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*Contains the Remois Technology of Alcare Co., Ltd.



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Ostomy Products



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HOURS OF BUSINESS

Monday-Thursday

8.30am - 3.30pm

Friday 8.30am – 1.30pm

For current information go to:

nswstoma.org.au

DIRECTORS

CHAIRPERSON Allen Nash

SECRETARY Renee
Constantin

TREASURER Ian Niccol

OTHER

DIRECTORS Carol Quast
Ian Murray
Eugene Tomczyk
John Hickey
Graham Lawson
Lynda Frost

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nswstoma
LIMITED

CONTENTS

Business Hours & Contact Details	3
Notice Board	5
From the Chair	6
From the General Manager.....	8
Fáilte mo chairde, (hello my friends) from Anne Marie Lyons	14
Farewell Michael O'Connell	16
Meet our newest board member – Lynda Frost	18
Say Hi to our lovely team	19
Sydney Education & Information Day at Hornsby	20
Travel with a Stoma by Scottie Galloway	24
ASPOA conference, Singapore.....	30
Donations	32
The National Public Toilet Map & MLAK	36
NSW Ostomy Support Groups	39

NOTICE BOARD

Christmas Closing

We will close at 12pm Friday 22nd December, 2023 and re-open 8.30am on Wednesday 3rd January, 2024

Onsite Stomal Therapy Clinic

The clinic is open and free to all our members and operates for the first 3 Thursdays of each month at our Stanmore premises. Members can also contact Anne Marie via phone or email. Appointments are essential.

Anne Marie Lyons STN

phone or text: 0468 582 951

email: stomanurse@nswstoma.org.au

Products for Sale

Product	Code	pack size	Member Price	Non-Member Price
Rediwipes Silk Wipe	ARS3033	100	\$10.00	\$12.00
Micropore 1"	1530-1	1 roll	\$2.00	\$3.50
Micropore 2"	1530-2	1 roll	\$3.50	\$5.00
Metal Nightstand	Nightstand	each	\$45.00	\$50.00
Simple Nightstand Plastic	380431	each	\$15.00	\$17.00
Ostomy Scissors (curved)	9505	each	\$8.00	\$9.50
Hollister Leg Bag	9632	each	\$8.60	\$10.00
Hollister Leg Bag	9624	each	\$8.60	\$10.00
Urostomy Drain Tube Adaptor	7331	10	\$31.00	\$35.00
Odour Be Gone Hos-Togel	3300	each	\$36.00	\$40.00
Odour Be Gone Hos-Toma No Smells 500ml	10500	each	\$18.00	\$20.00
Odour Be Gone Hos-Toma No Smells 120ml	10120	each	\$8.00	\$9.00

CHAIRPERSON REPORT

from Dr Allen Nash October 2023



We had a year which was less eventful than the past three years and it is good to feel we are back on track with our operations working well. COVID has lingering effects but is more manageable in the effects on staffing and product supplies. Thanks to the dedication of our staff, we continue to be able to keep members supplies being delivered within a reasonable time.

I anticipate members will be pleased with our new portal (available in November) that will allow members to order their supplies on-line and see past orders etc. This innovation is part of our continued focus on finding ways to further support members. Implementing this new system has temporarily increased the workload of our staff and they have managed this with minimum disruption to member deliveries.

Shona Gawel is retiring as a board member at this year's Annual General Meeting. I would like to thank Shona very much for the great contribution she has made to NSW Stoma. She has supported the board through her high-level professional knowledge of organisational management and will be missed.

We are also welcoming a new board member, Lynda Frost, who has already demonstrated her commitment to ostomates through her contribution to the Newcastle District Ostomy Support Group. She is also a Fellow of the Australian Institute of Company Directors and brings a

range of experience across the public and private sectors in education and training, local government, financial services, travel, manufacturing, and engineering.

It has been a pleasure to be working with an experienced and committed board of ostomates who are working well together and are committed to providing the best service we can to members.

I also want to especially thank our members who have donated to NSW Stoma. Their donations have made a difference in keeping the organisation financially stable and allowing us to extend our services to members beyond providing supplies e.g., stomal therapy nurse support, information days around NSW, monthly zoom information sessions to members etc.

We have continued to grow with member numbers increasing over the year again this year. This trend is increasing pressure on our premises capacity, and we will need to be looking at expansion options over the next year.

I am pleased that I can reassure members that their association is in a sound financial state and operating within good governance principals.

Keep well.

Allen Nash

Chair - NSW Stoma Ltd



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“

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A message from Mary Egan, your General Manager



Another year is almost over, and it has been another year of change and challenges at NSW Stoma.

In the last 12 months we have packaged nearly 50,000 orders, claiming from Medicare over \$17 million in products on behalf of our members. While the logistics of processing and supplying your orders is just part of what we do, it is an essential service for all our members. We work hard to process your orders as efficiently and as timely as we can within the confines of the Stoma Appliance Scheme (SAS).

We saw some big changes to the scheme this year. Support pants were dropped from the scheme altogether in October. Your feedback tells us that this has adversely affected many of you. Women in particular find their body shape is not suited to the support belts which ride up and prove ineffective.

The other big change to the scheme was making cleanser wipes a restricted product, requiring all members to provide an authorisation form from their stoma nurse or doctor. While this put a huge administrative

burden on us, as your association, it put a lot of pressure and additional workload on stoma nurses and really upset a lot of our members. We appreciate the stress it added to many members lives just to access a product many of you have used for years and also having to renew that authorisation every 6 months, means that stress and additional work will continue.

These decisions are made by the Department of Health through the Stoma Appliance Scheme (SAS) and the Stoma Product Assessment Panel and products. You can contact them by emailing stoma@health.gov.au.

Other changes at NSW Stoma included totally changing our warehousing and order processing system. This change was driven by our desire to access a new member ordering system. Our backend software links to our new online member portal. If you aren't already using this portal, I urge you to give it a try. The portal shows you all your past orders, allows you to place a new order and gives you up to date information on the status of your order. You can make payments in the portal and the portal also lets you know when you need to pay us. Once you submit your order, a member of our team will assess it to ensure compliance with the SAS and if all





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Ostomy Care / Continence Care / Wound & Skin Care / Interventional Urology

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A message from Mary Egan, your General Manager (continued)

is well this is automatically entered into our backend system. If we need to make changes to your order (for compliance reasons) you will be notified by email. You can then track the progress of your order through our system. You can find lots more information about the portal on our website, including how to register.

Our website also contains lots of resources and information to assist our members to manage their stoma. We also provide access to a stomal therapy nurse in our weekly onsite clinic. Anne Marie Lyons is also available by phone and email to ensure all our members have access to this free service.

Our monthly member zoom meetings continue to grow in popularity with more of you joining us each month. Meetings are hosted by Anne Marie Lyons (our stomal therapy nurse with decades of experience), Carol Quast, NSW Stoma Director and Ostomate and me, as NSW Stoma Ltd manager. Between the 3 of us we cover the clinical, patient, SAS and association information. Meetings take place on the first Wednesday of every month at 6pm. You need to register for each meeting you want to attend.

A big thank you to all our members and supporters who have donated to us over the last year. Without this

support we would not be able to offer the additional support services we do. I also want to thank our volunteers who make a big difference whether they work in the warehouse packing your orders or at our front counter greeting our members when you collect your order. Our volunteer ranks continue to grow and we are looking for more. If you would like to join us as a volunteer please complete the application form on our website.

We have other volunteers assisting us in the background with social media. A big thank you to Lesley Frendo and Renee Constantin for that, and to Paula Garrod, the brilliant graphic designer who puts together our magazine on a completely volunteer basis.

The other volunteers who need thanking are our incredibly hard-working board. All volunteers and ostomates, who keep this organisation running, ensuring our governance standards are above reproach and making sure we stay financially viable.

Thank you to all who have contributed to this journal. I Hope you enjoy reading it.

Warm Regards,

Mary Egan

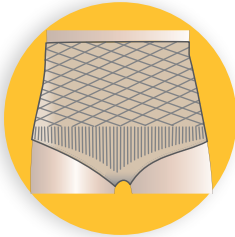
General Manager, NSW Stoma Ltd



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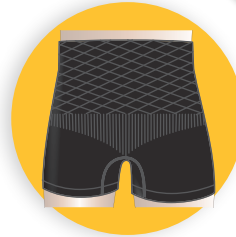
PRICED AT
\$45
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Omnigon Diamond Plus Women's Briefs

RATING 3 - MODERATE SUPPORT

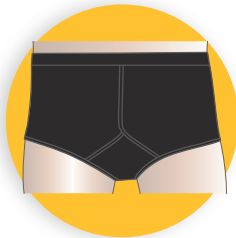
Ideal for everyday wear after surgery
and as patient resumes light exercise.



Omnigon Diamond Plus Unisex Boxers

RATING 3 - MODERATE SUPPORT

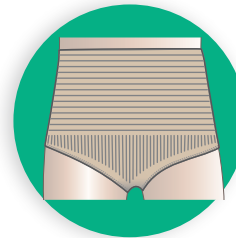
Ideal for everyday wear after surgery
and as patient resumes light exercise.



Omnigon's Men's Support Pants

RATING 3 - MODERATE SUPPORT

Ideal for everyday wear after surgery
and as patient resumes light exercise.



Omnigon Support Briefs For Her

RATING 4 - INTERMEDIATE SUPPORT

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- Neutralises mal-odours, doesn't just mask them.
- Neutralises mal-odours from urine, faeces, vomit and toilet smells.
- Is for hospital, medical, ostomy, continence and use in the home.

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120ml # 10120

500ml # 10500

1Litre # 11000

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A broad spectrum deodoriser gel designed to remove odours from a room or area. Used in Aged Care, Gastro, Palliative Care, Oncology Units, Pathology Laboratories, Operating Theatres, Forensic Centres, Chemical Storage areas and anywhere prone to mal-odours.

Product Code:

500g # 3300



Purchases can be made from your Association or contact our Customer Service on 03 5985 2828

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Stomal Appliance Scheme (SAS)
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**250ml Pump Pack
(1 per month)**

Product Code: # 1203

HOS-TOMA NO GAS

Designed for use inside appliances to prevent gas build up in the appliance. Neutralises mal-odours and prevents the growth of bacteria.

**250ml Pump Pack
(1 per month)**

Product Code: # 1103

HOS-TOMA NO SMELLS

Hos-toma dropper bottle
- Use to eliminate strong mal-odours and bacteria inside appliance.

**45ml Dropper
(2 per month)**

Product Code: # 1001



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Failte Mo Chairde (*Hello my friends*)



Wow, Christmas will be here before we know it!

We had our United Ostomy Association members and carers day on Friday 27/10 and unfortunately I could not attend, but from all accounts it was a great success.

I have written about the over ordering of products previously in 2020 and I feel it is time I brought this to your attention again, particularly for new clients who may not be aware.

Over the years I have worked at NSW Stoma I have noticed large numbers of accessory products and pouches being returned, unopened and unused. This includes products such as; stoma powder, stoma paste, seals, barrier wipes and adhesive remover. I'm raising this issue as I am concerned about waste, as these products are expensive and cannot be reused or redistributed to other members.

Some clients have informed me they have issues with their skin on discharge from Hospital and their Stomal Therapist has ordered these items to assist with skin conditions. Once the skin condition improves, the clients continue to order these products, but may not necessarily continue to use them.

Others may not have access to a Stomal Therapist offering out-patient services or live in remote areas where they cannot follow up with a Stomal Therapist

In some cases, their Stomal Therapist has ordered accessories in case they have an issue after discharge and some clients are not really sure how to use these products or in which situation they are required.

Therefore, each month, the client copies the previous order form including

the accessories products and is unaware they should remove them from order form to prevent the build-up of unrequired products.

I cannot stress the importance of maintaining contact with your Stomal Therapist after discharge. Ideally you should be reviewed a few weeks after discharge and at this time they can assist you to determine what products are necessary and adjust your order appropriately.

Alternatively, if you do not have access to a Stomal Therapist, you can call me, email me, or make an appointment to visit me in my room at NSW Stoma Ltd.

Members are fortunate to have access to one of the best Stoma Appliance Schemes in the world and we want to keep it that way. Ordering only the products you require and reducing the unnecessary use/ordering of accessory products is beneficial to maintaining access to a healthy scheme.

Just a reminder I am available for consultation on the 1st three Thursdays of the month 11am -1pm, please ring or email to make an appointment.

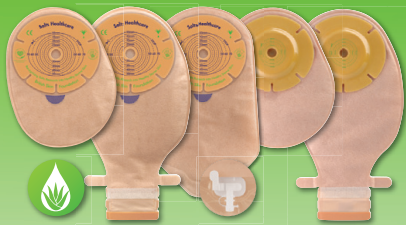
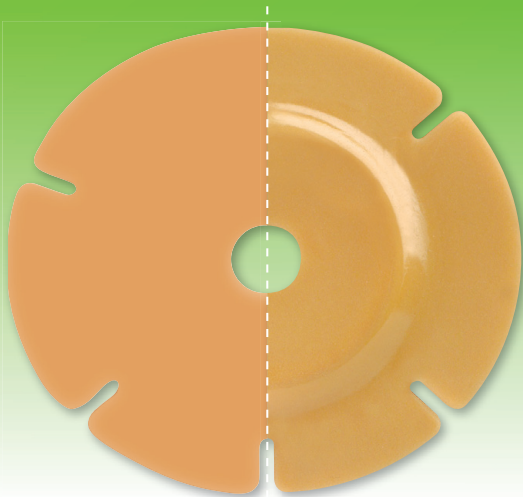
If you are in the association to collect supplies and you need to see me please wait a while and I will see you and answer your questions or make an appointment to see me at a later date if needed.

In the meantime take care and I do hope you all have a wonderful Christmas full of good fun, good wine, good food and most of all family/friends to enjoy it with.

**Beannachtaíant séasúir
(Christmas blessings)**

Anne Marie Lyons STN

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Patrick (Michael) O'Connell (1927-2023)

Obituary by Carol Quast, director NSW Stoma Ltd; Bill O'Connell (son) and Anne Maria Nicholson (niece).

It is with sadness that we announce that Michael, our legendary, long-time, highly valued member and past director of NSW Stoma, passed away on 24th September 2023 at the grand age of 96.

Michael was born in Wellington, New Zealand, on 27 February 1927, the youngest of five children to Katherine and John O'Connell who had emigrated from Cork, Ireland. He outlived his siblings Gerard, Mary, Stephen and Rose.

He was a shrewd and successful businessman, started and ran two contract cleaning companies and at various stages employed over 80 people as either fulltime employees or sub-contractors. While still working he served for a few years on the board of The Bondi Diggers RSL Club; He was a signed-up member and supporter of the Democratic Labor Party and a tireless community member in the Eastern Suburbs of Sydney. He retired at 60 but continued to give back to his communities and causes that were close to his heart.

In his post retirement years Michael still drove taxis into to his 80th year. He spent a substantial period of time volunteering for Calvary Hospice, Calvary Hospital, the Sisters of Charity, St Vincent's hospital and St Vincent de Paul Society. Michael also volunteered and drove children from the airport or Central railway to the Royal Far West Home



at Manly (for which he was awarded a commendation by the NSW State government minister Andrew Constance in 2012). He was a passionate driver and held his licence to drive his Ford right up to his 95th birthday.

For many years Michael volunteered and assisted Stoma patients with enthusiasm and good cheer often when some members were at a very low point in their lives. He was fitted with a Stoma bag himself after suffering from bowel cancer.

Many members might remember Michael as our trusty "chauffeur", the first one to put his hand up to ferry committee and members around if required. Before NSW Stoma Ltd became a company in 2016, Michael held a position on our management committee of the Colostomy Association of NSW.

Michael only retired as a director from NSW Stoma Limited in 2019.

Our board presented him with a special Certificate of Appreciation for all the hours and support he put into our association and company over the years.

Michael lived at home in Arncliffe until earlier this year and cared for by his long-time friend Julio Martinez and his family (in particular his niece Katherine Owen). He moved to Calvary Aged Care, Brighton-Le-Sands and remained there until his death on 24 September.

A great traveller, Michael was still flying to and from NZ to visit family and friends until recently. He was a fun-loving gentleman; he had an enthusiasm for betting on the horses and followed the form right up to two days before his death (he left a tip for a winning horse on his bedside table and the family backed the horse, sadly it didn't win, at least on this occasion! He always enjoyed the company of others and visits from family, friends and colleagues especially over a glass of Resch's (his favourite beverage).

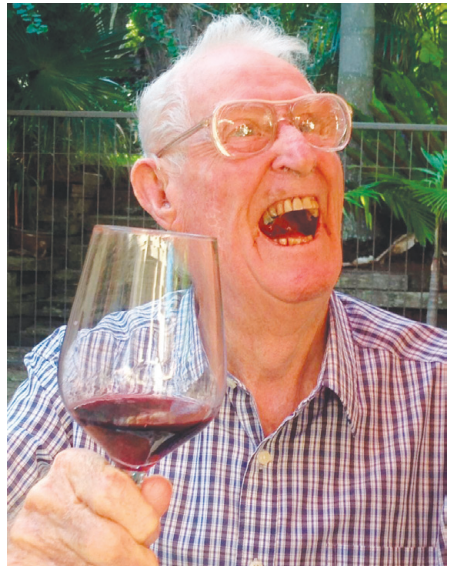
A Requiem Mass for Michael was celebrated at St Francis Xavier's Catholic Church, Arncliffe, by Father Norvin Dias on 5 October 2023 and was attended by dozens of friends and three generations of Michael's extended family. Members of Stoma NSW also attended to remember his years of service to the organisation. His son William O'Connell, his grandson James O'Connell and his grand nephew Stephen Westfield gave eulogies.

He is survived by his son William, grandson James, granddaughter Madeleine and a large extended family.



We will miss Michael's laugh, his zest for life, even through adversity, and of course his generous nature and positive outlook. Raise a glass of Resch's to him and indulge in some Roses chocolates when you have a chance.

Vale, Michael, R.I.P.



Meet our newest board member – Lynda Frost

Lynda has been Secretary of the Newcastle District Ostomy Support Group since 2016. Lynda has a range of experience across the public and private sectors in education and training, local government, financial services, travel, manufacturing and engineering. She is currently employed in the vocational education and training sector. Lynda has experience in management and small business, marketing and communications, finance and administration services and information and communications technology.

Lynda is a Fellow of the Australian Institute of Company Directors, having



held board positions in the financial services and travel industry. As a Board Director she has also been a member of audit and risk management committees. Lynda also operates her own business providing online business management services.



NSW STOMA MEMBERS ZOOM MEETING

The meeting is designed to give you an introduction to NSW Stoma Ltd and the services we offer, as well as provide some explanation of the Stoma Appliance Scheme and how to place your orders.

We recognise how important it is to feel supported on your stoma journey.

The meeting offers lots of tips and tricks for new ostomates and our more experienced ostomates usually learn something too.

Whether you are a new member or have been with us for some time you are welcome to join us. There is lots of opportunity to ask questions too.

The meeting is hosted by Anne Marie Lyons, our Stomal Therapy Nurse, Carol Quast, NSW Stoma Director & Ostomate, and NSW Stoma Manager, Mary Egan. To attend please email: customer.service@nswstoma.org.au and we will send you a zoom invitation on the day of the meeting. You need to register your interest for each meeting you wish to attend.

Meetings are held at 6pm on the first Wednesday of the month via Zoom.

Not a new member?_

If you would like us to cover other topics, please let us know by emailing:
customer.service@nswstoma.org.au

OUR TEAM



Left to right: Eddie Lathouwers, Toby Quast, Mary Egan, Carlos Soares, Jackson Gaskell, Fiona Lau, Nich Berg, Sheila Ekoue, Talei Vakalutugone, Robin Reps, Greg Spencer.



Robin Reps & Talei Vakalutugone



Jackson Gaskell & Matt Lalor



Eddie Lathouwers



**Eugene Tomczyk
Volunteer &
Board Director**



Sheila Ekoue & Toby Quast

Sydney (Hornsby) Education & Information Day



Dr Allen Nash NSW Stoma Ltd Chair

More than 150 people attended our Education Day, held at Hornsby RSL Club on 27th October. We were thrilled to see so many of you there. The event is put on by both the NSW Associations - NSW Stoma Ltd and Ostomy NSW Ltd - working together for the benefit of all our members.

The day began with our fabulous supportive suppliers (Hollister, Dansac, Coloplast, Convatec, Omnigon, Sutherland Medical and Future Environmental Services) displaying their products with members able to peruse and ask questions. I know many of you love to be able to see what is on offer from all the suppliers and appreciate the opportunity to ask them questions about the products. The day would not be possible without these wonderful suppliers contributing to the cost.



Mathew Boyd-Skinner

Carol Quast, our amazing NSW Stoma Board member and ostomate, gave our Acknowledgement of Country and warmed up the crowd by asking everyone to introduce themselves to their neighbours. The audience was asked to find out about the person next to them and those who dared took

part in 'tell 2 truths and a lie'. The feedback indicates this was a great success and asked for more of this next time round.

Mathew Boyd-Skinner spoke about his ostomy journey, from birth to a stoma at 9yrs of age, followed by a reversal, another permanent stoma as a young adult and a total 35 operations. Mathew's generosity in sharing his story and his positivity to life is an inspiration to us all.

Lee Gavegan, STN at Westmead Hospital and



Vivian Nguyen, STN at Hornsby Hospital



Lee Gavegan, STN at Westmead Hospital



Left to Right: Mary Egan, Stephen Lardner, Carol Quast & Lee Gavegan.



Supplier's Representatives

ONL spoke about parastomal hernias, their prevention, causes and treatment. We all learnt so much. Vivian Nguyen, STN at Hornsby Hospital, spoke about the different types of stomas and the reason we need so many appliances available on the Stoma Appliance Scheme.

Carol Quast gave us her hints & tips for life with a stoma, including travelling & swimming.

The day wrapped up with a Q&A session and the number of people still there at the end is testament to just how much they gained from the experience.

Feedback has been overwhelmingly positive. One of our members said: 'I felt so alone until today. Now I feel like I'm part of a much bigger community'. With nearly 50,000 ostomates in Australia and 14,000 of those in NSW, you are definitely not alone.

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Preparation



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Removal



As many as **75% of ostomates** report skin complications.¹ **Convatec is your solution.**

...with our specially designed range of ostomy skincare accessories

- ✓ Everything you need to build a skincare routine tailored to your needs, while caring for and protecting your skin
- ✓ Our comprehensive range spans preparation, application, security and removal
- ✓ Covering leak protection, to odour control and Sting-Free Skincare, our range helps you say “Hello, World” with the confidence you deserve

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1. Salvadalena et al. “Lessons Learned About Peristomal Skin Complications Secondary Analysis of the ADVOCATE Trial”. J Wound Ostomy Continence Nurs 2020;47(4):357-63. ©2023 Convatec Inc. All trademarks are the property of their respective owners. AP-64644-AUS-ENG-v2 O640 October 2023

We were extremely lucky to travel to Italy recently, and before we left, I spoke to Fiona at New South Wales Stoma regarding ordering additional supplies for the trip. She mentioned to me that a lot of the members have a real fear of travel due to their stoma, and that led me to think perhaps I could write something and share my experiences with the travel we have been lucky enough to do and try to help people to be less fearful of travel.

History

In 2013, I went for a routine check up/colonoscopy at the Dubbo Base Hospital, and emerged to find that I had a likely tumour in the lower colon. I do remember the surgeon saying to me that this is life-changing, and that I had an 80% chance of making five years. He was certainly correct about the life changing part. I had been working on the construction of the new Dubbo hospital at the time, and I knew the surgeon well. In fact, I was assisting him and the broader team with design and construction of the new operating theatres that they were about to construct. I didn't then expect to be receiving that news from him.

Fast forward and I was able to have incredibly good care at St Vincent's Hospital in Sydney and emerged with a colostomy following lower rectal surgery to remove the tumour. Fortunately, they were able to remove the tumour in entirety, but a very heavy duty session of chemo and

radiation followed to ensure as my oncologist put it, "to spray for bindies in winter so they don't come back in summer".

Prior to surgery my surgeon said to me that having a bag was not really that big a deal. He was both right and wrong. I'm now 10 years past that, and the upshot is, it does get easier. I've learned quite a few tricks and methods that have helped me avoid the dreaded blowout, and I'm hoping to share some of that insight with you in the hope that you might be able to glean some tricks that help your lifestyle, particularly with travel. You might well help me with tips also.

The good news is I made five years, and the fact that the surgeon had said that to me at the initial shock of discovering I had cancer really set me into a mindset of competition. There's no way this cancer was going to beat me.

At the five year mark we went away for a holiday and to, well, to celebrate that I hadn't been beaten which was certainly a win. We had a fantastic trip. My wife continued onto Europe afterwards for a work trip, my daughter and I flew back to Australia. A few days later, on the same trip that marked my five years clear, I received a call from my wife concerned there was a lump in her breast. Fast forward again it turned out she had breast cancer followed by huge amounts of surgery, radiation, and chemotherapy. Arguably her treatment was significantly worse than mine.

Fortunately, my wife is in good shape and at the time of writing this has just received a five year all clear, but we have both probably had enough of surgery and chemo and hospitals.

We were lucky enough to go on a holiday last month to Italy. A friend of ours had a 50th on the Amalfi Coast and we were fortunate to be able to join a big crew of friends. It was fantastic fun. Since I had surgery, we have travelled quite a bit overseas, and each time I learn a few new tricks. Whether you have a colostomy or an ileostomy, being organised for travel is really quite straightforward, and in terms of leaks, a few more tricks might assist you to be confident in travelling. In short that shouldn't force you to stay at home.

Life Uninterrupted


Probably the biggest concern that someone with a stoma has is leakage, more so when travelling, but it need not be a major concern. I have had what I call "Category 1 blow outs" whilst travelling, they have caused me huge embarrassment, but on reflection, they were once or twice and did not impact my trip and really



Quality lunch brought to my chemo session by my lovely wife.

were probably going to happen at home anyway, in the supermarket or at the rugby, where it is also most inconvenient!

The key with travelling is allowing for adequate stoma gear and keeping it with you in your carry-on luggage. That way you have avoided the second largest fear of travel, lost luggage. For a really long trip, I have put a proportion of the stoma bags, plugs etc in my checked in luggage.

With carry-on luggage, you are obviously going through airport security. The only time I had an issue 



A 3,500km adventure motorbike trip we undertook past Alice Springs some years ago. I irrigated whilst camping without too much issue.

was when I left a pair of scissors to cut the stoma bag opening sometime ago and in my early days of having a stoma. It was incredibly embarrassing and the great big security guard in the airport maybe feel like a right fool. He pulled all of my stoma gear out and put it on the airport security table found the scissors, waved them in front of my face, if to say, how dare you, and then promptly pushed everything back across for me to reassemble. This was the first trip after I had been through the whole chemo surgery ordeal. I was pretty annoyed, but I won't travel with scissors ever again. When I go through security, I sometimes am concerned that people might think that I have contraband, hidden, i.e. drugs or something, given that the stoma bag sticks out a fraction. So before they pat you down and accuse you of doing something, you're not supposed to, I just slightly lift my T-shirt or shirt and show the security guard the stoma. I guess they

are trained to know what a stoma looks like and in my experience they wave you through without issue. In the security section, no one other than the guard can really see you anyway so I don't really find it embarrassing.

For the flight part of travel, which is probably the one part of a trip that causes the most angst, I irrigate in the morning. As a colostomate it makes things easier I guess to have that option. After the morning irrigation I then put a bag on (as opposed to a stoma plug), but always use brava elastic tape around the perimeter of the bag to ensure it is firmly stuck on and highly unlikely to leak. I put on two strips, one over the bottom flange of the bag, and one on the top flange, so it completely surrounds the bag and sticks it on securely. An ileostomate I'm sure would operate similarly in terms of leak prevention. On our recent trip, I did have one episode with a slight bit of discharge during the flight, it happened while the fasten seatbelt sign was on, but I didn't panic as soon as I was able to, I got up, and I always keep several spare bags, waste bags, and tissues in my pocket. A pair of cargo shorts is brilliant for that. What you don't want to do is have all your emergency spare bags etc in your carry-on, up in the overhead locker and then face the difficulty of trying to get an emergency bag in a rush.

Once you arrive at your destination, you really don't need to be much different to how you operate at


home. On our recent trip, we were wandering around, looking at the sites in Rome, and I had a plug on as opposed to a bag, I very rarely get discharge as I irrigate every day, but in this case, something gave me a bit of an upset stomach. Trying to find a toilet then to change things over was a little problematic, but the appliances are so good that I didn't have an issue. I was able to change it and get on with the day and enjoy the trip. I'd be lying though if I said it didn't cause me a bit of anxiety, but that's no different to being at home.

Of course, it isn't always smooth sailing, after I had my major chemo/surgery, and I was in the clear able to travel ready to live life, we went on a great big trip for three months overseas. I was glad to be alive, literally. Our daughter was then aged four, we were on a ferry in Venice, and we'd been out to one of the outer islands. It was a great day a few beers in the sun, a lovely lunch, and then a massive blowout on the ferry coming back. I couldn't believe it. Looking back I had all the wrong equipment with me. I brought a plug, not enough spare tissues, etc. I was completely ill prepared. What I know now would have likely minimised the issue and the anxiety I had at that time. I remember being absolutely mortified. There was poo everywhere all down my shirt all down my shorts And I thought the



I kept some spare bags in the tank bag on the motorbike in case of emergency.

whole ferry could see and smell my predicament and be aghast at my situation. I was really stressed out, it was probably the biggest category one blowout I've ever had in the most awkward spot. I got back to where we were staying, I put my clothes in the wash, jumped in the shower dried off put a new bag on put new clothes on and went to dinner, and as best as I could promptly forgot about it.

The same thing happened again in Japan some years later. We were skiing and my daughter and I were having a fantastic ski, beautiful day, great snow, then I could feel a blowout coming on, I skied down a bit further away from everyone over near the trees on the side of the run, I undid my ski jacket, pulled out a spare bag (always take several) and changed it then and there. It wasn't quite that simple, there was a whole lot of discharge that went everywhere and I was again mortified. I trudged back to the lodge with skis, boots, poles, deep snow and a category 1 blow out. I expected to see a huge mess, and it really wasn't that bad I discovered. 

The bag tends to cover anything that has discharged below anyway, and even if it doesn't, you have a shower you get changed and you get on with it. You haven't really got a lot of choice and I have refused to let this thing beat me.

Whilst we were overseas recently, I did have several problems, but they didn't cause me massive angst. We did a lot of swimming and boating with friends, and I don't feel on reflection that I was stopped doing anything really. Most of my friends know I have a stoma, but no one really made any comment whilst we were away and when they did, it was in genuine support.

Sport

Before this whole Stoma episode in my life, I used to do a lot of sport. After this whole stoma episode, I do a whole lot of sport. I haven't let it change. I don't play rugby anymore mainly because I'm old and I don't really want to play anymore, but the point is it is not stoma-related. Probably the most difficult environment I find would be water related activities. I still do a lot of long ocean swims, and whether I have a bag or a plug, so ileostomy or colostomy patients alike, I put brava elastic tape at the top and bottom of the flange, as mentioned above, which adheres very well in the wet. In the case of using a plug, I would put a blue dot that Coloplast supply with their bags that covers the small pinprick hole that allows filtered gas

to escape. I then put a Band-Aid over that and then about three rows of rock tape, which is like Elastoplast but sticks better. My logic is that I have irrigated, and I'm usually at the beach or a pool or wherever, and have irrigated in the morning so there shouldn't really be any discharge in my system until later in the day. What people see is really what looks like a wound dressing over stitches or something. At least that's how I see it and it reduces my concern. If I have a bag, I do the same thing and put tape over the top, as in the rock tape, to disguise the top of the bag, the lower part of the bag I tuck into my boardshorts. The other thing you can do with a bag is buy a thing called a stealth belt <https://www.stealthbelt.com/> and I bought one before I was able to irrigate and that was fantastic. I did a lot of ocean swimming, and I don't think anyone was aware I had a stoma. In fact, I still swam when I had chemo and I had the porta-cath in my upper chest. I don't think my oncologist was too impressed, but the key thing is I never had a leak.

Day to Day

Day to day, I keep spare supplies everywhere, including in my wife's car, my car, my briefcase, etc. I'm never far from supplies if I can sense an issue arising. If I do go to say a function, I'll put spare supplies in my suit pocket or if I'm in a pair of jeans at the footy, I'll put two bags and two plastic bags in my rear jeans pocket or jacket. That

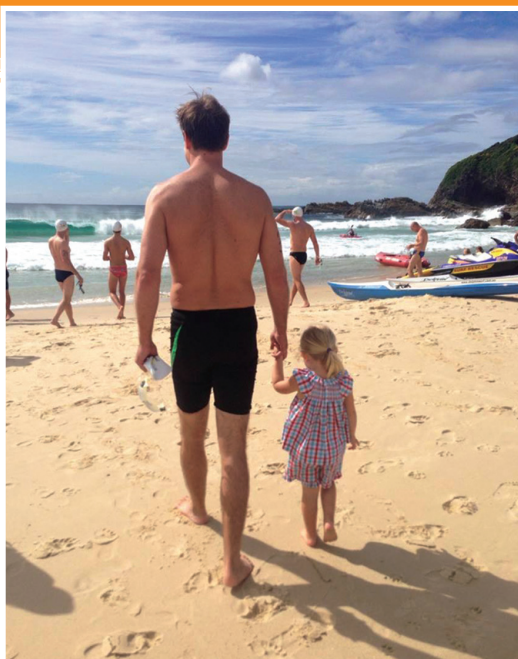
process has got me out of jail a lot of times. Generally I only need one bag change and you can get on with the day. I always where possible use a handicap bathroom so you have a bit more room to spread out. I know it's probably not quite right to use the space but if no one is waiting, I figure I have more room to spread out and it is a bit more personal than a regular bathroom cubicle.

In the bathroom at home I find it really important to have all of my stoma equipment organised. I have a Tommee Tippee Sangenic nappy trash unit which we had when our daughter was a baby. I use it to put the waste stoma equipment to this day and I think a must for any stoma patient.

<https://www.tommeetippee.com/en-au/product-support/support-sangenitec-nappy-disposal-system>

In terms of admin and ordering supplies, each month when I send off my appliance orders, I have a PDF on my computer ready to go. All I have to do is change the month. Drop the form onto an email and send it off to Fiona and her wonderful team. Without NSW Stoma I would be in a world of difficulty and I am immensely grateful to them.

For monthly orders, If computers aren't really your thing, I would suggest what I used to do and photocopy say 12 order forms for a full year of orders, and then just hand write the month on the form and change any necessary changes that you have, in addition to



My daughter Poppy and I as I went for a fairly long ocean swim/race at Forster. You can just see the "Stealth Bell" covering the stoma bag.

a bunch of envelopes pre-stamped ready to go. That way you're being organised and it doesn't become a pain in the neck every month and something that reminds you of the fact that you have this impediment. I found that by being organised like that means I don't really think about having a Stoma too much anymore.

Conclusion

My stoma journey has been on the whole, far less daunting than what I had anticipated when I received those initial frightening words from the surgeon. Certainly strong Faith for me and some stoma-related techniques have made the journey less difficult.

To share your travel experience email: customer.service@nswstoma.org.au

Asia & Pacific Ostomy Association (ASPOA) Conference

The conference of the Asia & Pacific Ostomy Associations was held in Singapore on 21st October. Dr Allen Nash, our NSW Stoma Chair is also ASPOA President (and re-elected again at the end of the meeting). Allen opened the meeting and outlined the Associations strategic plan and objectives. Its role is primarily to assist communication between its member associations with a view to assisting ostomates in the region to live their best lives. This includes facilitating the distribution of surplus products to places most in need.



Dr Allen Nash

The conference was attended by delegates from 10 countries in the region: Australia, Hong Kong, Indonesia, Japan, Korea, Malaysia, New Zealand, Philippines, Singapore & Vietnam. Each country reported on association activities in their respective countries.



ASPOA Conference delegates 2023



Jon & Stenu Thorkelsson



Representatives from the Indonesian Ostomy Association

It was fascinating to hear the different challenges for ostomates in those countries with government funding of supplies in many countries, being either very limited or non-existent. We are certainly fortunate in Australia with supplies issued under the Stoma Appliance Scheme and the advantages offered by all members belonging to an



Dr Martha Tara Lee

association which can then offer additional support services.

Ian Thorkelsson, head of the Icelandic Ostomy Association, also attended in his capacity as president of the European Ostomy Associations. He reports that ostomy supplies are free to ostomates in Iceland and covered by their National Health Insurance.



Japan's ASPOA delegate with Carol Quast

We also heard talks from experts working with ostomates. Esther Thng (from the Wound Ostomy Continence Nurses Chapter of Singapore Nurses Association) spoke about parastomal hernias and Martha Tara Lee (Clinical Sexologist in Singapore) spoke about Sexuality, Cancer & Stomas. The speakers were both informative and entertaining.

All attendees declared the conference a great success.

DONATIONS

A huge thank you to all our members and supporters for your generosity, without which we would not be able to offer additional services, such as our Stomal Therapy Clinic, STN Scholarship, Zoom member meetings and more.

We have seen a huge increase in the number of members needing our financial assistance and it is so gratifying to be able to offer that assistance. Thank you for making that possible.

I also want to acknowledge our members who are no longer with us and the generosity of their loved ones who made donations on their behalf.

Some of you choose to remain anonymous but your generosity and philanthropy are noted.

The names of those of you who have given us permission are listed below and include donors from 1st April 2023 to 30th September 2023:

Donations to NSW Stoma Ltd are tax deductible.

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THE NATIONAL PUBLIC TOILET MAP

A Project of the National Continence Program (NCP)

www.toiletmap.gov.au

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The National Public Toilet Map shows the location of more than 16,000 public and private public toilet facilities across Australia.

Details of toilet facilities can also be found along major travel routes and for shorter journeys as well. Useful information is provided about each toilet, such as location, opening hours, baby change room availability, and accessibility for people with disabilities and details of other nearby toilets.

The Toilet Map is funded by the Australian Government Department of Health as part of the National Continence Program.



WHAT DOES THE TOILET MAP DO?

The Toilet Map improves independence and quality of life for the estimated 3.8 million Australians who are affected by incontinence by providing:

- the location of the nearest public toilet
- details of opening hours, accessibility, parking and other features
- the capacity to plan toilet breaks for short or long journeys
- the ability to save toilet information and trip plans
- access anytime using a mobile phone

It is also convenient for people with young families and those holidaying or travelling to new locations.



HOW DO I USE THE TOILET MAP?

- browse the map in a particular State/Territory
- Search for toilets by postcode, town or suburb, near a specific address or location such as a sports ground
- Plan a trip with the Trip Planner - Enter your starting address and destination to get a turn by turn description for the quickest route and the toilets along the way

When you find toilets near an address, at a point of interest or at a latitude/longitude you can select additional toilet features and opening hours in the right hand column of the page.

There are a number of different features listed, including baby change facilities, sharps disposal, MLAK access (see below) and accessible parking.

Unfortunately, it is not possible to release hard copies of the Toilet Map information to the general public. The main reason is that the toilet information is updated on a regular basis and so a hard copy of toilet information would quickly become out of date. However, feel free to print out toilet information from your browser to take with you on your travels.

The National Public Toilet Map is also available on:-

- Any mobile phone with an Internet browser. Go to m.toiletmap.gov.au on your phone to be automatically directed to the mobile site.
- Apple's iPhone. Just go to the App Store on your iPhone or use iTunes to download the National Public Toilet Map App. It's free.
- You can also use the Toilet Map with a Global Positioning System (GPS).

MASTER LOCKSMITHS' ASSOCIATION KEY (MLAK)

MLAK stands for **M**aster **L**ocksmiths' **A**ssociation **K**ey. The **MLAK** is a master key that fits into specially designed locks allowing 24 hour a day access to public toilets. Eligible people (those with a disability and a letter of authorisation from a doctor, disability organisation, local council or community health centre) can purchase a key that opens all accessible toilets displaying the MLAK symbol.

For information about where to obtain keys or locks within your area, contact the Master Locksmiths Association of Australasia (phone 03 9338 8822).



MLAK FACILITIES

The Spinal Cord Injuries Australia organisation maintains a directory of MLAK-enabled facilities across Australia. To view this directory please go to:- <http://scia.org.au/sci-resources-and-knowledge/public-toilets>



NEED TO USE A WHEELCHAIR ACCESSIBLE TOILET?

Have you ever been too embarrassed to use a DISABLED TOILET when you have to change or empty your ostomy appliance? Or have you ever been challenged when entering or leaving a DISABLED TOILET (wheelchair accessible)?

Where available, a DISABLED TOILET will provide the privacy and space needed for an Ostomate to change or empty their appliance. However, to the general public most Ostomates do not appear as if they should be using them.

To help avoid such problems, **an information card** has been provided to all NSW Stoma Limited members. Keep the card in your wallet or purse for quick access if needed.

You can also show this card when asking to use the toilet at a shop, restaurant or other business. It doesn't guarantee access to their toilets (as every business has different health and safety rules), but it proves you have a genuine medical condition that requires the urgent use of a toilet. Many places will try to help you.



VOLUNTEERS WANTED

Ever thought of volunteering?

Volunteering not only benefits your association, it's good for you too. Gain professional experience, meet new people and learn new skills while helping us improve and expand our services.

Volunteer workers at NSW Stoma are valued and appreciated and play an important role in supporting our strategic objectives. We currently need assistance in the following roles: stock receipt and dispatch, administration and customer service/reception. Whatever your skills, full training is provided.

While the majority of volunteers working within the association environment either have a stoma themselves or have a close family member who is living with a stoma, our association welcomes volunteer enquiries from any interested person.

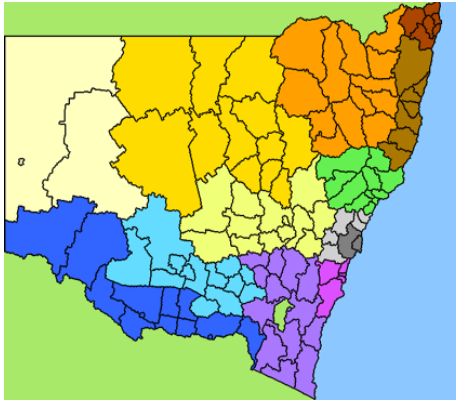
NSW Stoma Ltd provides a clean, safe, friendly and happy work environment and we are seeking friendly positive people to help us cope with our ever-increasing workload.

To apply download our application form here:
<https://www.nswstoma.org.au/volunteers/>

or just email volunteer@nswstoma.org.au and we will send it to you.

*Eugene Tomczyk,
our fabulous
volunteer who
works every Friday
in our warehouse.
Thank you!*





Ostomy Support groups are a great way for ostomates to support and care about each other. Friends and family are also welcome to attend support group meetings.

We recommend you contact your group for information regarding Covid-19 restrictions.

If you are involved in a support group and would like us to include information about your meetings in our journal and on our website please email:

info@nswstoma.org.au

For current information on support groups please go to: **<https://www.nswstoma.org.au/becoming-a-member/support-groups/>**

NSW STOMA LTD MEMBERS SUPPORT GROUP ZOOM MEETING

All members, carers & friends are welcome to join our monthly Zoom meeting at **6pm on the first Wednesday of every month (except January).**

Hosted by Anne Marie Lyons (STN), Carol Quast (Director & ostomate) and NSW Stoma Ltd manager, Mary Egan, this is

designed to give information about the services we offer, the Stoma Appliance Scheme and loads of information to assist and support ostomates.

To attend please email:

customer.service@nswstoma.org.au

and we will send you a zoom invitation on the day of the meeting. You need to register your interest for each meeting you wish to attend.

WOMEN'S OSTOMY SUPPORT GROUP

This group is for women about to, or who already have an Ostomy and/or Stoma, regardless of where treatment has been received.

Where: San Cancer Support centre, Jacaranda Lodge, Sydney Adventists Hospital

When: Check with the group organisers for advice on scheduled meetings.

Contacts: San Cancer Support Centre (02)9487 9061 or **support@sah.org.au**

OSTOMINGLE - YOUNG OSTOMATES SUPPORTING EACH OTHER

Looking for some young, like-minded Osto-mates? Ostomingle is a group of ostomates 18 and over who come together over a meal to share their ostomy experiences and learn from one another.

Each meet-up will be held at a different venue around Sydney so we can mingle around town.

When: Check with the group organisers for advice on scheduled meetings.

Contact: Renee Constantin
www.ostomingle.com
ostomingle@gmail.com



NSW OSTOMY SUPPORT GROUPS

BEAT BLADDER CANCER

Register at: <https://www.beatbladdercanceraustralia.org.au/>

Where: Macquarie University

When: 7pm – 8.30pm
last Tuesday of the month

Contact: Adam Lynch **0421 626 016**

SYDNEY METROPOLITAN AREA

BANKSTOWN – LIDCOMBE AREA

Where: Revesby Workers Club

When: 2024 dates TBA

Contact: Your Stomal Therapy Nurse or Carolyn Nichols on **0419 335 046** or carolyn.nichols@dansac.com.au for further information

RSVP for catering purposes

CONCORD AREA

People with bowel cancer and carers/family are welcome to attend this free monthly service.

Where: Survivorship Cottage, Concord Hospital, Gate 4, Nullawarra Avenue, Concord West

When: Check with the group organisers for advice on scheduled meetings.

Contacts: Sonia Khatri **(02) 9767 5943**

LIVERPOOL AND CAMPBELLTOWN AREA

Where: Campbelltown Catholic Club, 20/22 Camden Rd, Campbelltown

When: 2024 Dates TBA

Contact: Erin Wagner - **0419 224 662** or Lu Wang – **0417 026 109**

Afternoon tea provided - RSVP essential for catering purposes.

NORTHERN SYDNEY AREA

All Ostomates, friends and supporters welcome.

Where: Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Road, Wahroonga

When: Check with the group organisers for advice on scheduled meetings.

Contact: San Cancer Support Centre on **(02) 9487 9061** or email: cancersupport@sah.org.au

PENRITH AREA

Ostomates, family and friends are welcome to attend our educational support group

Where: Sydney Medical School, Outpatients Department, 62 Derby Street, Kingswood (opposite Nepean Hospital Emergency Department at roundabout, Outpatients is at left hand side of building)

When: Check with the group organisers for advice on scheduled meetings.

Contact: Naomi Houston (Stomal Therapist) on **(02) 4734 1245**
Naomi.Houston@health.nsw.gov.au

RAMSGATE

The Stomal Therapy Nurses from St George Public, St George Private, Kareena Private, Hurstville Private and Sutherland Hospital's together would like to invite you to attend a stoma support group for ostomates and their families.

Where: Ramsgate RSL (meet in the front foyer), Corner of Ramsgate Rd and Chuter Ave, Sans Souci,

When: 2024 Dates TBA

Contact: Your Stomal Therapy Nurse
Everyone is welcome.
RSVP for catering purposes

JOURNAL

DECEMBER 2023

NORTH COAST REGION

TWEED / BYRON AREA

Ostomates, family and friends are welcome.

Where: South Tweed Sports Club, 4 Minjungbal Dr. Tweed Heads South.

When: Check with the group organisers for advice on scheduled meetings.

Contact: Lisa Clare STN:
(07) 5506 7540 or **0429 998 928** or
Lisa.Clare@health.nsw.gov.au
Kate Rycroft **0432 251 703** or
rycroffkate@gmail.com

FAR NORTH COAST

All Ostomates plus partners and friends are welcome to attend meetings.

Where: Lismore Workers Club, 225-231 Keen Street

When: Check with the group organisers for advice on scheduled meetings.

Contact: Marie Taylor **(02) 6686 7248**

CLARENCE VALLEY OSTOMY SUPPORT GROUP

All Ostomates and friends are welcome to attend meetings

Where: Aruma, 175 Queen St, Grafton

When: Bi-monthly – 2nd Tuesday of the month

Contact: Gary Tobin **0400 675 277**

COFFS HARBOUR

All Ostomates and friends are welcome so come along, have a cuppa and be a part of it.

Where: Sawtell RSL Club, First Ave, Sawtell

When: Check with the group organisers for advice on scheduled meetings.

Contact: Mandy Hawkins STN:
(02) 6656 7804
Mandy.Hawkins@health.nsw.gov.au

HASTINGS MACLEAY

Where: Port City Bowling Club, function room, 4 Owen Street Port Macquarie

When: 10am - 12pm Third Wednesday of every second month Feb, Apr, Jun, Aug, Oct, Dec

Contact: Neil **0427 856 630** or Glennie **0410 637 060**

MANNING / GREAT LAKES

Where: Venue TBA

When: 10.30-12pm approx. 1st Wednesday of every 2nd month

Contact: Karla MacTaggart STN
(02) 6592 9169

NEWCASTLE REGION

NEWCASTLE DISTRICT

Stomal therapists and company representatives will attend and help with any queries. New members and friends are welcome.

Where: The Hub, Hamilton Wesley Fellowship House, 150 Beaumont Street, Hamilton

When: 1.30pm – 4.30pm approx. Last Saturday in Feb, May, Aug & Nov

Contact: Geoff Robinson
0411 221 193 (Jan)

ILLAWARRA / SOUTH COAST REGION

BOWRAL

Where: Bowral Bowling Club, 40 Shepherd Street, Bowral

When: 1pm – 3pm Tuesday 2024 Dates TBA

Contacts: Lu Wang & Erin Wagner
Stomal Therapists, Liverpool Hospital
(02) 8738 4308

Everyone is welcome but must be double vaccinated to attend (proof required on entry)

RSVP for catering purposes



NSW OSTOMY SUPPORT GROUPS

EUROBODALLA

All from the NSW South Coast region are welcome.

Phone clinics only during Covid-19 times.

Where: Moruya Hospital,
River Street, Moruya

When: Check with the group organisers for advice on scheduled meetings.

Contact: Trena OShea (02) 4474 2666

ILLAWARRA

Where: Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree

When: 10am-12pm, Wednesday.

Contacts: Helen Richards CNC STN Wollongong Private Hospital
(02) 4286 1109

richardsh@ramsayhealth.com.au

Julia Kittscha CNC STN Wollongong Hospital mob: 0414 421 021

julia.kittscha@health.nsw.gov.au

SHOALHAVEN

Where: Nowra Community Health Centre, 5-7 Lawrence Avenue, Nowra

Also: Ulladulla Community Health Centre, cnr South St & Princes Hwy, Ulladulla

When: Check with the group organisers for advice on scheduled meetings.

Contact: Brenda Christiansen
(02) 4424 6321 or 0422 006 550 or
Brenda.cristiansen@health.nsw.gov.au

ACT

Where: ACT & Districts Stoma Association, 2nd Floor, City Health Building, 1 Moore St Canberra

When: 10am-12pm, Tuesday 2024 TBA

Contact: Your Stomal Therapy Nurse

JOURNAL

DECEMBER 2023

WESTERN NSW REGION

BATHURST

Where: Daffodil Cottage,
365 Howick St, West Bathurst NSW 2795

When: Check with the group organisers for advice on scheduled meetings.

Contact: Louise Linke (STN/continence advisor) (02) 6330 5676

DUBBO

Where: Dubbo Health Service,
Ian Locke Building, Room 8 or join virtually via Pexip or phone.

When: Last Friday of the month. 2pm-3pm

Contact: Thulisile Moyo on
0408 769 873 or

Thulisile.Moyo@health.nsw.gov.au

GOULBURN

Where: Goulburn Workers Club,
1 McKell Place Goulburn NSW 2580

When: 10am – 12pm Wednesday 2023
Dates TBA

Contact: Your Stomal Therapy Nurse
RSVP for catering purposes, car parking available on-site

GRIFFITH AND DISTRICT

An invitation is extended to all persons in Griffith and Surrounding areas (including Coleambally, Leeton, Yenda, Hillston and Hanwood) with a Stoma formation to attend our meetings and share experiences.

When: Check with the group organisers for advice on scheduled meetings.

Contact: Barry Maples (02) 6963 5267 or
0429 635 267; Kim Hallam 0434 785 309

WAGGA AND DISTRICT

Where: Men's Shed, 11 Ashmont Avenue, Wagga Wagga

When: Check with the group organisers for advice on scheduled meetings.

Contact: David (02) 6971 3346 or
0428 116 084



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