

Ostomy

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PRESIDENT’S MESSAGE

The *Ostomy Australia Journal* is published three times a year, in April, August and December, and provided free to every member of an Australian ostomy association. This year there was no August edition due to a change of editor for the journal but we are now back and under the direction of our new editor, Ms Rebecca Herbener.

Bec hails from Western Australia and volunteers at the Western Australia Ostomy Association (WAOA). She is also the editor of WAOA’s newsletter. I would like to welcome Bec to the role and wish her every success. I am sure that Bec will put her own personal stamp on the journal over the coming issues.

In October the Australian Council of Stoma Associations (ACSA) held its annual general meeting and annual conference for member associations in Perth. It was well supported, with representatives from 16 of Australia’s 21 stoma associations attending the two-day event. Delegates appreciated the opportunity to discuss issues affecting the Stoma Appliance Scheme, along with the operational effectiveness of those associations and other matters of the day.

The theme of the conference was ‘Yesterday, today and tomorrow’, which was very appropriate as this year WAOA celebrated its 50th Anniversary. Professor Keryln Carville spoke to ‘Yesterday and Today’ and recounted the history of bowel surgery and types of appliances available to early ostomates. I am sure delegates were very thankful that medical procedures and products have improved since those days. I don’t think the saying ‘Life was simpler back then’ applies to ostomates. We also heard about the excellent work WAOA’s stoma therapy nurse, Tania Norman, is doing ‘today and tomorrow’ by taking her stoma therapy clinic into the remote and rural communities of Western Australia. Every ostomate needs to have regular assessments

by a stoma therapy nurse and the service WAOA provides is ensuring that this is happening, no matter where in Western Australia the ostomate is living.

I congratulate WAOA for organising the conference. It was wonderful that so many associations could come together and celebrate this special occasion with them.

Recently the Department of Health sought feedback from ostomates and other stakeholders on the operational effectiveness of the Stoma Appliance Scheme. This feedback will influence potential improvements to the scheme that would ensure ostomates continue to have access to products and support services they need to manage their stomas.

It is likely that some ostomates did not get the opportunity to provide feedback, as the department’s original consultation period was just three weeks. It was only after ACSA raised concerns that this would not give associations enough time to get the word out to members that the consultation period was increased to six weeks, even though ACSA requested even longer. The department received more than 2000 responses and the feedback is currently being analysed. Considering the difficulties that associations had in telling ostomates about the consultation, this is an excellent result. ACSA is looking forward to learning the results and working with the department to improve the operations of the scheme.

Considering the department’s heightened level of interest in the scheme, it is worth remembering that the scheme operates to ensure that ostomates have access to the appliances they need. This places an obligation on every ostomate to obtain only the supplies that he or she requires, not the maximum quantities available.

I would like to wish everyone a very healthy and peaceful Christmas season, filled with happiness.



The Christmas season reminds us of the importance of generosity and caring, and as we spend time with friends and family, to do our best to look after each other.

It is the season for reflection on the year past and of hope for the year ahead, and I encourage you all to take a few minutes to think about this. We really have so much to be thankful for—our health care system, supported by dedicated stoma therapy nurses, is excellent and the Stoma Appliance Scheme is considered one of the best in the world.

To the staff and volunteers at all the associations throughout Australia, thank you for the important role you continue to play in supporting the Australian ostomate community.

May your year end on a joyful note and make way for a bright New Year.

David Munro PRESIDENT



Delegates of Australia’s 21 Ostomy Associations at the 2019 ACSA Conference

Your say
Letters to the editor

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



Dear Editor,

Firstly, thank you for an informative and interesting magazine. I’m hoping you can help me.

I’ve been an ostomate for two-and-a-half years and going along very well. I belong to Peninsula Ostomy Association and they are a wonderful team.

My question is—a couple of months after surgery, when I would shower before a bag change, quite often I would have a leak while drying or preparing to put the new bag on. This is annoying. I asked a company if there was a product to wear temporarily after showering to avoid this problem but they replied that there was no such product.

I invented my own product (pictured above) using one of my colostomy bags cut out to fit a plastic disposable medicine cup attached by a stoma belt when I’d finished showering.

This has been a great help avoiding unpleasant leaks while drying and preparing to put the new bag on.

Is there no such product available?

Many ostomates must endure this problem and I was surprised something isn’t available.

Many thanks again for a great magazine.

Philip Stammers, VIC

Dear Editor,

I offer one or two tips from my experience to people using urine drainage bags.

I’ve been a urostomate for 32 years and for the last few years have settled into a simple procedure.

Equipment from the Cancer Council:

Wafers, urostomy pouches, urine drainage bags. Urostomy pouches last for four or five days, urine drainage bags two or three months.

Own supply: Vinegar and dispenser bottle, Sorbolene, plastic tubing to connect the bags, kitty litter tray.

My supplier provides two lengths (4 cm each) of plastic tube in each carton of day bags. These I have found to be useless as they are too short, so I have bought a length of suitable plastic tubing from the hardware store and cut off suitable lengths as I need them. I have written to the company about this, suggesting that one piece of tubing of twice the length would be useful, but there has been no action. Other than this, I have been pleased with their products.

Connecting pouch and bag:

About an 8 cm length of tubing is suitable. Cut the ends at an angle of about 45 degrees to the length of the tube. This makes it easier to slide on and off the outlet of the urostomy pouch.



In the morning, I empty the contents of the urine drainage bag into the toilet, then give a few squirts of cheap vinegar and some tap water into the bag. Then I leave it in the bathroom until the evening.

Just before going to bed, I empty the contents of the drainage bag into the toilet.

Lying on my back on the bed, I attach the urine drainage bag to the outlet of the urostomy pouch using a smear of Sorbolene as a lubricant on the joint.

I place the drainage bag flat in the kitty litter tray on the floor, positioning it so that the lead in tube is vertical and there are no kinks and the bag is flat, with no folds. I then turn over and go soundly to sleep.

With these steps, I’ve had very few accidents.

Jack Oliver, NT

Ostomates invited to 'pay it forward'

By Rebecca Herbener



The ACSA Executive at the national conference in Perth – from left, Secretary Rosemary Quick, Administrative Officer Kylie McGrory, President David Munro, Vice-president Erin Goodwin and Treasurer Robert Barsing with Dr Jenny Prentice opening the conference

Ostomates and stoma associations should do everything they could to protect the stoma appliance scheme (SAS) by strengthening existing relationships between the Commonwealth Department of Health, Medicare, ostomy product suppliers and stomal therapy nurses, Dr Jenny Prentice said when officially opening the Australian Council of Stoma Associations' annual conference in Perth in October.

The conference was held in conjunction with celebrations for WA Ostomy Association's (WAOA) 50-year anniversary, and had as its theme 'Yesterday, today and tomorrow'.

Dr Jenny Prentice, a stomal therapy nurse for 37 years and a renowned wound care specialist, told delegates to the two-day conference that Australian ostomates were privileged to have access to the stoma appliances and accessories that they required for the cost of the SAS access fee.

Jenny spoke on the need to 'pay it forward'—a phrase describing how the beneficiary of a good deed repays the kindness by extending it to others to positively affect as many people as possible, rather than just repaying the original benefactor. Jenny has seen first-hand the support that stoma associations and their volunteers provide to members, and believes the volunteers of Australian ostomy associations peer-support model this ideal. She said she had heard many stories from people going through their

ostomy journey that highlighted the gratitude, support and guidance they received from ostomy volunteers who helped them adjust to living with a stoma.

'We wish to ensure that ostomates in Australia continue to have access to the best appliances to augment the ostomate's quality of life,' she said. Jenny spoke about the differences between the Australian SAS and the access available to ostomates in other countries. She noted that in some countries, products had to be paid for individually or in line with medical insurance allowances. Some countries required ongoing prescriptions and, in others, there was simply little or no access to products.

It was important that associations and ostomates did everything they could to protect the SAS and ostomy product allocations, she said. They could do this by ensuring that returned stock was kept to a minimum, by strengthening relationships in the sector, and by ostomy associations working together to share experiences, ideas and processes, and by collaborating with each other and with ACSA to improve member services.

New structure for the Australian Fund

One way that ACSA and associations 'pay it forward' is through the Australia Fund, which supports ostomates in selected

countries by providing them with surplus products. At the conference the Australia Fund chairperson, Gerry Barry, from Queensland Stoma Association, reported that the *Australian Charities and Not for profits Commission Amendment (2018 Measures No. 2) Regulations 2018* required Australian associations and charities to take steps to ensure that the overseas organisations receiving donations (including supplies such as bags) comply with Australian operating standards.

Gerry told delegates that the Australia Fund was not equipped to do this under its current structure. He proposed that it be replaced with a grants program that would provide financial support so that individual associations could prove they met the requirements of the Regulations. This would allow them to continue to provide supplies to international ostomates. Conference endorsed this approach.

Supplies that are returned to associations are unusable—they cannot be reissued—and so are a cost to associations and taxpayers. With approximately 46,300 ostomates in Australia and upwards of 3,700 items on the scheme, it is essential that returned stock is kept to acceptable and minimal levels. However, sending these products overseas to people with little or no access to their own products is a great example of 'paying it forward' as well as preventing unnecessary landfill.



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Dr Jenny Prentice (right) with Ms Helen Simcock, a long-time volunteer at the WA Ostomy Association

Update on SAMS rollout

In the past few years three ostomy associations have transitioned to using the Stoma Appliance Management System (SAMS) owned by ACSA. The system is designed to manage distribution of products available under the SAS and to allow associations to better manage member supply orders and provide analysis on product usage.

'ACSA will provide support to any association that wishes to use SAMS' was the message from the ACSA President, David Munro. Delegates were told that ACSA intended that SAMS would be made available to associations through a hosted environment which will allow associations to use the technology and its benefits without incurring some of the larger costs that might have been required if they had had to upgrade their IT infrastructure to support the system.

The hosted environment might use a public provider such as Amazon Web Services (AWS) or Microsoft Azure, or a private environment hosted in a local datacentre. Once a decision had been made about the appropriate hosting environment, an implementation plan would be developed, he said. Delegates noted the proposal and ACSA will continue costing this approach.

Improving communications between associations and suppliers

Ostomy NSW (ONL) delegates Stephen Grange and Stephen Lardner presented delegates with

two draft service level agreements (SLAs) they had prepared, one to cover relations between ACSA and stoma associations and another between associations and product suppliers.

The SLAs are an initiative of ONL, which has argued that working relationships between ACSA, associations and suppliers should be strengthened.

The draft SLAs are seen as a step towards ensuring clear and measurable guidelines that detail the obligations and expectations of each party in the relationship. In doing so, they would provide an opportunity to improve customer relationships and ensure the business relationships were as successful as possible.

The ONL delegates asked conference attendees to provide feedback so that the drafts could be further developed to be ready for the agreements to be approved at the ACSA Conference 2020. The agreements are intended to be base documents that can be customised for each association.

Yesterday, today and tomorrow

In line with the conference theme of 'yesterday today and tomorrow, Professor Keryn Carville, of Silver Chain and Curtin University's School of Nursing and Midwifery, took us through the fascinating history of the development of ostomy care to its current practice and products.

Medical knowledge as well as the still recent drive to 'holistic' care (treating the whole person and not just the illness or its symptoms) and the fast-paced technological

changes show a bright future for treatment and care.

WAOAs stomal therapy nurse, Tania Norman, spoke about her work developing the STN clinic at WAOA, including the introduction of a regional care program, nurse education outreach and her hopes for the future of ostomate support in WA.

Awards for service and achievement

Four awards were handed out by the ACSA President, David Munro, and the Vice-president, Erin Goodwin.

Dave Patterson (Wide Bay Ostomates) was the recipient of the 2019 **ACSA Distinguished Service Award**. David has been involved with his association since 2004, when he began volunteering. He has been instrumental in key projects that have literally built the association to its current level and has worked tirelessly to improve the lives of local ostomates through the introduction of an STN clinic at the association and a new Ostomy One on One program which connects people who are scheduled for stoma surgery with an existing ostomate.

The prestigious award is made for exceptional service at a local, national or international level, and is intended to recognise exemplary or transformative leadership in the ostomy community; service, innovations or achievements which have advanced the physical or social wellbeing of ostomates locally, nationally or internationally; or outstanding service to the national ostomy community over many years.

Three deserving recipients received the **Professional Achievement Award** for their outstanding efforts in supporting ostomates.

Lorrie Gray (WAOA) has been the Program Coordinator, Stomal Therapy Nursing Education Program, for the WA branch of the Australian Association of Stomal Therapy Nurses since 1980. Lorrie has been a volunteer at WAOA since 2009 and a member of the management committee since 2012. Lorrie shows empathy and patience with ostomates, long-term and new, and finds time to visit nursing homes and to assist in teaching in regional hospitals when accompanying the association's STN on her country visits, as well as supporting and coordinating member support groups throughout WA.

Tom Flood (ONL) has given service at every level in his time at the association. Tom has manned the front counter, edited

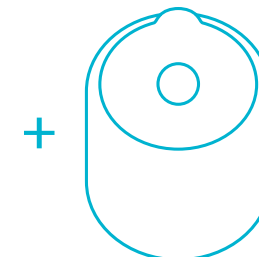
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ACSA Vice-president Erin Goodwin (right) with Professor Keryln Carville

the newsletter, been secretary then vice-president, and served as president of the board of directors since 1998. One of Tom's mottos is 'don't let problems mar being a useful person'. Tom says that he loves being part of a team bringing peace of mind to others through support, reassurance and the provision of information.

Val Macey (Ileostomy Association of SA) became a member of the IASA in March 1985 and has a reputation for being caring and empathetic. Being a 'people person' and recognising the need for support options, Val has been involved in setting up the monthly member support meetings and also coordinates the association's Australia Fund activities to send products to overseas ostomates who have little or no access to supplies.

SAS costs and revenue shortfall

For the past year ACSA has been in discussions with the Department of Health over the funding model for associations with regard to the delivery of products available through the scheme.

The president, David Munro, provided associations with an update of communications with the department about the financial pressures being experienced by associations with respect to their SAS operations.

There are some 46,300 members regularly being issued ostomy products from the pool

of approximately 3,700 items listed in the SAS Schedule. Currently, revenue generated by associations through the handling fee and the SAS access fee is an average \$110 per member per year, which is less than the cost of delivering SAS activities.

David said the department had been taking an active interest in association operations over recent months and had visited Queensland Stoma Association Ltd, Ostomy Association of Melbourne (OAM), Colostomy

Association of Victoria and ACT and Districts Ostomy Association to gain an understanding of how associations operate and the issues they face. Hermione Agee from OAM shared her experience of the visit by departmental representatives.

David confirmed that some 2,000 responses had been received to the Stoma Appliance Scheme Stakeholders Survey and said a summary of the responses was expected to be available on the department's website shortly.

Ostomy Support Bears WA

Lorrie Gray introduced delegates to Ostomy Support Bears WA, an initiative of ostomate Kelly Moss. 'I believe these bears have raised awareness and helped reduce any stigma attached to having an ostomy'. Lorrie said.

Kelly Moss, an ostomate for 20 years, set up Ostomy Support Bears WA after she received an ostomate teddy bear two years ago and decided that it was a great idea for people, especially children.

Kelly put out a call on social media and now has help from five women who help attach the stoma and removable ostomy bags to teddy bears bought from local stores. Kelly is appreciative of the support given by Omnigon, Hollister and Dansac in the supply neonatal bags for the bears.

Every bear is completely child-safe and has its own name. The bears are donated to children's hospitals and cost \$20 to purchase.

They are great educational tools and anyone struggling with having a stoma will benefit from owning a bear. For the recipient, the bear

brings comfort. It is a great companion, super cute, and can help people come to terms with their new life with a stoma.

From small beginnings in Western Australia, Kelly has sold bears throughout Australia, the USA, Canada, United Kingdom and South Africa.

Kelly only works on donations and the \$20 charged covers the cost of the bear, so no profit is made: everything goes back into buying or making new bears.

Kelly can be contacted at:

- facebook.com/groups/565874993881641 (ostomy support bears wa)
- gofundme.com/ostomy-support-bears
- instagram.com/ostomysupportbears



WA Ostomy Association President Murray Joseph with his new ostomy bear

Getting in shape for the future

By Amber Smart

After successful treatment for bowel cancer, Amber Smart is looking for ways to create a device that will make stomas less obvious.

This is the story of how I came to get my stoma—and about the supplies that are available for young people to use. I would like to design my own stoma plug and I hope someone can point me in the right direction to go about this.

I live on the Central Coast of NSW, I am 37 years old, and live with my husband and my two boys aged 10 and 8.

Back in 2015 I was diagnosed with stage 3 bowel cancer. They found a 4 cm tumour in my anal cavity.

Because of the size of the tumour, I was constantly in pain and bleeding and was unable to go to the toilet normally, so the first thing they did was book me in to get my temporary stoma.

After 25 rounds of radiation and chemo, the tumour had shrunk enough and the doctors were able to operate. I had my bowel removed, along with lymph nodes, as well as some muscle and part of my tailbone.

When I woke from my operation I was told that the operation had been successful but that, unfortunately, they had had to remove more muscle than they had anticipated. As a result my stoma would become permanent.

I had a further course of chemo to make sure they got everything, and October 2018 I was 12 months cancer free!

I love my stoma and am very grateful for it, but it was hard getting used to. Being so young, you think, 'I can never wear a bikini again'. You look at other girls with perfect bodies and you feel a bit down. But I realize as soon as those thoughts enter my head that I'm being silly. I am so lucky to have gotten through my cancer battle, and all I have to show for it is a couple of scars and a little stoma. No-one would ever know to look at me.



Amber Smart

I irrigate regularly now, and have worked out what foods work for me and what work against me. Most of the time I feel like I have a handle on things, but like any human being I overindulge every now and again with one glass of red wine too many, or too many slices of pizza. Then my tummy will start to gurgle and I can lose control and have a blow-out. Then I will get really upset because I am not in control. As long as I am in control of my stoma I am happy.

I use a combination of a small bag, a mini bag and a plug. But I would love to be able to design a plug that blends in to my skin better. I love the plug but why can't it blend – be more aesthetically pleasing? Why can't we have different colours for different skin tones? I would love the opportunity to create my own plug for young women who would still like to wear that bikini, who have come to terms with their stoma, and are not afraid to show it off, but just want something that looks a little bit nicer. I have the ideas to create such a plug, but I don't know where to start. I'd be glad to hear from someone who can give me advice on how I go about designing my own plug.



Members of YOU celebrating 30 years of support and stories

On Sunday 17 November, Young Ostomates United celebrated 30 years of friendship, support, stories and activities shared over those three decades.

In November 1989, ostomate Anne Maree and I, a stomal therapy nurse at the Preston and Northcote Community Hospital (PANCH), decided to set up a support group for young ostomates aged between 14 and 40. We placed an advert in the *Preston Times* and at the ileostomy and colostomy associations in Melbourne inviting young ostomates to an afternoon gathering at PANCH on 20 November 1989. To our amazement 13 people with a variety of stomas arrived, all eager to meet other young ostomates. This was the start of a long journey of support and friendship.

In February 1990 the first official meeting of the group named Young Ostomates United (YOU) was held and a constitution developed. Those early years were busy, regular meetings were held either at private homes, picnics or at PANCH. In October 1991 YOU held its first weekend away at Rutherglen, Victoria, at the request of one of our country members who later became president of YOU and in 1992 booklets relevant to YOU were compiled, *Problems and Practical Solutions*, *Thoughts of YOU* and later a *Just for YOU* Journal, produced biannually, thanks to Susan, one of our long-time members.

A counselling and visiting service was established, at the request of country and interstate ostomates. Weekends away at

Ballarat, Bendigo and Eagle Point were followed by visits to both Canberra and Sydney to launch YOU interstate, and many day trips to Geelong, due to the number of young ostomates in the Geelong area. In 1994 sixteen members drove in convoy to Adelaide for the eighth International Ostomy Association World Conference. Later that year members of YOU took part in the Video 'A Beginning not an End'.

Every June during Stomal Therapy Week a combined meeting was held at PANCH with the PANCH Ostomy Support Group. Wonderful friendships were forged between these two groups. Displays were held in Melbourne's Bourke Street Mall in conjunction with the Colostomy and Ileostomy Associations of Victoria.

In 1998 thanks to funding from the Royal Children's Hospital, YOU arranged a weekend away at Phillip Island. As well as having fun we wanted to help a young ostomate feel comfortable on a sleepover.

Over the years members of YOU have represented Australia at overseas youth forums and I have presented papers at stomal therapy conferences worldwide on the benefits of a support group and in 1993 I was awarded an Advance Australia Award for service in support of ostomates.

In February 2000 thanks to the help of one of our committee members, the YOU Constitution was revised and the group became incorporated enabling it to obtain funding from the Victorian Health Department. With the closure of PANCH,

meetings are now held at the Nurses Memorial Centre.

In addition, we hold annual educational meetings with appropriate guest speakers.

This year we updated our website (www.youinc.org.au) making it mobile compatible. Helen, our long time secretary, runs the YOU Inc. Facebook Page which currently has over 400 members. We believe these technologies where ostomates and their carers can ask for support and advice at times of need, are the way of the future and to this end we are investigating podcasts.

So many members have contributed to the success of YOU over the past 30 years—too many to name. Companies have supported our group and speakers have donated their time and expertise. Most of all the members of YOU Inc. have formed a community whose members have willingly shared their personal journeys to help fellow ostomates.



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may have requested within the same time period. The matter is made even more difficult when the same purpose products have different maximum allowances and issue timeframes, such as an annual allowance and a monthly allowance.

The 1 October 2019 schedule was released with 3,738 individual products. The number of same purpose products on the schedule were:

- 2,684 products to capture products from the gastrointestinal tract (monthly and annual issue)
- 445 products to capture urine output
- 33 plugs (monthly and annual issue)
- 96 catheter products
- 17 flange extenders
- 16 barrier products (monthly and annual issue)
- 23 cleaner and solvent products (monthly and annual issue)
- 87 seal products
- 12 paste products
- 13 night drainage bags
- 14 deodorant and lubricant products (monthly and annual issue)
- 10 cream products (ointments, healing creams and skin conditioning creams)
- 210 hernia support garments
- 8 skins protective sheet products
- 4 powders
- 16 small belts
- 50 miscellaneous products

All products have two identifying codes: a Stoma Appliance Scheme (SAS) code, and a supplier product code. For products within a supplier product range that are essentially the same product available in different sizes, such as a cut-to-fit product and a pre-cut product, the SAS code will be the same but the supplier code will be different.

For products that are not within the

The same purpose rule means the maximum amount of a scheme funded product you can be issued by your association can be affected by other 'same purpose' products you may have requested within the same time period.

same product range but have the same purpose, both the SAS code and the supplier product code will be different.

The computerised claiming systems built and funded by the largely volunteer based associations unfortunately do not have the capacity to identify same purpose products within a member's SAS claim. Association operators are therefore required to have an extensive knowledge of all 3,738 scheme listed products to ensure every SAS issue falls within the same purpose of use rule to remain compliant with the Stoma Appliance Scheme Operational Guidelines.

During 2018/19 the Australian stoma associations collectively issued a combination of 37,773,165 product units drawn from the pool of SAS listed products to meet the unique needs of over 46,300 scheme users. As each claim for products are assessed by association operators to ensure the SAS issue meets requirements of the Guidelines, the level of productivity within the associations can truly be appreciated. ●

Kylie McGrory
ACSA Administration Officer

S#@t Happens....

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

One of the most common questions I'm asked by new or potential ostomates is, "What happens if your bag bursts?"

Each time the question is asked it takes me back 17 years to my first week with an ileostomy.

Back in the day, keyhole surgeries were rare and laparotomies were the norm. This meant the usual stay in hospital was anywhere from 10 days through to three weeks. Thankfully this has changed considerably but on the other hand it leaves very little time for an ostomate to adjust to their new body.

So many questions are not answered. To be fair, as a patient all you're really thinking is 'When can I go home?'

My stay after surgery was three weeks on the dot. Whilst I was in hospital, I had awesome nurses who would let me sleep through the night and empty my bag for me. I had a problem as I wasn't aware when it was time to empty through the night. Pretty weird right? Another problem was when my body decided to dump one litre in one hit.

As I was young and appearance was everything, I chose a mini appliance. Though they felt like they were barely there and they looked like they were barely there, they weren't as forgiving when you had a high functioning stoma.

When I think back, this is where s#@t happened for the first time. Lol. Sitting in the hospital toilet the night before release, I became a problem solver. With an overfull bag ready to blow like Mount Vesuvius, I tried to

empty my bag into a jug just as I was taught.

Unfortunately for me, when I was unrolling the spout, it slipped out of my hand, my bag exploded and splashed my poo all over the back of the toilet door, up to the roof of the cubicle and finally all over my face. OMG! I'm sure by now you have the visual, in my head it was so much worse.

I sat there for a minute thinking; now, how am I going to get out of this cubicle, back to my room that I shared with three men, to grab fresh clothes, a new bag and all the stuff that goes along with it as well as getting back to the bathroom to clean the cubicle, shower and change? I knew one thing for sure and that was I wasn't about to walk back into my room, naked and pretend like nothing had happened.

I also didn't want a nurse to have to clean up after me because I thought if I showed any incompetence, I wouldn't be allowed home.

WHEN S#@T HAPPENS

Remember to:

- Stop
- Breathe
- Think of something funny and wiggle your toes

While sitting in the cubicle I decided right there and then to be a 'Master Problem Solver'.

I unrolled the toilet paper from the roll and wrapped myself up like a Mummy. I walked casually past the nurses station back into my room, pulled the curtains around me, found a towel, wiped myself down, grabbed some fresh clothes, popped them on leaving my stoma hanging out, wrapped the towel around my waist, grabbed a new bag and headed back past the nurses' station to the bathroom.



I managed to clean the toilet, shower, change my bag (which I had never done on my own), and walked back past the nurses' station and jumped back into bed.

It was as though I had become the invisible man. Not one nurse had realised I had actually left my bed in the first place. Talk about winning.

The next day I was released and that was the first time of many that s#@t has happened. The best way to handle the situation is with humour and an open mind. If you panic, you starve your brain of oxygen and then you will be unable to be the problem solver you need to be.

Remember to breathe. Four deep breaths in through the nose and out through your mouth. By breathing deeply and slowly, you will feed your brain the oxygen it requires to think clearly.

Think of something funny and finally, wiggle your toes. These simple exercises will lessen your anxiety and help you to figure out your next step.

Start with the end goal in mind and work backwards to find your solution. Often this will only take you a minute to figure out but if it doesn't, that's okay. You will find a way out and you won't be a prisoner to your own poo.

Learning to be a 'Master Problem Solver' is now a badge I wear proudly, and if you don't already, in time you will too. ●

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KAJ'S STORY

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Detouring into mental health

Fortunately, discussion of mental health issues and the focus on the prominence of mental health problems in society has increased in recent years. This is a very positive step. Change begins with awareness and progress is made with action.

The impact of stomal surgery on mental health

Stomal surgery can be a large and life-changing operation with many possible pitfalls, and the outcome for individuals can vary depending on many factors. The process of undergoing and then recovering from stomal surgery can momentarily take the light out of life. Afterwards, it may be necessary to make major adjustments, both physically and mentally.

I was recently talking with a group of ostomates at a support group meeting. One man said that he hadn't had any major issues with diet since his surgery, but had found that his mental health was more severely affected. This is completely understandable. Stomal surgery can affect body image and self-confidence in ways that other surgeries do not. There can be significant psychological adjustments to make after the physical healing is complete. It is important to become comfortable with the new sense of self in order to live a full and happy life as an ostomate.

However, at times it can seem as if you are being thrown a massive curve ball and are being challenged in a deep and profound way. You can feel overwhelmed and insecure about many things, such as how to cope with the new circumstances, what your life is going to be like from now on, and what the future holds. There can be a lot of uncertainty.

But these feeling don't have to be permanent. Over time you can

learn to cope, you can make the adjustments you need and you can find your way through the maze of uncertainty towards a way of life that is full of meaning and purpose. There are many support services and facilities you can use to help you with this process, such as:

- your local doctor
- your stomal therapy nurse
- a counsellor or psychologist
- your family and friends
- ostomy support groups

However, if you cannot access these services easily, or if they have not helped you in the way you desire, then another option is now available to you.

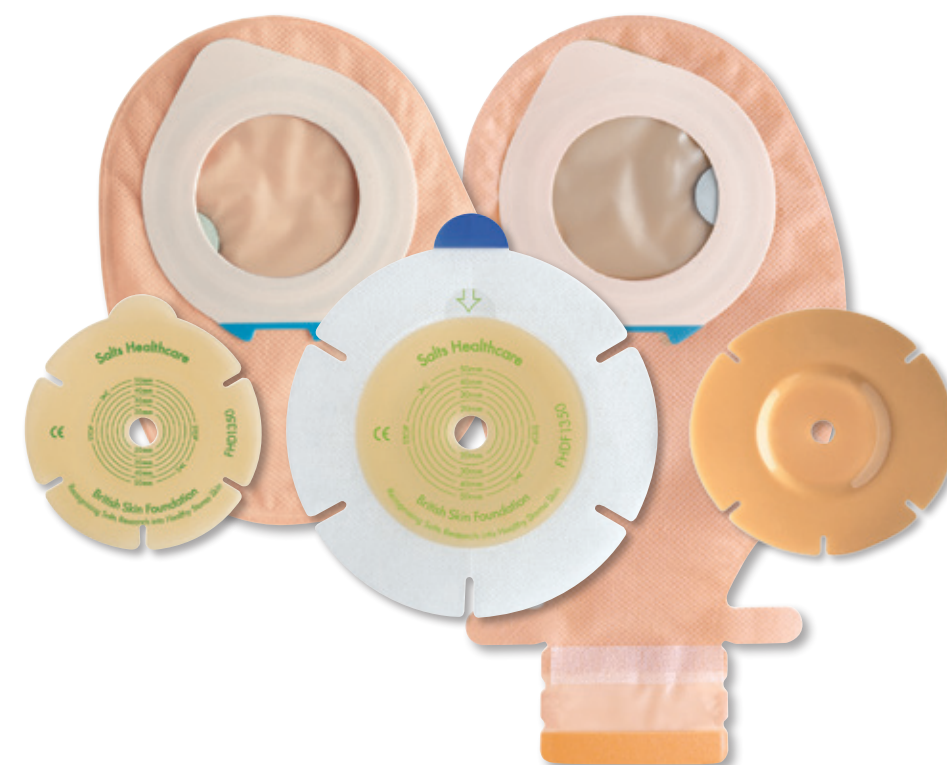
A new service supporting ostomates' mental health

I am a holistic practitioner, which means that I always endeavour to treat the whole person. For many years now I have been practising as a nutritionist and supporting ostomates and others in their desire for greater physical health and nutritional diversity. However, like the man at the support group, I have also been aware that addressing mental health is also part of the journey towards having a healthy and fulfilling life.

Recently I trained in a process that supports mental health and has the capacity to address fears, phobias, stress, anxiety and depression. I took this extra training because I could see it has the capacity to support ostomates in their journey towards greater health and self-acceptance after stomal surgery. I could see that it has the capacity to help ostomates adjust to their new way of life and experience greater certainty and freedom.

The process is called MAP and is carried out during a consultation

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which can be conducted online. The mind needs to be prepared for the sessions, so pre-training is required, which is completed by watching a video and listening to an audio session.

Mindful meditations are then used during the sessions which create a gentle, relaxed environment. You are asked to focus on the issue that is causing you concern, and a series of instructions are given to your subconscious mind to help clear and neutralise negative emotions around the issue. The progress and degree of success of the method are measured by you during the session. A second type of meditation is also used to re-wire your brain over time towards more satisfaction and happiness.

This process helps the brain to focus on comfort and success rather than dwell in doubts and fears. Those things can have a negative impact on the process of adapting

to the new circumstances after stomal surgery and can sabotage successful adjustment to life as an ostomate. This new approach can help an ostomate to work through their emotions and move forward in their life with more confidence and ease. It is most beneficial to have a series of sessions to provide the opportunity for deeper clearing of negative emotions and create greater momentum towards future goals. Self-help strategies are also provided so you can continue the process between sessions.

This offers an opportunity to address any fears and emotions you may have regarding becoming an ostomate, using a new approach based on recent breakthroughs in neuroscience. It can also be used to resolve issues not connected to your stoma. It is a private, painless and gentle technique that was developed by two psychologists and helps to create greater mental ease. You are

awake and in control of the process the entire time and can measure the results for yourself. Sessions can be conducted from the comfort and seclusion of your own home and are available to ostomates both within Australia and overseas. It is a powerful, positive process that can change your life.

If you wish to find out more about this service, how it works and whether it is suitable for you, you can contact me for a free 20-minute conversation via my website. We can discuss what you would like to address and how you would like your life to change. The past can't be altered but the future can be fashioned. This is a chance to fashion your future more in the way you desire.

Wishing you good health and happy days,

Margaret ●

Port Augusta and Beyond Ostomy Support By Audrey Christophersen



Members of the Port Augusta and Beyond Ostomy Support group at their first meeting

A new ostomates' support group started in Port Augusta, South Australia, in May this year. Nine ostomates met, joined by two spouses and the STN Jenni Edwards from the Port Pirie Hospital. Jenni leads the Port Pirie Ostomy Support group, and as Port Augusta was lacking a group, it was decided that we would form our own group. Genny Collinson popped in to offer her support as the continence nurse. Port Augusta does not have its

own STN at the moment.

The meeting decided on a venue for the next meeting, which was held on 24 September in the St Augustine's Church Library in Church St, Port Augusta. We hope to meet monthly at this stage but that will depend on the interest and the support by those who feel the need. The September meeting chose a name for the group, so now we are called 'Port Augusta and Beyond Ostomy Support'.

We hope that our get-togethers will also assist and reassure ostomates in surrounding localities, such as Quorn, Hawker, Wilmington and other towns in the Flinders' Ranges, and that they may benefit by their association with us. Advice and encouragement are sorely needed when sudden changes to our internal plumbing have been forced upon us and we might be feeling so alone. What next is going to change in our lives and how can we compensate to bring back some normality to our lives?

Meetings will be held every fourth Tuesday of the month at 1.30 pm. For those interested, Genny Collinson may be contacted at 08 8668 7706 or 0428 112 195 or you may email Genny at genny.collinson@sa.gov.au. A warm welcome awaits you whether you are a long-time ostomate or you are a comparative newbie. ●



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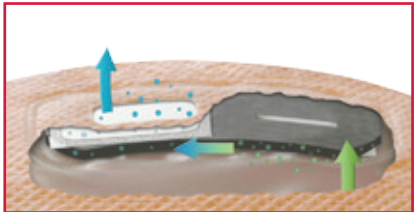
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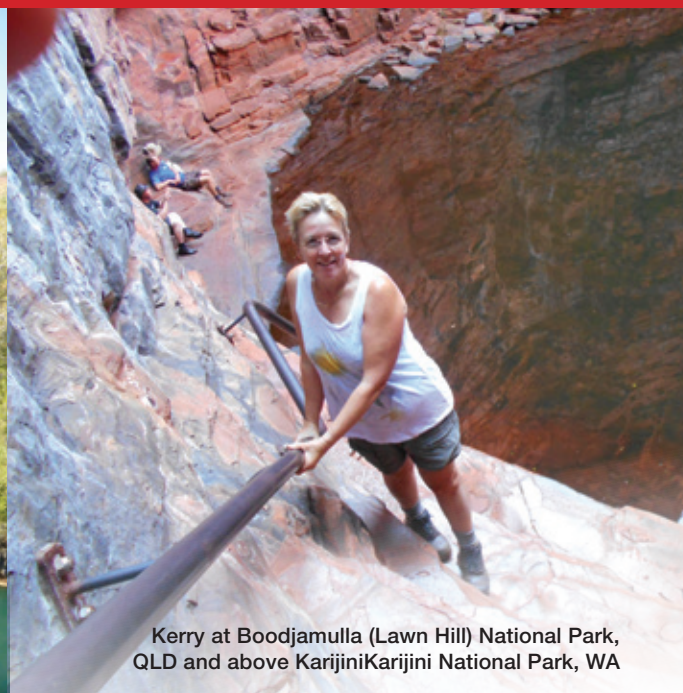
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Kerry at Boodjamulla (Lawn Hill) National Park, QLD and above Karijini National Park, WA

Many new ostomates wonder if their situation means that they will have to lead stay-at-home lives. However with experience, good advice, time and careful planning, people can have the confidence to keep exploring the world.

At the Illawarra Ostomy Day in June 2019, Kerry Kimbey talked about what she had learned on her travels at home and abroad.

I'm a Science/Maths teacher who retired with bowel cancer back in 2012. I am now a "blonde nomad" and committed traveller, in Australia and overseas.

My husband and I have been on long flights and we've also done several cruises. These are a few suggestions that I've collected along the way.

Here are 12 suggestions for long-haul flights:

Medical services: Australia has reciprocal health care agreements with 11 other countries, which means that we can get help with costs for medical care, including emergencies and treatment that can't wait. The level of cover is not the same for all countries but you can find the information by looking up the Australian Council of Stoma Associations (ACSA) website:

www.australianstoma.com.au/resources/travelling-overseas/

The countries are: Belgium, Finland, Ireland, Italy, Malta, the Netherlands, New Zealand, Norway, Slovenia, Sweden and the United Kingdom.

You still definitely need to have travel insurance. You also need to take your Medicare card, as it may be needed to access overseas services.

Scanning: When you go through security, it seems to be "luck of the draw" whether you just go through the metal-detector, or have a whole body scan. It may depend on the airport.

A colostomy bag certainly won't show up in a metal detector, but it will show up in a whole-body scanner—just look at the screen and you can see the scan.

You don't need a medical certificate to go through security. However, if you find yourself in the line for a whole-body scan, it may help to let the screening officer know that you have a bag.

You can have this conversation in private if you wish and you won't be required to expose your bag.

In May we went to New York and had plenty of metal detector scans (also in museums and other institutions), but just one whole body scan for the whole trip. Sure enough, my bag showed up

clearly. The woman asked me what it was, I told her—she'd never heard of such a thing, asked again, and then waved me through. Reckon it must have been the honest face that got me through!

If security staff want more information, then you have the right to ask for the examination to be done in private.

Travel certificates: Having said that you don't need to have a medical certificate, it's not a bad idea to carry a doctor's letter or travel certificate for clearing customs. ACSA has a good one (www.australianstoma.com.au/wp-content/uploads/ACSA-Travel-Certificate-2019.pdf) that clearly explains your personal details and your doctor's contact details. It advises security staff on how a search should be conducted to preserve the dignity of the person. The ACSA certificate is in all major languages.

Ostomy suppliers overseas: Before I leave, I search for an ostomy association in each country, and even a major hospital near to where we'll be staying. I email the details to myself, just in case, then I can access it anywhere.

Ostomy supplies: Always take enough supplies to cover the worst-case scenario, such as getting stuck somewhere for an extra period of time.

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Visit www.crohnsandcolitis.com.au to learn more about how CCA support the Crohn's and colitis community.

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I've seen suggestions that travellers should take twice the quantity that they should need, but I've found this is not really practical for a colostomy. However, I always take enough so that I still have plenty left when I come home. I see that as a sign of good planning—I wouldn't want to be down to my last bag!

Cabin baggage: A most important point—I always take my ostomy supplies in my cabin baggage: it's no good getting to the other end and finding that your suitcase has disappeared.

Extra cabin bag: Before going to New York, I'd read that it might be possible to take an extra cabin bag containing medical supplies. I rang Qantas and the person I spoke to said yes, I could take an extra bag with ostomy supplies. He even gave me his name in case there were problems, but he wouldn't give me anything in writing.

I then did an online-chat with Qantas, so that when they agreed that I could take an extra bag of the same size, I had it in writing. But this still only applied to Qantas, and we had internal flights with Alaskan Air and American. I think it would be necessary to check with each carrier.

I also took a letter from my GP to explain the need for an extra cabin bag of medical supplies—I don't know if it would have helped. If you have any sort of medication, you're advised to have a letter from your GP listing anything you take, so the ostomy supplies could be added to that list. As it turned out, my minimalist husband didn't need his cabin bag so he took my ostomy bag as his cabin bag.

In September, we are flying to London with British Airways and they have given permission for me to take an extra cabin bag.

Scissors: may still be a point of contention. According to the Department of Home Affairs website: 'Prohibited items and weapons include pointed metal scissors, manicure scissors and scissors with blades more than 6cm long. Permitted items include blunt-ended or round-ended scissors with blades less than 6cm long' (www.homeaffairs.gov.au/travelsecure-subsite/Pages/Items-you-cannot-take-on-plane.aspx).



Ballooning of bags: I have read that ballooning of bags worries some people in a plane but I have never found anything like that.

Changing your bag on board: On a long flight, be ready to change your bag on the plane. I change my baseplate on the day we fly, I change my bag about half an hour before boarding, and I have several emergency packs within reach at all times. On a flight of 16-18 hours, I'd change my bag twice—I don't wait until it's full, I just do it when it's convenient and I can get up the aisle.

Tummy upsets: These can be a problem. If you usually use a closed bag, it's a good idea to take some drainable bags as well. These are always good in case of unexpected upsets. And, if you get stuck somewhere without enough bags, you might be able to empty and re-use them.

Finally, **Travel insurance:** Yes, it's necessary but can be hard to get. I don't worry about declaring an existing condition. I think that the only related thing that can go wrong is that I might get a blockage, and in that case, there's not anything that can be done except wait until it passes and I need to be able to deal with that by myself.

Cruises are great for bag people but you still have to be organised ahead of time in order to alert the crew that you will need to dispose of your bags.

I have tried the early email contact approach – emailing the company and hoping they will pass on the message—but that approach doesn't seem to work too well. I've arrived on board and found no messages have been passed on.

I still send the email, but these days as, soon as I arrive on board, I head to the medical centre for a chat. They usually need to notify the house-keeping department who will explain it to our cabin attendant.

Usually the medical centre supplies me with red biohazard bags to keep in our cabin. I triple-seal my bags and then put them in the biohazard bag, which is removed once a day by the cabin attendant. Either he/she keeps me supplied with biohazard bags, or I go back to the medical centre when I need more.

Within a day or two we usually have a good system going and there are no further problems. It ensures the cabin attendant will get a good tip at the end of the trip.

Here's an example. In September, we are doing a cruise up the Norwegian coast with Hurtigruten.

I wrote to Hurtigruten saying:

I am writing to let you know that as a result of bowel cancer 7 years ago, I have a colostomy which necessitates the disposal of colostomy bags. In effect it is no different to disposing of dirty nappies. On previous cruises, the

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Kerry in Windjana Gorge, NT

ship's Medical Centre has supplied me with red Biohazard bags, into which I can seal the already sealed bags. These are then removed by the cabin attendant and disposed of. Can you please let me know whether we can sort out a similar arrangement on the Hurtigruten ship?

Hurtigruten wrote straight back and said they had alerted the ship's doctor, and even offered to order colostomy bags in for me if I sent the details. They couldn't have been more helpful.

I had a different experience when we stayed in Japan after a cruise a few years ago. I wrote to our Tokyo hotel and explained my needs. I thought it might help if they knew beforehand, having had good experiences on cruise ships.

Instead, the hotel said they didn't know anything about this and couldn't help me. We could feel free to go to another hotel if we wanted to. When we arrived at the hotel, they were obviously waiting for us and asked what we were planning to do about it. We told them not to worry and that we'd deal with it.

At the same time I'd sent the same letter to our Kyoto hotel and received the opposite response. Management said they didn't know anything about such things but they would do everything possible to help and to make our stay comfortable and to please let them know what we needed!!

Travel in Australia

Here are several tips for ostomates travelling in Australia:

Public toilets. We are lucky that almost every little town in Australia has public toilets that are well maintained. Many have a disabled bathroom, which really helps with a stoma.

Disabled bathrooms. We've had three camper-trailers, and I would often use the disabled bathroom in caravan parks to irrigate. Again, you have to be prepared. When booking in, I would ask if there was a disabled bathroom, as they are often kept locked. I've been asked if there's someone in our party who needs the disabled bathroom, and I've also been asked if I need to use it. I just look them in the eye and answer 'yes'. I don't need to explain what I use it for.

Sometimes there is a problem of looking well and not being in a wheelchair. Not everyone who needs the facility is in a wheelchair, as a lot of people think. Fortunately, I think this perception is starting to change. But you shouldn't have to explain why you want to use a disabled bathroom. You can get a card from ACSA that explains simply why you need to use a disabled bathroom.

MLAK key. Recently I bought an MLAK key—that stands for the Master Locksmith Access Key—a key that opens locks to some public facilities, including those in National Parks, many local council facilities, and train stations. The locks are fitted with a special MLAK cylinder and are sign-posted. These keys can be purchased from a locksmith, all you need is a letter from your doctor or stoma nurse saying that you need one.

Look after yourself. One thing to emphasise is that it's very important to

be able to treat yourself if you get sick, especially if you're out in some remote place such as the Birdsville Track, at the top of the Kimberley, halfway across the Nullabor or even if you are in a small town and it's a weekend.

For me, the worst thing that can go wrong is that I might get a blockage. I've had enough of these that I know what to do now. I have to pre-empt blockages and be prepared. We always make sure we have a couple of cans of Coke (sometimes they help move blockages along), I always pack a hot water bottle, and I carry Movicol in our first aid kit as well as Buscopan, a gut relaxant. I might just have to lie up for a day. If it happened when we had the camper-trailers, our plan was to go straight to a motel for a day (if there were any).

Planning ahead. Finally, going away for an extended trip takes a lot of planning. You can order your supplies ahead of time but you need to send in a letter of explanation and an itinerary, because your association has to be able to justify the extra supplies to the Government. I always ring the Sydney office beforehand. You don't need a separate order for each month that you are going to be away, just put in for double or triple what you would order for one month.

For further information, many of our Australian suppliers have great customer care links on their websites. Some have videos, some have ostomates' accounts of how they deal with life. There's also a company called Shield Healthcare, which has been suppliers of ostomy and other medical supplies in the US since 1957 and they have an 'Ostomy Lifestyle Specialist'. She is a young woman, named Laura Cox, who developed ulcerative colitis at 18. She has made several videos including *How to change a bag*, *Ostomy tips*, *Ostomy life FAQs*, *How to dress with an ostomy*, *How to tell someone you have an ostomy*, *Travelling with an ostomy* (<https://www.youtube.com/watch?v=G9x0xSx57kk>) and *Swimming with an ostomy*. Her role is to spread awareness, normalize and educate people about life with a stoma, and she has done an excellent job. ●

'Mega' problems? Focus on the good stuff

By Jacquelyn Kovaievic

Hi my name is Jacquelyn and I am 60 years old. I am very active and in really good health, despite having an ileostomy. I do believe I am lucky because I haven't had bowel cancer or any other diseases.

But all my life I had problems with my bowel. Constipation was my biggest issue at first. Being young I really believed my condition was normal. You never talked about these issues' years ago.

When I first met my husband at the age of 23, I started to have serious problems. My bowel motions just stopped. I saw a specialist; he had no answers. Finally, about four months later, the problem was gone. I was OK.

When I was 26 this mysterious problem started again, and as the years went by my abdomen started to increase in size from bloating. I couldn't wear jeans, dresses or skirts. The only type of clothing I could wear were track pants. Yuk. One day at work, someone asked me if I was pregnant.

I had seen numerous specialists, all in vain. I finally went back to the first specialist, the one I had seen years earlier. At this stage I was depressed and desperate. I asked was it possible to have my colon removed. On my 31st birthday I had a sub-total colectomy procedure. This procedure removed three quarters of my colon and then joined the rest of it to my rectum. I spent ten days in hospital. When I returned home, I was able to look after my 18-month-old and the six-month-old twins with the help of my supportive husband.

My problems never really went away but my bloated abdomen did.

About 25 years later I suffered a prolapse of the rectum. This was repaired but I had incontinence of the bowel. It was extremely embarrassing. I didn't want to go out and I had no idea what to eat.

I was increasingly depressed and my symptoms were

causing me grief. I was sent to another specialist in June 2015 who did an X-ray with a dye contrast after giving me a drug to relax the digestive track. My next appointment, which had been scheduled for November, was pushed back to early the following year as the specialist was going on holidays. I went to my local doctor who made some phone calls only to be told my test results were OK and they couldn't find any problems.

Two days later I received a phone call from the specialist who did my prolapse repair. He wanted to see me. He explained that the X-ray from six months earlier showed no sinister problems (thank God for that). It showed that organs like the liver and stomach were healthy but I noticed that half of the X-ray was dark. The doctor explained the dark area was the problem. The small portion of colon I had was about the size of a football.

The only solution was to remove the colon and have an ileostomy. I had this procedure about four years ago. It wasn't without its problems. I lost nine kilos and I had problems with leakages. Eventually I found the right products to use, and that has helped me. I feel much better and people have said how well I look.

I am a very active person. I do lap swimming, go to the gym, do weight training and lots of walking. I have no regrets.

I still need to come to terms with having a bag. I am not sure if I ever will. The problem I had was called a mega colon. I believe it was a birth defect.

A mega colon is an abnormal dilation of the colon. The dilation is often accompanied by a paralysis of the peristaltic movements of the bowel.

The reason I have written this story is to make people realise that no matter what happens in life, don't just give up. Make sure that you enjoy life. ●

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The week I won't forget

By Jacqueline Davies

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

The week I won't forget is the week I don't remember.

Sunday 29 October 2017. It all started rather innocently; a bit of red skin, a bit of pain—but hey, I am tough.

Fast-forward to Tuesday 7 November 2017.

I awake to hear the Melbourne Cup being run.

Wait! What? How did that happen?

I had just woken up in ICU.

So what had happened? Piecing the story together was a journey in itself.

After I got into the ambulance—something I do remember—I was taken to the Childers Hospital. I don't remember arriving there, despite it being only a ten-minute trip.

I was in the Childers Hospital and in a pretty bad way. My husband, Alan, rang my daughter, Michelle—she had driven up from Brisbane, about a three-hour drive—on Monday, 30 October. I don't remember Michelle coming in to see me or speak to me. Michelle told me later that I could have doubled for Bart Simpson, I was so yellow. The rest of that day, according to the Childers nurses, I was having good moments and bad moments.

On Tuesday, the doctors thought I was getting better. However, things took a potentially deadly turn. Luckily for me an inquisitive student nurse and a senior nurse soon diagnosed my situation and the urgency required. I was immediately packed into an ambulance and rushed to Bundaberg Base Hospital.

Later that day, according to Alan and Michelle, I was doing OK when they came

to the hospital. We all knew that I was going in for routine surgery and I spoke to both of them again (on the phone) just before my surgery commenced. Little did we know about the storm that was to be our lives.

Alan had promised to pick up our neighbours at the airport after their holiday. They were both surprised to see Michelle with Alan, who explained what had happened to me and that I would probably spend the night in recovery. They decided to go home, thinking they would come back on Wednesday to visit me. Back home, Michelle and Alan had just sat down to dinner when the phone rang.

I was told that the detached voice said something like: 'This is Bundaberg Hospital. Jacqueline Davies' family needs to come to the hospital and say their goodbyes. We are airlifting her to Brisbane and she may not last the flight, let alone the night.'

They left their dinner on their plates and raced to hospital—within the speed limit, of course. They said goodbye to me as I was wheeled off to meet the Westpac rescue helicopter for my trip to Royal Brisbane and Women's Hospital. No sightseeing this trip.

As they drove home, their minds in turmoil, it was decided that Michelle would drive straight down to Brisbane that night so that I would have someone with me. Alan would have to organise care for the dogs and ensure the house was secure before coming down the next day.

According to the hospital records, when I arrived in Brisbane I was operated on again. The surgeon rang Alan at approximately 3 am to let him know that I had survived the second surgery and that my prospects were looking a lot better.

'What was it?' I hear you ask. It was necrotising fasciitis on the backside, near the rectal area.

I had nine operations in total over the next two weeks, to ensure all the affected tissue had been removed. When it was clear all the diseased tissue was gone, it was time to start the healing process. The medical team used a vacuum-pack bandage system on my wounds to progress the healing rapidly. Back in the ward for the first time I was introduced to Nigel (no friends), my new friend for the



next 12 months—a loop stoma that would be reversed, I was reassured. Being a pragmatic person I figured that 'having a stoma helped save my life', so I would deal with it—and it was only for 12 months.

The Royal Flying Doctor Service transferred me back to Bundaberg Hospital, where I stayed for the weekend. Then there was another ambulance trip back to Childers Hospital, which completed the circle of my unplanned travel. I was in Childers Hospital until 5 January 2018. Almost two long months had passed since I went for my original ambulance ride. It would take another two months at home before I was completely healed. Just in time to go on a cruise on the Queen Mary.

My tenth operation in the saga (my reversal) was scheduled to take place almost 12 months from the time of my original surgery, but the surgeon just wanted to make sure everything was OK, as there was a lot of scarring and the possibility of other damage. Off to the specialist to have the diagnostic tests done on my sphincter muscle. When I went back to have my follow-up appointment I was given two options: one, keep Nigel for life, or two, have the reversal and if it worked, then be back in 10 years to get re-acquainted. So as I write this (18 months after my first surgery), Nigel has settled down for the night and tomorrow we will do what we will do for the rest of my life. Main thing is, I have my life to live.

I just want to finish this story with a big thank you to all the staff at the RBWH and Childers Hospital for their dedication. I would also like to thank the Wide Bay Ostomates in Bundaberg who have been strength to me for the past 18 months. ●



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1. Gary et al. 2005. A review of 16,470 patients on
the American Ostomy Association Registry



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Blessed to be here: my life with Crohn's disease By Nichola Hamilton

*In her new book, **Living with Crohn's Disease - Turning Adversity into Opportunities**, author and speaker **Nichola Hamilton** shares her experience with Crohn's disease and inflammatory bowel disease, and how a holistic approach played a crucial part in healing the body, mind and spirit.*



My name is Nichola Hamilton and I am very excited to publish my second book.

I was diagnosed with severe Crohn's disease at age 17.

Over the years I have endured over 25 surgeries. My large bowel, my rectum and all gynaecological parts are gone and I have only a small part of my bowel left.

I have had a permanent ileostomy for 25 years.

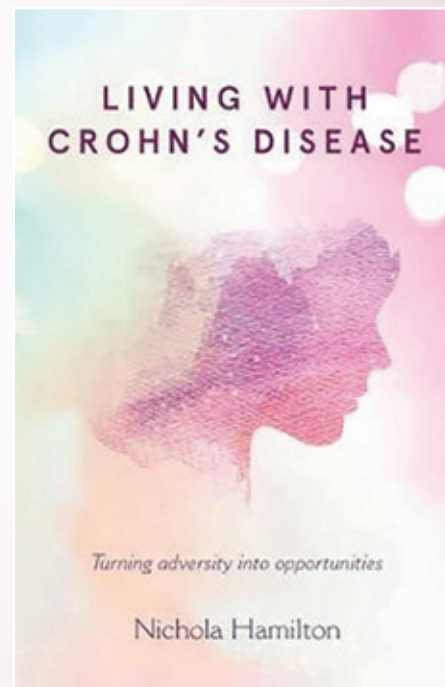
I have also battled depression, which was very challenging for me and my loved ones.

I recently turned 50 and I just felt blessed to be here.

My story is rare and I have written this book to share all the modalities and treatments that have helped me simply get this far in my life.

I am the mum to beautiful West Highland Terrier boys. I have had Winston for 13 years and now I have cheeky Boomer, who is 5 years old. They give me purpose, exercise, joy, and unconditional love (amazing therapy).

I really hope IBD patients and their families enjoy the book. If one word or line touches a heart to make a difference, my dream will be achieved. I wanted to pay it forward to help others.



My message is to please look after yourselves, diet-wise, stress-wise, and always listen to your body as Crohn's does not like stress.

My book is available in book shops or booktopia.

Love and light, Nichola ●

Looking ahead to a future with 'twins' By Sylvia Riedel

In March 2016, twins were 'born' to my husband, Allen, then 69—stoma twins Col and Uri.

After six months from diagnosis, several hospital visits, seven weeks of chemo tablets and radiation, a wonderful team from a Brisbane hospital operated to remove most of his colon, bladder and prostate, and provided him with the two stomas.

His recovery from this major operation was very quick (home within three weeks) due to excellent care and feeding him with a high-calorie nutritional food supplement recommended by the dietician during his chemo treatment. The Cancer Council provided great accommodation and excellent stoma nurses set us up to come home to North Queensland.

Over the years we've modified supplies with access to free samples from advertisements in *Ostomy Australia* and a thoughtful, helpful association. We've been on many holidays, both overseas and driving in Australia. We pack weekly supplies in a portable cooler container and always have a daily supply handy.

I will explain our routine, as it works so well for us. Allen uses a two-piece system. We change baseplates twice a week—we couldn't get by without adhesive remover.

While I cut the baseplate to fit and smooth on the protective seal, my husband removes the old baseplate, cleans the area with skin lotion tissues, wipes on the skin barrier and squirts on stoma powder, dusts with a cosmetic brush, then presses on the new baseplate

and snaps on the pouch. He then puts on a hernia belt and walks around for half an hour or more to make sure everything sticks—we've had very few leaks since he's done this.

Allen changes Uri's bag twice more in the week and Col whenever necessary, using lubricating oil and gel crystals for odour control, always squirting stoma powder on to the stoma. Since we've done this Col's skin has had many fewer lesions. Baby wipes and baby bags in lots of 100 have been our friends.

Col and Uri are really like two naughty babies. They gave us a few surprises but we've had three almost trouble-free, wonderfully happy years. We're looking forward too many more, with our 50th wedding anniversary in 2020. ●

Great Comebacks celebrated amidst adversity By Kerry Kimbey



Finalists, Margaret Bambrick, Dian Cheyne, Barbara Taylor, and Samantha Abarca were recognised at the Great Comebacks Awards in Sydney earlier this year

The September 2019 ConvaTec Great Comebacks Awards recognised WA man William Cusack and NSW stomal therapy nurse, Julia Kittscha for their unwavering spirit, resilience and determination in living with a stoma, and supporting those with a stoma.

William is this year's recipient of the Great Comebacks Award. Having faced and overcome immense challenges with illness throughout his life, William was thought to be one of the youngest Australians ever to be diagnosed with Crohn's disease.

Julia, a stomal therapy nurse with the Illawarra Shoalhaven Local Health

District, has been awarded the Stomal Therapy Nurse Great Comebacks Award for her untiring commitment and support of ostomates and dedication to stomal therapy.

Barbara Taylor, Margaret Bambrick, Samantha Abarca and Dian Cheyne, who've risen to and conquered the challenges of living with a stoma, were recognised at the awards ceremony held in Sydney as finalists as well.

'Our finalists have all shown an unwavering resilience against adversity and we're thrilled to be celebrating their Great Comebacks with them,' said Erin Goodwin of the Great Comebacks Steering Committee.

"Living with a stoma is very confronting and it's encouraging and inspiring to see what can be achieved during such difficult times."

Great Comebacks encourages people who have had ostomy surgery or are living with a stoma to share their stories, and in doing so, inspire others who are facing the same challenges. This unique program celebrates the success and effort of the individuals



Louise Walker, Great Comebacks Steering Cte with 2019 winner Julia Kittscha

and health care professionals who have gone above and beyond to help ostomates gain their optimal quality of life.

"ConvaTec is delighted to be celebrating and sharing the achievements of our 2019 Great Comebacks," declared Bruce Moncrieff, Acting Vice President, General Manager, ConvaTec Australia. "Each of our finalists has shown astounding determination and we are most humbled by their incredible achievements and stories of strength." ●



Richard McNair, GreatComebacks Steering Cte with 2019 winner William Cusack

Under usual social situations this could be quite an admission, but when it refers to a self-help group reaching such a tremendous milestone, I believe it is cause for celebration. As the single distributor of ostomy supplies to the approximately 3,500 members living in Australia's largest state, life at the Western Australian Ostomy Association (WAOA) is invariably busy. Although only open to members three days a week and one Saturday a month, staff and volunteers are on site each day to ensure that we are able to meet our goal of efficiently supplying members' products within a 14-day window. Despite being so busy, we have still found time to celebrate.

At the end of May, we hosted a 'Back to WAOA' afternoon tea for former volunteers who had played their part in developing the WAOA's processes and reputation within the wider community. Many friendships were rekindled and personal stories shared at this gathering.

In October we hosted the national ACSA conference, giving us another

venue to share our celebrations. The theme of 'Yesterday, Today and Tomorrow' enabled our guest speakers to reflect on the history of ostomy surgery, the development of self-help groups both in Australia and internationally, and the services provided to all Australian ostomates, as well as pose some questions about where we want to be going in future. Exciting times for us all. A birthday cake was part of the dinner that concluded the conference—I was grateful I didn't have to blow out 50 candles.

WAOA's AGM in November will also enable us to reflect on the achievements of the last 50 years. From beginning with a small group of interested people working in borrowed premises to distribute the few products available in 1969, now we have managed to purchase our own building to distribute the 3,700 items available under the nationally funded Stoma Appliance Scheme. There are four paid employees, around 60 loyal volunteers, a local and regional stomal therapy nursing service, several support



Jessie Whitehouse and Lorrie Gray from WAOA cutting the cake at the 2019 ACSA conference

groups and a growing community presence.

We are proud of what has been achieved, but recognise that there remains much that could be done. Time, finances and more personnel are needed to drive our ongoing endeavours to make the next 50 years as successful as these past half-century has been. ●

National Directory of Ostomy Support Groups

AUSTRALIAN CAPITAL TERRITORY

WODEN VALLEY

Hellenic Club
2nd Tuesday of each month
10am – 12pm
Contact/RSVP:
Clare Jacobs 040 092 1901

NEW SOUTH WALES

ALBURY/WODONGA BORDER DISTRICT

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

BATHURST

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

BROKEN HILL

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

CENTRAL COAST

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

COFFS HARBOUR

Meets 2:00pm to 3:30pm
2016 meeting dates to be advised.
Venue: Sawtell RSL Club, First Avenue, Sawtell.
Ostomates & friends welcome.
Contact Mandy Hawkins STN on (02) 6656 7804

EUROBODALLA REGION

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

FAR NORTH COAST

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

GRAFTON & DISTRICT

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

ILLAWARRA

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

MANNING/GREAT LAKES

Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Venue: Skills for Life Building, 5-9 Elizabeth Ave. Taree NSW (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 Oliver 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 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SYDNEY - PENRITH AREA

Nepean Educational Support Group meets 2pm-3.30pm, 10 May, 26 July, 27 September, 29 November.
Venue: Sydney Medical School, Clinical School Building, 62 Derby St., Kingswood.
Family and friends welcome, afternoon tea supplied.
Enquiries: Naomi Houston (stomal therapist) (02) 4734 1245

SYDNEY - NORTHERN AREA

Meet: First Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Rd. Wahroonga.
Contact: San Cancer Support Centre (02) 9487 9061

TWEED-BYRON

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

WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00am to 11:00am.
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-East Health, 4-12 Clarke St., Wangaratta, April, Aug., Dec. Benalla Community Health, 45 Coster St., Benalla, Feb, June, Oct.Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943.
Email: mgpwang@gmail.com

BURWOOD

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

MELBOURNE

Colostomy Association of Victoria. Meets 10.30am - 12.00pm, second Wednesday of alternate months from February to December.
Venue: Australian Prostate Centre,

Level 8, 14-20 Blackwood Street, North Melbourne.
Website: www.colovic.org.au
Contact: Colin Hunter 0437 070 657 Tues. and Wed.

MILDURA

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

SOUTH GIPPSLAND

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

SUNRAYSIA / RIVERLAND

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

WARRNAMBOOL & DISTRICT

Meets at 10.30am on the second Friday of the month in Feb - Apr - Jun - Aug - Oct - Dec.
Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093
Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

WESTERN AUSTRALIA

ALBANY

Meets at Albany Hospice conference room, 9.30am to 11am 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 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre, 10 -18 Mt. Warren Bvd. Mount Warren Park QLD.
Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107

BOWEN

Meets the first Wednesday of each month at Bowen Hospital, 10.30am.
Contact: Natasha Leaver (07) 4786 8222 or Valerie McDonald 0407 691 160.

LOGAN

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

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MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov).
Venue: Meeting Room, Mackay Mater Hospital.
Contact: Graham Stabler for further information on 0428 776 258 or email: grahamstabler@bigpond.com

SOUTH BURNETT

Meet second Tue. each month at 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
candjrobinson@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, emby1936@gmail.com; Leanne Wilshire (07) 4630 0629, leanne.wilshire@bigpond.com; emby1936@gmail.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.
Please contact Wide Bay Ostomates (07) 4152 4715

TASMANIA

'SEMI COLONS'

Meets in Hobart on the third Friday of every month from 1.30pm to 3.30pm.
Enquiries: Renata, Cancer Council Tasmania, (03) 6169 1900.

NORTH & NORTH-WEST

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

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

Contact: Adrian Kok
on 0498 196 059

SOUTHERN TASMANIA

Meet at Ostomy Tasmania Office, Amenities Building, St Johns Park, New Town, 10am-noon on first Wednesday of March, June, Sept, Dec. New and existing members welcome.
Further information:
Adrian Kok: 0498 196 059

SOUTH AUSTRALIA

CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov.
When: 2pm.
Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End.
Information: (08) 8234 2678

FLEURIEU

Meet: 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbour.
Please contact Sue McKay STN for further information on 0412 692 418

PORT AUGUSTA AND BEYOND

Meet: Fourth Tuesday of every month in the Library/Bookshop behind St Augustine's Anglican Church, Church St. Port Augusta
Please contact Secretary Anne Wensley for more information.

SOUTHERN

Meet: First Wednesday of Feb, April, June, Aug, Oct, Dec.
When: 2pm.

Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs.
Information: Val: (08) 8381 1646

NORTHERN TERRITORY

DARWIN

Meet: 5.30-6.30pm on the first Tuesday of every month.
Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810
Contact: Marie Purdey:
(08) 8944 1800

YOUNG OSTOMATES UNITED (YOU)

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

BOWEL GROUP FOR KIDS INC

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

PARENTERAL NUTRITION DOWN UNDER

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

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



ConvaTec

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



Sutherland Medical

PO Box 1194, Huntingdale, Victoria 3166
Phone: 1300 664 027
Fax: 1300 664 028
Website: www.sutherlandmedical.com.au



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