meat pies than at home, to bloody big trout and amazing water.

One thing that my challenges have taught me is to make the most of what you can, so I rang my good friend and editor of Freshwater Fishing Australia magazine, Bill Classon, and begged, cajoled and probably threatened him to get to New Zealand to fish together. Bill and I have been friends for decades and fish together way too infrequentlyso I said simply, 'it's time'.

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### Fishing with a bag limit



But it is the behind-the-scenes stuff that is pertinent to this story.

Being a bag man means a little bit of extra planning and a lot more care as you go along. If you trip over a rock, you can pull the bag from its base and-well, we all know what that is like and how much fun that would be.

So here we are, on the Hawea River, trying to get some extra footage for the fishing show. I had assured the boys that there were good fish to be had and Nigel was at a good spot where we were planning to do some 'to camera' shots about fishing in stronger current.

As usual, I was lagging behind when, you guessed it, tripped over and had bag issues. It took me 20 minutes to get back up to Nigel, and the segment that went to air does not have even the merest hint of the drama that went on behind the scenes-or of Bill and Nigel's patience and understanding while I composed myself.

I lost a giant 30 pound trout (fish are always in pounds and centimetres they are bigger numbers) on camera, and then landed a 33 pound fish from the canals near Twizel. That was very special. To put it into context for

non-fishers, brown trout are found on all continents except Antarctica. There are literally millions caught around the world each year, and probably no more than 100 or so of that size. I was really stoked.

But that is nothing to the feeling of satisfaction and fulfilment I had when that massive brown trout swam back into the canal. It felt as if all of my hard work in hospital had been worth it, and although it would have been perfect if my family had been there, having good friends to share that incredible moment made it very special.

I was also lucky to be able to lead a group of Australia's brightest young fishing leaders to Canada for the World Recreational Fishing Conference last year. I am a great believer that the next generation can avoid the mistakes of the past if they are empowered and supported through adversity. There are many parallels with health in this.

As part of the investigation part of the trip, we went fishing for white sturgeon. This species was pushed to the brink of extinction by people wanting their eggs for caviar, and their recovery is due to a partnership between anglers, scientists, first nation peoples and the community.

#### Continued from page 28

My scars and stoma were well and truly tested when I caught and then released a 229 cm and 220 pound (105 kilos in metric) fish. It had been tagged five years earlier and information on its growth and movements were able to contribute to the conservation of this species.

I don't think that the people on the New Zealand and Canada trips realised just how wonderful and important those trips were to me. When I was sitting in a hospital bed with upwards of 10 tubes coming out of my body, filled with chemo, in serious pain and feeling miserable, it was hoping to make trips like these that enabled me to keep focussed.

It is important to be distracted when you are chundering into a naso-gastric tube! Along with the wonderful support of friends and family, it was the thought of being able to do something that I love something that was important to the essential me-that kept me going. The removal of each tube, the very slow return of my strength took me a step closer to my 'normal' recreational activities.

Many of us face bigger struggles than mine every day. We have to play the hand that we get dealt in lifeand just get on with it. We cannot underestimate the importance of having an activity like fishing as an incentive and goal when we seek to overcome adversity. In the end, it isn't a bag limit at all—it's just a bag.

Footnote: On my return to the WA Ostomy Association our stomal therapy nurse asked how I found wearing a support garment while fishing. When I confessed that I wasn't aware that I needed one, I was quickly educated and now wear one when doing any strenuous activities. I am lucky that neither adventure (nor carrying the canoe) led to a hernia.

# NEW

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## **Speaking out** marks World Ostomy Day in WA

By Natasha Batten

World Ostomy Day is an international event, held this year on 6 October, and celebrated by Western Australian Ostomy Association (WAOA) with an open day at North Perth Town Hall. There were a variety of stalls, kids' entertainment, and refreshments.

This year's theme was 'Speaking out changes lives'. Our guest speakers included a former stomal therapy nurse, an exercise physiologist, a dietitian, a carer of a teenager with a stoma, a representative from the Health Consumer's Council, a representative of Carer's WA and an advocate for Hirschsprung's disease.

Some brave members of WAOA took to the stage to speak about their personal stories. This was followed by a question and answer session. Speaking about their stories—each one unique—and sharing their experiences proved to be valuable for new and old ostomates alike. It was also an eye-opening, educational experience for those who do not have an ostomy.

There were various fund-raising activities, including face-painting, emoji balloons and popping a balloon with a dart throw. A 'Guess the Jelly Beans' activity gave people an opportunity to guess how many jelly beans were in a colostomy bag, an ileostomy bag and a urostomy bag. The appearance of Polly the Poop, our mascot for the day, provided a fun photo opportunity.

The various stalls included those selling giftwares, jewellery, handcrafts, candles, bath and beauty products, household items and ostomy accessories. Representatives of ostomy suppliers were present, as were various charity representatives, allied health professionals and health products, with food trucks and a coffee van outside.

WAOA sends a big thank you to the volunteers who organised and ran this event, to the stallholders and speakers who attended, and to everyone who came to the event and showed their support. Next year the association will be combining World Ostomy Day with WAOA's 50th anniversary celebrations. The event will be held at Forrest Place in the Perth city centre on Sunday, 20 October.



Kerstin and Dave Huband at the WAOA front desk which included Guess the Jelly Beans competition.

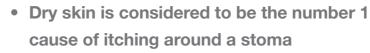


Polly the Poop with the ladies from Scope Nutrition.



for Hirschsprung's Disease, held in September.

# Do you suffer from "itchy" skin?



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1. (How Common is Peristomal Itching in the Absence of Visible Skin Problems? Ginger Salvadalena, Melissa Menier, Hollister Inc. (n= 164 patients + 259 WOC/ET). © 2018 Hollister Incorporated. AUH141



Ostomv Care Healthy skin. Positive outcomes.

## Educational support: OAM's rewarding program

By Andrea Farrugia



Andrea Farrugia conducting an education session

Andrea Farrugia is the Clinical Nurse Consultant, Stomal Therapy, at Ostomy Association of Melbourne. Learning about stoma management is a continuing task for new and old ostomates alike, but support and knowledge aren't always available. Ostomy Association of Melbourne has taken a successful formal approach to help its members.

∧ t Ostomy Association of Melbourne, we Hare always challenging ourselves to improve our service delivery to members.

Last year, management asked me about developing a support group with an education focus for members. Initially I had reservations about initiating something like this, as I could see the amount of work that would be involved and what a big commitment it would be. I was concerned about such a commitment! Did I have the energy? Would I have do this all on my own?

But I needn't have been concerned, because I had the full support of OAM management in making the concept a successful reality-I was allocated time to develop the educational sessions into something that would meet members' needs, that OAM would be proud of, and that we could develop and refine as our experience grew. We were inspired by the efforts of Erin Goodwin, at the time President of the WA Ostomy Association, and Tania Norman, their stomal therapy nurse (STN), who, with the benefit of

their experience, kindly answered all my questions and offered helpful suggestions.

The format we chose was to hold an hour-long orientation meeting for new ostomates that would be followed, after a break, by an education-themed meeting for established ostomates-though new members would be welcome to attend too. We would have a guest speaker when possible. We decided to hold these education days on Saturdays, so that people who work during the week would be able to attend.

We held the first meeting in February 2018, and have held them every month since, usually on the third Saturday of the month. The last meeting is planned for November, which means we will have held ten meetings this year. They are a great opportunity for members to meet the staff, volunteers and other members.

At each educational meeting I have been supported either by OAM Manager Sue Read or Assisistant Manager Hermione Agee, along with such great support staff as Lindy McDonald, our receptionist and events co-ordinator, and clerical officer Margie Hambridge. The days have been run as a team effort, giving members an insight into the energy that OAM's working environment fosters.

The day begins with the new member orientation meeting. Then we break for a tour of the facility, a cup of tea, a chat and a chance to look at a stoma company trade display. The education-themed meeting for both new and established members then follows. Members are welcome to bring their partners and support people.

#### New member orientation

New members are invited to the orientation meetings by email and letter, being asked to arrive at 9.15am for a 9.30 start. They are welcomed, given a name tag and a door prize ticket, offered a beverage and introduced to others in the group.

The orientation presentation begins at 9.30. New members are introduced to the staff who are present, and shown a photo/slide show of staff and volunteers to give them a glimpse of the people behind the scenes who ensure that their orders are processed and received in the most efficient manner possible.

A range of topics is covered during the first part of this meeting, including an explanation of what a stoma is, the reasons why stomas are created, the basic anatomy of the bowel and how the bowel functions. There are diagrams and photos of 'newish' stomas of various types. We make a point of covering important practical questions—how to measure a stoma (important to adjust the appliance opening to accommodate changing stoma size, especially during the first six to eight weeks post-op) and how to cut out a new appliance. In a 'things to remember' segment we pass on hints that have been collected from more experienced members. We cover the basics of selecting appliances, explain what pouch types are used to manage different output types, and look at accessory types and how to use them appropriately.

We do this to reinforce the pre- and post-operative information members might have been given in hospital by an STN. New members and their support people can ask guestions and clarify any information they might not have grasped during their post-op recovery. Members are encouraged to talk to their STNs if they have queries.

Later in the orientation meeting we help members to understand how the Stoma Appliance Scheme works, and how people acquire stoma care products both at the local and national level. We briefly go through a new member welcome pack which they will have received with their first supply. They see screen shots of the OAM website and are given an explanation of ordering options—filling in a hard copy order form to drop off, post or fax, or emailing orders and using online ordering.

We use a slide show to demonstrate the process from the time that an order is received, through goods ordering and receipt, to order selection and preparation for dispatch or collection. By making this a visual experience, we demystify the process.

At the end of the presentation the new members are shown useful website addresses and are free to collect any printed information we have available. The orientation meeting takes about an hour, depending on questions.

By 10.30am we are all ready for a break. New members are encouraged to take a walking tour of the OAM facilities. The orientation meeting ends with refreshments and an opportunity to chat with each other and visit the trade display. They are welcome to stay for the education-themed session if they feel up to it.

#### **Education-themed meetings**

OAM believes it is important for people with stomas to be armed with the information that will benefit them and support their quest for independence and self-care, supported by the knowledge that help is close by and available should they need it. The education-themed meetings are designed to provide this.

So far, the educational topics we have covered are easy-to-fix stoma care problems; avoiding discomfort through

stoma management trouble-shooting; products and accessory selection, and using them appropriately; travel adventures; and healthy nutrition for people with stomas.

Future topics will include improving application technique: exercise and hernia prevention-is it achievable? And are support garments right for you?

The education days are held in addition to the STN-led clinics that OAM offers on Tuesdays and Thursdays. Ten appointment times are available on these days, 45 minutes in duration for those attending for the first time and 30-minute slots for those who have been to earlier clinics.

## New members have found the orientation sessions helpful and reassuring

#### How do we get the word out?

New members receive emails and posted invitations to attend new member orientation meetings. All members can find information about the educational meetings via the OAM website, A5 handouts given to members picking up their supplies, notices printed on the back of packing slips, and posters advertising forthcoming events.

Word is spreading and members are coming back for more information.

#### Feedback and the future

Feedback has been very positive. New members have found the orientation sessions helpful and reassuring. They report feeling encouraged and supported, and have been motivated to attend future educational sessions. Our aim has been to provide a friendly environment where members feel welcome and comfortable to ask questions and seek clarifications if they are unsure.

Established members say they have learnt something new at sessions they have attended and intend to attend future sessions.

I was concerned that the information provided might be too clinical, or the images too confronting, making some attendees uncomfortable, but those attending have said they were interested in seeing what was normal (to compare with their own stomas) and what was not, to give them an idea of what to look out for and what to seek help for.

I would like to develop evaluation forms to allow the attendees to give written feedback. Constructive and objective. feedback will help me determine whether members' needs are being met, what other information they would like, and what topics would they like to learn more about.

Educational days are held at OAM's Distribution Centre in Burwood, but there may be opportunities in future to take the days 'on the road' to regional areas for members who cannot travel to Melbourne easily. Education in aged care facilities would also be useful for those caring for members with stomas.

There may be an opportunity to record our education sessions. This would offer the potential to create webcasts of presentations that members could access at any time via the OAM website. Recording educational sessions could allow us to evaluate our presentations with a view to 'tweeking' and improving them. Member feedback would also point to improvements that could be made and topics that members would like to learn more about.

Developing educational support meetings has been valuable for all involved. Our aim has always been to meet the needs and exceed the expectations of our members. By offering education to members and their families, we can empower our ostomates with knowledge, give members an opportunity to meet others in a similar situation, help them to become familiar and comfortable with ordering procedures, and encourage people with stomas to seek help if they are experiencing discomfort or stoma management difficulties. 

## From Kylie's desk ACSA Administration Officer

# Guidelines set the framework for our activities

In July 2018 the federal Department of Health released an updated version of the Stoma Appliance Scheme Operational Guidelines for Stoma Associations. The guidelines are the rules by which a stoma association must abide with respect to its scheme-related activities.

The guidelines are important because they provide the framework within which Australia's successful Stoma Appliance Scheme operates. They set clear parameters for the scheme, and in doing so, they aim to ensure that members can get the supplies they need in a cost-effective way.

Because the requirements of the guidelines essentially direct when and how associations can issue a scheme-listed product to members, it's important for members to be familiar with some of the relevant aspects of the guidelines so that they understand the conditions that must be met before a stoma association can fulfil a request to supply a member with the products they require.

## Q: Has the member paid the Stoma Appliance Scheme access fee for the current financial year?

To access the Australian Stoma Appliance Scheme (SAS), members of a stoma association must pay the SAS access fee. The fee is a uniform annual amount determined by the federal Department of Health in consultation with the Australian Council of Stoma Associations. The SAS fee is compulsory and must be paid each financial year to the stoma association from which a member usually obtains their stoma supplies. The access fee for the 2018–19 financial year is \$60, but this will be reduced to \$50 on presentation of a current concession card. Under Operational Guidelines clause 4.2, a member who is not able to pay the access fee because of financial hardship may apply to their association to pay the sum by instalments.

Guideline 4.3 allows stoma associations to also charge an additional membership fee for services they provide that are not covered by the access fee. These services might include a professional stomal therapy advice and support service, or access to initiatives such as peer support groups, ostomate events and publications. This additional membership fee is separate from the access fee.

#### Q: Is the member eligible to receive the SAS funded supply within the timeframe requested and in the quantities requested?



The Stoma Appliance Scheme Schedule is a list of stoma-related

products that can be made available to association members who have paid their access fee for the current financial year. The schedule contains information on each product, including its description and maximum monthly or annual limits. These arrangements are set out in clause 6.1 of the guidelines.

Stoma associations have a responsibility to ensure that no more than the maximum allowable quantity of any SAS-funded product is provided to a member unless that member has submitted an application for additional supplies on a form PB050. This authorises a temporary increase in allowance for that product, but to be eligible for additional supplies, the member making the request must be under the continuing care of a medical professional (either a registered health practitioner or a stomal therapy nurse) and receiving regular and ongoing reviews. An approved application for additional supplies is valid for up to six months. At that time, if extra supplies are still required, the member must lodge a new application signed by their medical professional. These arrangements are covered by clause 9.5 of the guidelines and subsequent sub-clauses.

There are a number of other issues that associations must take into account when assessing a member's request for supply.

For example, if the member is requesting more than a onemonth standard supply of any product and doesn't have a PB050 application in place, an association must ask if the member is eligible to adopt a two-month ordering cycle. The two-month cycle is available to members who have had their stoma for six months or more. Under guidelines clause 6.4.1, the two-month cycle can be suspended for members during any period when the stomarelated products they order are subject to change or review.

Has the member told the association that they will be travelling overseas? Members are entitled to have up to six months' supply if travelling abroad. Members requiring more than two months' supply of products will need to supply their stoma associations with proof of travel, such as an itinerary.

If a member is ordering multiple products that have the same or similar purpose, under guidelines clauses 6.5.2 and 6.5.3, an association must determine whether the supply falls within the standard allowance for that type of product. When a member is using multiple products that essentially have the same or similar purposes—barrier wipes and barrier sprays, for example, or closed pouches and drainable pouches—the maximum that an association can issue is the maximum limit for that type of product. For instance, if a member chooses to use adhesive remover wipes with a maximum allowance of two boxes of 30 per month and adhesive remover spray with a maximum allowance of two cans per month, the most that an association can issue per month is one box of wipes (50 per cent of the allowance) and one can of spray (50 per cent) unless an application for additional supplies is in place.

It is also important for members to be aware that a missed monthly order cannot be issued retrospectively or added to any subsequent claim for SAS supplies. Guidelines clause 6.5.4 makes this clear.

#### Q: Is the requested product available?

Unfortunately, sometimes a product that a member requests may become unavailable because it has been placed into backorder by the supplier or because the supplier has decided to discontinue the product. In these cases, the stoma association may tell the member about the situation and may recommend that they discuss suitable alternatives with their stomal therapy nurse. The stoma association can only supply an alternative product when an order for the alternative product has been received from the member, as guidelines clause 6.5.7 specifies.

#### Q: Do any restrictions apply to the requested goods?

Some SAS products have issue restrictions which mean that, when a member orders that product, the association must ensure that the restriction conditions have been met. These requirements are set out under both guidelines clause 9.6 and the SAS schedule).

The SAS product restrictions are:

R1 - requires stomal therapy nurse or health care professional authorisation. These products include irrigation equipment, tieman tip catheters and ACE stoppers. Gelling sachets have also recently had an R1 restriction applied.

## We want to hear from you!

Ostomy Australia is looking for your contributions your stories, your experiences, your letters, your photographs.

Ostomy Australia is your publication. Ostomates continually tell us how much pleasure—and how much useful information—they get from knowing what their fellows are doing, and how they are dealing with some common problems. But the journal relies on your contributions. It is as good as members make it.

When you send a contribution, we ask you to follow a few simple guidelines:

 in preference, send your contribution in electronic form—attached to an email or as a email; handwritten items take more time to process;

Members seeking additional supplies must submit an authorised application and be under the continuing care of a medical professional.

R2 - No authority for an increase in the yearly allocation can be granted. Products affected include travel wipes and hernia support garments.

R3 - Strict usage restriction—requires STN or health care professional authorisation, including clinical justification. This affects the Hollister Adapt Medical Adhesive (product code 7730).

R4 - Strict usage restriction—requires colorectal or general surgeon authorisation. No products are affected at the time of writing.

These are just some of the factors that stoma associations need to consider when issuing product through the Stoma Appliance Scheme. The full version of the SAS operational guidelines can be accessed at www.health.gov.au/stoma.

- please don't identify medical professionals unless they have agreed to their name being used;
- try to avoid identifying companies or their products;
- give us your full name and address, and your contact details. We use full names whenever possible.
- photographs should be JPGs and at least 1 megabyte in size. If there are people in the picture, let us know that they agree to publication, and tell us who they are.

Send your contribution to: Journal@australianstoma.com.au or PO Box 3378, Weston Creek, ACT 2611.

## 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: 1.30pm 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 2:00 pm to 3:30 pm 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. 11.30 am - 2.00 pm 1st Saturday March, July, December. Contact: Marie: (02) 6686 7248

#### **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 at 10 am to 12 noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec. Inquiries: Neil 0427 856 630 or Glennie (02) 6583 7060

#### **ILLAWARRA**

Meets 10am to noon, April June, October and Decembe (Christmas Party).

**Ostomy Australia** November 2018

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 (wheelchair accessible) Website: www.mglostomy.co.cc Contact: Karla MacTaggart on (02) 6592 9469

#### NEWCASTLE DISTRICT

Meet at 1.30pm 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 1.00pm 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 in April, June, August and 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. 10.00 am - 11.30 am 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 2.00pm on the third Monday of each second month. Venues: Wangaratta: North-Fast 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

#### **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

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Meets at 10.30 am 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) (03) 5563 1446

#### WESTERN AUSTRALIA

#### ALBANY

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, 1pm-3pm.

## QUEENSLAND

#### BEENLEIGH

Meets 10 am - 12 noon 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: gldstoma.asn.au/bosvs.htm Operating Hours: 7 days, 8 am to 8 pm. Operated by Qld Stoma Assn and Qld Ostomy Assn.

#### LOGAN

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

#### 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

#### REDCLIFFE

Meets first Tuesday each month at 10.00 am in the Shillam Room.

#### Redcliffe Cultural Centre - off car park SOUTHERN TASMANIA 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

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 1.00pm 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'

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

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

Meet: Third Tuesday of Jan, March,

Where: Ileostomy Assoc Centre,

Meet: 10.00 am until 12 noon at the

Meet: First Wednesday of Feb, April,

112 Elizabeth Rd, Christie Downs.

Information: Val: (08) 8381 1646

Meet: 5.00-6.00pm on the first

Where: Cancer Council NT. 2/25

YOUNG OSTOMATES

Tel: Helen (03) 9796 6623

Email: helshae@hotmail.com

**BOWEL GROUP FOR KIDS** 

Email: enquiries@bgk.org.au

Secretary on (02) 9987 1978

PARENTERAL NUTRITION

Email: contactpndu@gmail.com

Web: www.parenteral-nutrition-

MITROFANOFF SUPPORT

PO Box 256, South Melbourne,

info@mitrofanoffaustralia.org.au

Web: www.MitrofanoffAustralia.or

Web: www vouinc ord au

Young Ostomates United

Tel: (02) 4659 6067 or

Web: www.bgk.org.au

down-under.webs.com

DOWN UNDER

**AUSTRALIA** 

Victoria 3205

Email:

0431 857 188

Vanderlin Drive, Wanguri NT 0810

Tuesday of every month.

Contact: Marg Lavery:

UNITED (YOU)

(08) 8944 1800

Facebook:

INC

**NORTHERN TERRITORY** 

Flinders Rural School, Bay Road,

Please contact Sue McKay STN

for further information on

#### CENTRAL

When: 2pm.

FLEURIEU

Victor Harbour

0412 692 418

SOUTHERN

When: 2pm.

DARWIN

June, Aug, Oct, Dec.

Where: Elizabeth House,

May, July, Sept, Nov.

73 Roebuck St, Mile End.

Information: (08) 8234 2678

#### Stoma Appliance Scheme Product Suppliers





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#### ..... AinsCorp

PO Box 572, Niddrie, Victoria 3042 Toll Free Number: 1300 784 737 Email: service@ainscorp.com.au Website: www.ainscorp.com.au

#### Dansac

PO Box 375, Box Hill, Victoria 3128 Phone: 1800 331 766 Email: customerservice@dansac.com.au Website: www.dansac.com.au

#### ------Coloplast

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PO Box 240 Mt Waverley Vic 3149 Freecall: 1800 653 317 Email: au.care@coloplast.com Website: www.coloplast.com.au

#### ConvaTec PO Box 63, Mulgrave, Victoria 3170

Freecall: 1800 335 276 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

#### Hollister

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PO Box 375, Box Hill, Victoria 3128 Freecall: 1800 335 911 Email: customerservice@hollister.com.au Website: www.hollister.com/anz/

#### Nice Pak Products Free call: 1800 506 750 Email: healthcare@nicepak.com.au Web: www.nicepak.com.au

..... **Omnigon Pty Ltd** PO Box 5013, Burnley, Victoria 3121 Freecall: 1800 819 274 Email: info@omnigon.com.au

Website: www.omnigon.com.au 

**3M Australia** 

Locked Bag 19, North Ryde NSW 1670 Phone: 136 136 Website: www.3m.com.au

Statina Healthcare Australia 3/30 Leighton Place, Hornsby, NSW 2077 Toll Free Number: 1300 365 404 Email: sales@statina.com.au Website: www.statina.com.au

## 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. 10.00 am -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 8.30 am - 2.00 pm 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 - 3.00 pm Office Manager: Sharleen Condon

#### NTH QLD OSTOMY ASSN INC.

Shop 4, 52 French Street, Pimlico Telephone: (07) 4775 2303 All correspondence & orders to: PO Box 1017 Hyde Park, Castletown 4812 Operating hours: Monday 9.00 am - 4.00 pm Thursday 9.00 am - 3.00 pm Email: admin@nqostomy.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 9.00 am - 3.30 pm 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: qldstoma.asn.au Operating hours: Mon to Thurs -8.30 am - 2.30 pm Last Saturday of each month -8.30 am - 12.30 pm 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

(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 10.30 am - 2.30 pm 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 7pm - 8pm 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.

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 10.00 am - 2.00 pm and second Tues of each month from 9.00 am - 3.00 pm 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 9.30am - 2.30pm 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 - 4.00pm 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