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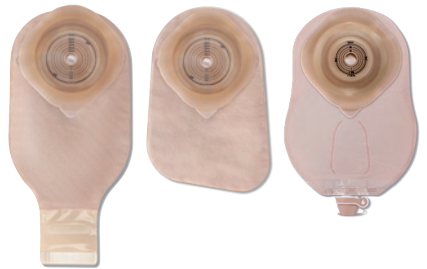
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For current information go to:

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nswstoma
LIMITED

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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.



Robert Anderton, who volunteers every Monday and works in our reception area. Thank you!

NOTICE BOARD

Christmas Closing

We will close at 12pm on 24th December and re-open on Friday 3rd January at 8.30am
Fridays in December we close at 12pm
To guarantee dispatch before Christmas please place your order by 13th December.
We wish all our members all the joy of the season and a fabulous 2025!

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

Stoma Appliance Ordering Portal for members

For information, FAQs and instructions go to:
<https://www.nswstoma.org.au/nsw-stoma-members-portal/>

POSTAGE	STANDARD POST	EXPRESS POST
1 Month Issue within NSW	\$16	\$26
2 Month Issue within NSW	\$32	\$52
1 Month Issue Interstate	\$25	\$36
2 Month Issue Interstate	\$50	\$72

 **Please be aware that Australia Post do not guarantee delivery times for Standard or Express Postage**



NOTICE BOARD

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	\$16.00	\$18.00
Ostomy Scissors (curved)	9505	each	\$9.00	\$10.00
Hollister Leg Bag	9632	each	\$10.00	\$12.00
Hollister Leg Bag	9624	each	\$10.00	\$12.00
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

Did you know you can purchase products from any of our suppliers through us?
We offer special pricing for our members and can provide quotes on request.
Please note all cash sales must be paid for at the time of ordering.

CHAIRPERSON REPORT

from Dr Allen Nash October 2024



It was great to meet members at our information day in Orange. We are committed to continue our information days which have been very well received by our members and the Orange Information Day was another successful event.

We have had a member of the board retire and I would like to thank John Hickey for his contribution while on the board. At our upcoming Annual General Meeting we will have one board position to fill and look forward to welcoming a new member to the board.

The Health Department who funds our ostomy supplies is again reviewing the Stoma Appliance Scheme. There are two parts to the review. One is reviewing the product range and number of products available on the scheme. This may affect members directly if products they are using are removed from the scheme.

The second part of the current review is looking again at the distribution arrangement which is the role of your stoma association. The government has caused much concern among members and the stoma associations with their continual review of the scheme. We operate

an efficient supply of products as a nonprofit association that exists solely for the benefit of ostomates, and we work very efficiently. I really hope there is no disruptions to members from the decisions the Federal Health Department comes up with because of this process.

Whatever changes the Health Department proposes, we will do our best to ensure there is a minimum disruption to members getting their supplies. There has also been no response from the Department on the submission our national body ACSA made to increase our funding which has not increased in many years.

We are still managing to operate effectively despite the pressures and appreciate very much the donations we receive from members and others to assist in providing the additional support services for members.

Keep well.

Allen Nash

Chair - NSW Stoma Ltd

A message from Mary Egan, your General Manager



Another year has flown by! In the last financial year we supplied 7,883 individual members through the Stoma Appliance Scheme (SAS). We signed up 1,641 new ostomates to the SAS and prepared 51,227 orders with Medicare paying us \$17,846,987 (plus 2.75% handling fee). An average order is valued at approximately \$348 each--that's a lot of statistics and a lot of money. I hope every one of you feel you received value from both the Stoma Appliance Scheme and NSW Stoma. Our staff and volunteers work hard to give you the best possible service and process your orders as quickly and as accurately as we can. While the 2.75% from Medicare doesn't come close to covering the cost of getting those products to you, your membership fees and postage fees help make up the shortfall.

The generous donations we receive allow us to offer all the other services we couldn't otherwise provide. These include our in-person education days, our stomal therapy clinic with the fabulous Anne Marie Lyons, our STN Scholarship, monthly Zoom meetings, information and resources on our website and of course--our journal. We have also seen a big increase

in the number of members needing financial assistance. The last few years have been difficult for many but because of the generosity of those who can, we are able to offer subsidies to those who can't afford it so that all ostomates have access to the vital supplies they need. Thank you!

Last October we introduced our online member portal which many of you are now using to place your orders. The portal allows you to see your past orders and products you've previously used, and you can pay your postage and membership fees there too. The feedback is very positive: order anywhere, anytime. In September more than 35% of our orders came through the portal and we hope to increase this by adding more features while keeping it simple and user-friendly. If you haven't tried it, I highly recommend it--you can register using your email address, surname and member number. The portal is for your convenience, but it also helps us streamline the ordering process. Once we approve your portal order it is automatically entered to our warehouse management system without any extra keying. This means less errors and a faster turnaround for your orders. For those who prefer not to use online ordering, we'll continue to take your orders in whatever format is most convenient for you. Please be aware that due to Medicare





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- Provides a smooth appearance for discretion



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- Looks like normal underwear



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

regulations we do need to receive your orders in writing.

Now, our usual focus is on assisting members to live their best lives with a stoma (or two or three). However, it is a reality for enough of you that reversals warrant our attention too. Most of our members have their stomas for the rest of their lives but I also know many have a temporary stoma while their bowel heals from life-saving surgery. This issue, we're focusing on some of our members who did get their stoma reversed and their experience with the process. I know for some of you this is a difficult decision and not everyone is happy with the result, and we're always grateful to members who share their stories with the NSW Stoma community.

This year we also said farewell to two long-term staff members, Diane Habib and Greg Spencer. Greg worked in our warehouse for 13 years and his smiling face is certainly missed by all of us. Diane worked in both our warehouse and administrative team for over 20

years and we saw her become a mother—now she's a grandmother! I'm thankful to have such passionate & dedicated staff and hope they are both having a wonderful retirement.

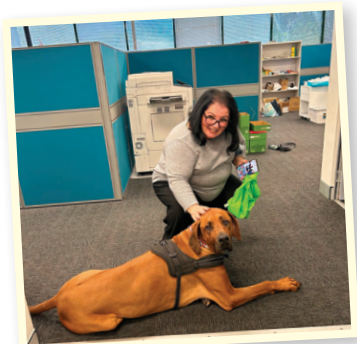
While we're on the topic of our hard-working team I can't forget to acknowledge the wonderful work of our volunteers. If you've ever collected an order from our Stanmore office you might know these friendly and familiar faces! As a member-led organisation, having volunteers who are also ostomates is a key principle of NSW Stoma. We're endlessly thankful for the volunteers who donate their time and energy and keep this organization running. We couldn't do it without you. That includes our hard-working board of directors and the wonderful, clever Paula Garrod who puts this magazine together. Thank You!

I wish all our members all the joy of the season and the best possible 2025.

Warm Regards,

Mary Egan

General Manager, NSW Stoma Ltd



◀ Diane Habib
& Barry.

Greg
Spencer



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Application



Security



Removal





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Disclaimer: Speak with your doctor, physiotherapist, or nurse before doing these exercises, and ask them to show you how to do the movements correctly. If you've had a very complex surgery, have an unstable hernia, or other complication, please check with your doctor or ask for a referral to a clinical physiotherapist.

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Hope this note finds you well.

This journal's topic was decided by Mary (our manager), Paula (our graphic artist/editor) Carol (our director) and I. My colleague Jess (Jess Lin ERAS Nurse Coordinator | Clinical Nurse Consultant | Colorectal Department) also assisted me with compiling this information.

We thought it would be a good idea to seek the opinion of a few patients who had their stoma reversed, as we believe many of you reading this will be looking at reversal of your stoma in the future.

I sent out 6 questionnaires and had 4 responders.

This topic proved to be a lot more challenging than I first thought!

2 of the 4 people answered the questions in their own words (which was an option) and gave beautiful accounts of their journey and how life is today for them.

These 2 stories will be included in this article in point form, they will also be published as a whole, too as they are very detailed and very informative.

What type of stoma did you have?

- Marco and Joy had a colostomy, Ian and Luke had loop ileostomy.

Why was it formed eg: cancer, diverticular disease, trauma, inflammatory bowel disease?

- Cancer two, necrotic bowel due to adhesions one and one perforated diverticular disease.

How long ago was your stoma closed?

- 3-6 months range for all 4

Were you given sufficient information on what to expect after having your stoma closed?

- Ian said "Not enough information was provided (very little)".

- Marco said "Yes – Anne Marie, Roger, and Ian were extremely helpful, letting me know what to expect, letting me know what help was available".
- Joy said "Yes, my surgeon was very informative. As were his registrars after the surgery".

Did you have control over your bowel function straight away?

- Ian said, "No it took some days to get some control then further time to feel reasonably comfortable".
- Joy expressed "No, I didn't. But it did come in what I considered a fairly quick time".
- Marco said "no, but I am almost back to normal life".

Were you incontinent/loss of control? If so for how long?

- Marco and Luke advised 'no' Joy said "yes I was, it would have been a few months, still have an occasional occurrence"
- Ian said "yes I was incontinent for the first few days".

Do you have urgency (have to rush to the toilet)?


- Joy said 'yes I do, it seems to be on and off but I am very conscious of any bowel action"
- Ian said "previously yes currently not so often" both Marco and Luke said "no".



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Reversal of your stoma

How much warning do you have to get to the toilet?

- Joy expressed "Sometimes lots of time and other times most urgent. I am just always aware".
- Ian said "normally enough time"

Do you have to visit the toilet multiple times before you feel you have emptied your bowels adequately?

- Joy expressed "Sometimes! Other times no problem and then oh dear several visits". Ian said "yes".

Do you suffer from constipation?

- Joy said "No, I have never had constipation. But I do take Metamucil every morning. I began using it very early as I was having a burning sensation and the surgeon said this would help and it did!". Ian said "no".

Do you ever have soiling, where some stool has escaped, and you were unaware? When does this happen and what was the consistency of your stool at the time?

- Joy said " At first this was a problem as I was not always aware of needing to empty my bowels. Now not so much, it does happen occasionally. The stool is usually softly formed but not loose. It also depends on what I have been eating".
- Ian said "unfortunately I have a lot of wind so during the night I might have a mishap and hence the soiling".

Do you always have a sensation that you need to go to the toilet?

- Joy expressed "Mostly. This sensation began fairly quickly. But I am still not all that trusting of these sensations".
- Ian expressed ". No , but during the mornings and evenings i do have a sensation for toilet visits

Have you changed your diet since closure?

- Joy said "No, my diet has not changed, I had my gall bladder removed in 2018 and I am a type 2 diabetic. My taste buds have always been suitable to these conditions and am not a sweet tooth.
- Both Luke and Ian expressed "no'.

Do you take any medication to thicken your stool? Gastro stop, fibre supplements?

- Joy expressed "I use Metamucil to prevent any acidic sensations".
- Ian, Luke and Marco said "no".

Do you need to wear a pad?

- Joy explained "I do, mainly as I have mobility problems and worry about not reaching the bathroom in time".
- Ian Marco and Luke said "no"

Did you have an exercise programme to strengthen your anal sphincter muscles after surgery?

- Joy explained "Yes I do, you advised me at our first meeting. Telling me it is a muscle and needs exercising".
- Ian, Marco and Luke said "no".

Did you seek advice about how to improve your bowel function? (from your surgeon, GP, stoma care nurse etc)

- Joy explained "The surgeon gave a lot of information. There are times when I cannot be sure that the stool has completely exited, so extra care is taken".
- Ian explained " I was advised at the hospital that things would improve with time".

Have you considered seeing your surgeon and requesting that you have your stoma formed again?

- All 4 expressed "no"

Overall, are you satisfied with your bowel function now that your stoma has been closed?

- Joy expressed "Yes very happy with the result."
- Luke and Marco expressed "yes" and Ian said ". Time has helped but it still has a fair way to go to be totally happy, life goes on and of course we adjust to the moment".

As you can see from the responses it is quite complex and for future people answering these questions, I would advise to stick to the questions to allow us to have a better understanding of the overall outcome.

From this minute study it is evident that the control of movement after surgery is an issue, but it improves, and confidence returns.

It is also evident that all four patients were happy to have their reversal.

What I am seeking in the future is for more of you wonderful people having your stoma reversed to complete the questionnaire, this is best done 3-6 months after closure.

Armed with this information I am hoping to improve our knowledge base and assist more effectively those facing future closure.

Finally, I am wishing you all a very happy and blessed Christmas, stay safe and enjoy your family and friends.

Slán agus beannacht agus Nollaig Shona Duit

(bye and blessings and merry Christmas to you)

Anne Marie

Anne Marie Lyons STN



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

Stoma reversal...

the good, the bad and the somewhat gross



“When one door closes, another door opens.”

Alexander Graham Bell probably wasn't talking about buttocks when he said this, but it's an apt quote for an article about my experience with stoma reversal.

Gastroenterology for dummies

2022 ended with me waking up from emergency surgery with a double-barrelled ileostomy (aka my guts were hanging out) in an overseas hospital. I wrote about the experience previously (June 2023 NSW Stoma Journal).

To bring you up to speed: if your digestive tract gets blocked, it's **very** bad. My situation was “necrosis of the distal ileum with grade IV adhesions”: I had internal scar tissue which created a twist in my small bowel. The solution was laparotomy (open gut surgery) to remove the scar tissue and said

“distal ileum”. Then a stoma (literally “opening”) was created at the excision point to introduce the end of my small bowel to the world, promoting it to “anus”. Some people like to name their stomas. I called mine Alicia Silverstome. Ms Silverstome would deposit my waste into a small bag for manual evacuation instead of the traditional way.

Stomas can be reversed under favourable conditions. The procedure simply entails reconnecting the pipes. I would go on to live with a stoma for six months before reversal. You might be reading this because you're considering, or preparing for, a reversal.

Sunset over at Batu Bolong, Bali

JOURNAL

DECEMBER 2024

by Luke McConaghey

If so, I'll give you a picture of what to expect. It is a wild ride but as you'll see: there is light at the end of the anal passage.

Stoma life

I recovered well from my laparotomy under the aegis of Medicare and my long-suffering parents. Physical rehabilitation had started in the gym pool with the octogenarians. After the first session, someone in the class walked into the changing area already somehow completely stark-naked, as old men seem to do. He exclaimed, "Welcome to aquarobics!" I responded at length: "Thanks, good to be here. You should've seen me a few weeks ago. I was like Neo waking up from The Matrix: 20 kilos lighter with 8 tubes coming out of me and covered in medical gel. It's been really tough. You know, life sucks sometimes and that's OK, some things can just be for cinematic value..." He finally cut me off, stating simply and loudly: "Mate I don't have my hearing aids in, can't hear a word."

The training soundtrack transitioned from '70s pop classics to gangsta rap as I graduated from aquarobics to challenging WOD-style functional classes. With my returned health, My surgeon Dr Stewart "brownlit" my large bowel for active duty again: it was time to consider reversal.



Goblin mode - hiding from the world whilst under construction



Apart from the gym, but Parkrun community featured heavily in my recovery

Cutting Gordian Knots

Public or private surgery? I agonised over this decision for weeks.

Public would be free (with a wait time), versus \$18000 AUD for private (immediately). This would be out of my own pocket: I am still fighting with Safety Wing (criminally negligent travel insurer) about covering my medical costs, and Australian readers should note that anything less than bronze-level private hospital cover is somewhat useless, as I learned the hard way.

\$18000 isn't life-changing, but it is year-changing. It's three snowboarding vacations in Sapporo, a very good bottle of Aussie red for every day of the year, or 180 collector's edition PS5 games (more than exist).

Such maths, whilst arbitrary, dominated my thinking, because other factors proved



ambiguous. The medical system is famously incomprehensible. I knew the cost of not waiting, but was there a cost of waiting? Did the chance of complications increase? I was a category B patient: "semi-urgent, recommended for surgery within 90 days". But how urgent was "semi"? Apparently not that urgent, because my estimated wait time varied from 3-12 months depending on who I talked to. Could I influence the wait period? Each surgeon has their own wait period (it's not a singular pool), so changing surgeons can change the wait time. But it also resets the entire process, necessitating a repeat of all consultations and procedures. But then, which surgeon should I choose? Private cover grants the perk of selecting the surgeon... but what do I know about surgeons? Every medical professional and patient had said of Dr Stewart: "he's really good". I like my surgeon... but what else are they going to say? "He is mediocre — honestly, I wouldn't trust him to cut my sandwich let alone my vital organs"? There is no Google Reviews for surgeons: patients can only trust that someone with "Dr" in front of their name is someone who you can trust.

When I hit at a wall in my research, I meditated, wrote a pros-and-cons list and went for long walks. Still: "what to do?"

I didn't know it at the time, but one day soon, I would jump on a scooter after work and ride to Batu Bolong, Bali, to play beach volleyball. Even at sunset, the heat would be intense, bouncing off the shore's black sands, and I'd jump

into the sea between games with my partner Hana, her athletic tanned body projecting a perfect silhouette against a peach-coloured sky (alongside my more utilitarian rig, panel-beaten with swapped-out parts and surgical seams on display). When it was too dark to continue, the two of us would go and eat nasi campur by candlelight.

This future day would be an exact replay of the day that I first got ill, except it would end in a hug and a kiss instead of a rushed transit to the ER.

I couldn't have predicted that day with Hana, but with a little imagination, I could wonder what might happen... and on the flipside, remember that not a single future day is guaranteed. If there was something to look forward to, I wasn't moving toward it. Sure, \$18000 is year-changing... but so is one more year free of medical concern.

A hard decision became a very simple one. There are details and complications in medicine and life in general, but cutting through the Gordian knot of noise was a notion of possibility, forward-motion, Hana rising sunsoaked from the sea... whatever "life" means.

I shattered my piggy bank, called Gosford Private, and things moved quickly from there.

Bye Alicia

In the operating theatre, the anaesthetist advised I would shortly fall unconscious and not even remember entering — "For example, you won't remember that my favourite band is the Foo Fighters". Obviously I do remember,



Life on the edge - Table Mountain over Cape Town

and proudly told my nurse to pass it onto him when I came to. She patiently reminded me that I'd told her four times. Anaesthesia plus endone is a trip.

I'd woken up with my bowels reunited (and with a ventral hernia repair and revision of my zipperline scar thrown in). Now I just needed to earn my discharge from hospital. The ticket to freedom: a successful number two. It would take me a full week to get there.

I kept a journal in hospital; one particularly poignant entry sums up my time there:

"Brain = mush"

I was nauseous, insomniac and miserable the entire time. Dr Stewart seems unconcerned: "Hypo-peristalsis like this is pretty normal".


A note on the ward's message board read, "Positivity will get you home".

By day 2 I had none left so I opted for distraction instead. My brother brought me a pen-and-paper strategy game designed for a single player, but I found myself so bereft of mental faculties that I couldn't concentrate enough to play it.

When you're losing a one-player game, it is not a good day.

The final night was the toughest. Lots of pain and fear, and no sleep. St. John of the Cross spoke of "the long dark night of the soul". Well, this was "the long dark night of the arse".

But the night is darkest before the dawn: toward the morning, my body hit the master reset button. I arose to use the men's room for the first time in half a year. Although nerve-wracking, the primary emotion was victorious relief. It was clockwork from then on: a new

continued on page 24 

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“event” every 40 minutes, almost to the minute (yes, I timed it). I was a new man by sunrise.

Wild things

Some people are incontinent for the next fortnight weeks at this point. I never had issues here, just sporadic timings, so I stayed close to home just in case. In short: I wouldn't advise any four-hour hikes immediately after stoma reversal.

Close to the dunny is close to our animal nature. Perhaps it was for this reason that during my final recovery, I took inspiration from an unlikely source.

Two plovers came to nest on our neighbour's roof. The plover (or “masked lapwing”) is known for its terrible life decisions, especially nesting in carparks and other moronic locations. Indeed, this couple had nested here last season and their eggs had rolled down the roof resulting in chicks trapped in the gutter, and having learned nothing the avian simpletons had returned. Once again, my dad donned his goggles and bike helmet for a rescue operation, being harassed and screamed at by the portly waterbirds the whole time.

The family would make their journey from our street to the lake edge (where they would have nested if they had a brain larger than a peanut). The journey



The Plover family on their pilgrimage to the lake edge

was not long but the supreme idiocy of these birds made every step of the way life and death. Yet, they made progress. All they had to do was trust their instincts and move slowly but surely in the right direction, day by day.

Recovery feels slow then fast as little steps snowball and one day, you realise that you're

at the lake edge. This is bird-brain zen. The final weeks of “potty training” and rehabilitation were uncomplicated and suddenly, things were better.

Dr Stewart said that he hoped never to see me again: the best thing a

surgeon can say. My bowel calibrated itself and I was comfortable at the gym. I struggled with core strength but honestly, I always had.

I applied Bio-Oil to lighten my scars and as a way to massage the site. Does visceral

massage do anything? I went to an osteopath — the kind with crystals on shelves and gurus on walls — to ask. She said my aura needed work. The consensus in the medical world is “it probably won't hurt”, and it felt good so I persisted with it until I ran out of oil and patience. My scars faded but I seemed to be stuck with a small “rice belly”; it seems this is simply the shape of my body now, post-hernia repair. Any dreams of being a Calvin Klein

***“I never saw a wild thing
sorry for itself.
A small bird will drop
frozen dead from a bough
without ever having felt
sorry for itself.”***

— DH Lawrence, Self Pity

underwear model were now well and truly dashed, but I was healthy enough to be mad about it.

Life's dirty little pleasures

To my delight, my diet reverted to "no requirements" after closure. Alicia Silverstone had demanded a "low residue" diet: nothing challenging to digest. Fried chicken is my comfort food and I'd missed it so one night soon after recovery, I found myself on a Sydney street bathed in the welcoming glow of a KFC. I procured a pile of chicken pieces to eat on the train ride home.

Eating on trains is gross. Eating KFC anywhere is arguably gross. But it was one year from the start of my journey, and I was celebrating. A Balinese doctor had predicted a one-year span from initial catastrophe to absolute recovery, and it seems he'd been eerily accurate.

I was halfway through feverishly devouring my meal when I realised: no refreshing towelettes. Not even any serviettes. If you're a Dirty Bird fan, you'll understand the gravity of the situation. All I could do was shamefully retreat further into the corner of the carriage and complete my meal. And as I sat there covered in grease, gnawing on chicken bones like some kind of goblin-man, I thought to myself:

Now this is living!

Epilogue

Dr Stewart was supportive of my return to digital nomadism, merely reminding me that if I find myself in hospital on foreign soil again, to be ready to be the ultimate Karen, make a scene, shout



*Traveling to foreign peaks again -
Table Mountain over Cape Town*

loudly in any language I know that I'm having an emergency and need to see "the manager". In support of this, I made a short document comprising an emergency checklist and relevant medical history should anyone ask, and it's travelling with me on all my devices and in the cloud. I called it my "Arseport".

I've continued my travels beyond Bali and am writing from Valencia, Spain, whilst eating fried squid, blood sausage and spicy potatoes. It's wild how much cruel and unusual punishment the body can withstand, what one can put it through and live to tell the tale. It has to work flawlessly, non-stop across your lifespan, or you're dead within days... on the other hand, thanks to modern surgical intervention, I had whole centimetres of a vital organ cut out and it's *todo bien*: all well and good. ■

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Education & Information Days for Ostomates



We have enjoyed days at Ballina (14th June) and Orange (20th September) this year and by the time this journal is published we will have also been to Penrith.

We run these with our sister association, Ostomy NSW and they are made possible by the generous support of our suppliers: BBraun, Coloplast, Convatec, Dansac, Future Environmental Services, Hollister, Omnigon and Sutherland Medical. They make a inacial contribution and are a major attraction on the day. Feedback tells us that you are keen to see what is on offer to help you manage your stoma.

Of course, the most important part of the day is our stomal therapy nurses who provide really informative presentations on everything from hernia prevention & treatment, types of stomas, diet, choosing accessories, skin health & complications and make themselves available for all your questions.

A big thank you to the following Stomal Therapy nurses: Anne Marie Lyons, Lee Gavegan, Heather Hill, Ed Cooke, Jane Kulas, Lisa Clare, Mandy Hawkins, Joe Webster, Louise Linke, Renee Chandler, Naomi Houston and all nurses who attended these days. These nurses volunteer their time because they recognize how important



it is for the stoma community to receive this support and value the opportunity to bring ostomates together.

I also need to thank the ostomates who share their stories. All of you have a different story and it is so inspirational to hear those very personal journeys and the way each of you have dealt with adversity. I want to thank Jackie Carusi, Bob Lund & Carol Quast for generously telling us their stories. Carol is also one of the chief organisers of these days and gives so much her time supporting members, whether it's having a cup of

coffee with a new ostomate, a chat on the phone or the more formal support she offers through these days and our monthly zoom meetings for members.

I also want to acknowledge how nice it is to work with Stephen Lardner and his team at Ostomy NSW to put these days together for all our members. Sharing our resources in this way allows us to offer more for our members.

Mostly, I want to thank all of the ostomates and their family and carers who attend these days and make them the success they are.



Just 10 years ago, at the age of 61, I was diagnosed with malignant bladder cancer. It came as a bit of a shock, since I had been diagnosed with a slow-growing form of prostate cancer some years earlier, and was confidently told that, other than the occasional check-up, I shouldn't worry until age 85 or so. I had no immediate symptoms – and this is the core issue with this sneaky cancer.

Bladder cancer is more predominant in males; current statistics show about 3,000 cases recorded each year in Australia, of whom about 2,400 are males. Smoking is a known cause – but I am a non-smoker. I wonder if red wine has something to do with it?

I was lucky as there are rarely symptoms of bladder cancer, and men tend to ignore those anyway. I noticed a very small amount of blood in my urine, and eventually discussed this with my GP. He sent me for a scan, and days later I was having several tumours removed. My then urologist informed me I had malignant cancer, and sent me off to another urologist who was a robotic surgeon.

Not everyone diagnosed with bladder cancer will have a radical cystectomy. I had both advanced prostate cancer (Gleeson 9 I think) and T3A bladder cancer which had fortunately not yet metastasised. I woke up with my new companion, Henry Stoma.



Jacques & Ken
Honolulu 2022



Recovery Cruise 2014

After becoming comfortable with a plastic bag attached, and plugging into a night bag on retiring to bed, I figured it was a lot better than the alternative. Thanks to our great stoma nurses I adjusted well and was able to return to the office 10 days later – although on a very quiet schedule.

An initial disappointment was inability to perform properly in the bedroom, as some of the nerves required had not survived the surgery. That's something I have come to terms with, and home life has not suffered – we console ourselves with "it's an ageing thing" and just get on with life.

My thoughts quickly returned to travel. How would everything change given the amount of equipment I had to take with me. Lots of urostomy bags, remover, wipes and of course the night bag on its stand. So the first trip as part of my recovery was a cruise to Vanuatu and Noumea. When wearing swimming shorts the top of the bag was visible. Embarrassment! No problem





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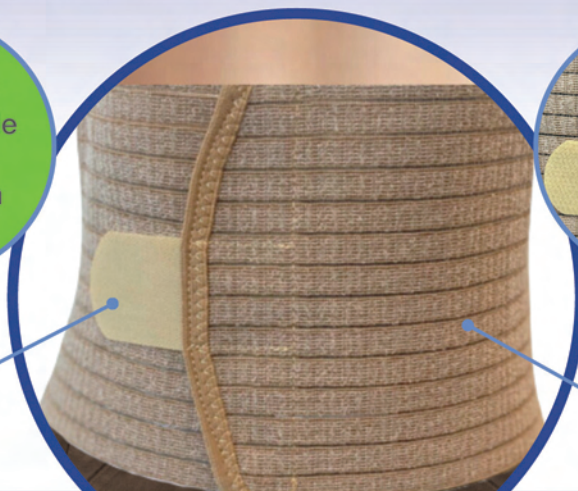
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SBNLXL23	LGE/XLGE	23cm	80-155cm

Living with a Urostomy Stoma...

(Or how I learned to live without a bladder) *Continued*

– I wore a rashie at first. I very quickly abandoned the rashie; I just got over and on with it. Sometimes people ask questions and I'm happy to oblige their curiosity.

We've now travelled extensively with my appliances in tow; Japan (twice), USA, Tahiti, New Zealand and the Cook Islands on international jaunts. Not to forget Tasmania (via Victoria and the car ferry) NSW and Queensland adventures. Look out WA – that's next!

My travel advice is simple. Take about 20% more appliances than you think you need, and take as much as possible in carry-on luggage when flying. And get yourself a sunflower lanyard! Not all airport staff recognise the lanyard (yes, Cairn's airport and Jetstar I'm looking at you). At Kansai Osaka airport it was recognised and the staff were extremely supportive. Winner!



Music Museum Tokyo 2018



Kurashiki, Japan 2024

Henry has suffered three para-stomal hernias; the third one is limping along and currently behaving. I've informed him I'm far too busy to contemplate more surgery. Normally he's well behaved, although sometimes the unexpected bag leak does happen. A few months back Omnigon advised the night bags I used were going out of production. Disaster as that meant changing the urostomy bag as well. Flanges are all different sizes. Eddie at NSW Stoma pointed me in the direction of a few of the local suppliers, who obliged sending me samples to test. Happily I quickly found a solution and now back in business.

My last thoughts are for all ostomates to sit in on a Zoom information session conducted by Mary Egan (our GM) Carol Quast (educator, and one of our directors) and often Anne Marie (our stoma nurse). These are on a monthly basis. Plus if in your area, get along to one of the education days. You never know what you'll learn – even if you're an old hand.

GALLERY



Anushka



Deidre



Andrew



Eddie



Fiona



Mark



Nicholas



Toby



▲ Member Teresita Cruz & Fiona Lau

Teresita Cruz & Son Klaus ▶



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 with special thanks to the Penn Foundation for their continued support of our STN Scholarship. Donations to NSW Stoma Ltd are tax deductible.

The names of those of you who have given us permission are listed below and include donors from 1st April 2024 to 30th September 2024:

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THE NATIONAL PUBLIC TOILET MAP

A Project of the National Continence Program (NCP)

www.toiletmap.gov.au

© Commonwealth of Australia 2001 - 2013

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 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.



Hastings Macleay Ostomy Support Group Celebrations

The Hastings Macleay Ostomy Support Group recently marked a remarkable milestone—their 25th anniversary—with a special celebration at the Port City Bowling Club. This milestone event was made possible in part by the generous support of the club's travelling bowls group, which helped fund the day's festivities.

The support group, established in August 1999, originally held its meetings at Port Macquarie Community Health until the COVID-19 pandemic forced a pause. However, it was the first local group to resume meetings, transitioning to outdoor gatherings after lockdowns were lifted, eventually moving to their current venue at Port City Bowling Club.

The event was filled with nostalgia and appreciation as attendees looked back at the group's history of supporting ostomates and their carers. The group has seen many members come and go over the years, and while some moved away or had their stomas reversed, the sense of community has remained strong.

One special guest at the event was Heather Hill, a renowned Stomal Therapy Nurse from the South Coast of NSW, who made the long trip via train to be part of the day.

Heather, a regular attendee of past meetings, gave a heartfelt speech: "I have been involved with many support groups across Australia and internationally, but this is the best support group there is."

Maria Emerton Bell, CNC for Stomal Therapy in Hastings Macleay, has been with the group since its inception.

In her speech, she acknowledged the contributions of previous presidents,

committee members, local surgeons, and guest speakers who have supported the group over the years, recognising past and present stomal therapy nurses and representatives from stoma companies providing ongoing education and resources.

Maria went on to highlight what makes this group truly unique.

"This group goes beyond the traditional definition of a support group. I've seen emotional and financial support, assistance with transport, social connections, and so much more. Creating awareness displays at the local library, donating to stoma associations and nursing scholarships, or arranging shipments of excess products to countries like Papua New Guinea and Samoa, this group continuously finds ways to give back."

The Hastings Macleay Ostomy Support Group is one of the longest-running support groups within the Mid North Coast Local Health District, and the longest-running ostomy support group in the Mid North Coast and Northern Rivers regions.

Maria concluded with an inspiring message to the group: "Congratulations to you all. You've given and gained support for many people, helping each other through the challenges of ostomy surgery and recovery. Enjoy today's celebration—filled with food, friendship, and a sense of pride for all you've accomplished."

The event was a fitting tribute to a quarter-century of resilience, community, and care. Kind regards,

Casey Luke

*Stomal Therapy Clinical Nurse Specialist 2
Hastings Community Nursing - Mid North Coast
Local Health District*



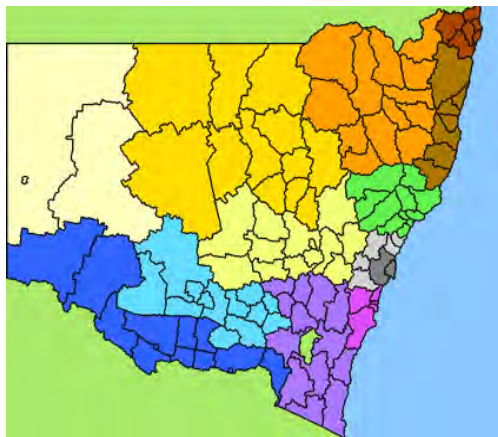
L to R: Janet Kesby, Maria Emerton-Bell, Lynne Henry, Glennie McCartney, Wren Mathews, Neil Lang, Quenton Henry.



Heather Hill,
Jeanie McCarroll



▲ Past and present stomal therapy nurses: Kate Hallett, Casey Luke, Maria Emerton-Bell, Jeanie McCarroll, Nez Cook, Michael Rohr.



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.

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. Hosted by Anne Marie Lyons (STN), Carol Quast, NSW Stoma Director & Ostomate, and NSW Stoma Ltd manager, Mary Egan, this is designed to give information about the services we offer and provide some explanation of the Stoma Appliance Scheme and**

how to place orders. If you would like 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 not currently active.

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 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

BEAT BLADDER CANCER

National support group (online via Zoom) for bladder cancer patients/carers from all across Australia. All welcome.

Last Tuesday of every month @ 7:30pm – 9pm AEST

Contact: Adam Lynch **0421 626 016**

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

[beatbladdercanceraustralia.org.au/](https://www.beatbladdercanceraustralia.org.au/) 

NSW OSTOMY SUPPORT GROUPS

SYDNEY METROPOLITAN AREA

BANKSTOWN – LIDCOMBE AREA

Where: Revesby Workers Club
2B Brett St, Revesby (02) 9772 2100

When: 10am-12 noon, Wednesday 11 Dec 2024

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

Please 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 & CAMPBELLTOWN AREA

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

When: Thursday 1.30pm-3pm 2024

Dates: 5th Dec

Afternoon tea provided. RSVP is essential for catering purposes.

Contact: Erin Wagner - 0419 224 662 or Lu Wang – 0417 026 109 (STNs)

NORTHERN BEACHES AREA

Where: Forestville RSL Club, 22 Melwood Avenue, Forestville

When: Contact for information on next meeting

Contacts: Bob Cooper
email: bob.cooper542500@gmail.com

NORTHERN SYDNEY AREA

This group is not currently active.

Where: Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Road, Wahroonga 2076

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: 2pm-3.30pm TBA

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 Hospitals 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: There are no dates currently scheduled for this location.

Contact: Your Stomal Therapy Nurse or Mariam Mellor on 0400 921 901 or email: aumael@coloplast.com

Everyone is welcome. Car parking available. Tea, coffee and finger food provided. RSVP for catering purposes.

NORTH COAST REGION

TWEED / BYRON AREA

Ostomates, family and friends are welcome.

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

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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 rycroftkate@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 plus partners and friends are welcome to attend meetings.

Where: Aruma, 175 Queen St, Grafton

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

Contact: Gary Tobin Ph: 0400 675 277

COFFS HARBOUR

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

Where: Sawtell RSL Club, First Avenue, Sawtell

When: 4th Thursday of every second month.

Contact: Mandy Hawkins STN: (02) 6656 7804

Mandy.Hawkins@health.nsw.gov.au

HASTINGS MACLEAY

Where: Port City Bowling Club, Function Room, 4 Owen St, 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/CENTRAL COAST REGION

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

HAMILTON

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 on 0425 315 726 or Lynda on 0425 209 030

MAITLAND

Where: Maitland Hospital Education Rooms, 51 Metford Rd, Metford

When: 11am First Wednesday of Feb, May, Aug, Nov

Contact: RSVP Annika 0429 002 760 or Jackie 0412 445 498

WYONG

Where: Wyong Community Health Centre, 38A Pacific Hwy, Wyong NSW 2259

When: 1.30-3.30pm Thursday 12th December 2024 - please RSVP for catering.

Contact: Local Stoma Therapists: ph: (02) 4320 3323 email: CCLHD-Stomatherapy@health.nsw.gov.au

ILLAWARRA / SOUTH COAST REGION

BOWRAL

Where: Mittagong RSL Club, 146 Old Hume Highway, Mittagong

When: 1pm-2.30pm Tuesday 2024

Dates: 3rd December 2024



NSW OSTOMY SUPPORT GROUPS

Contacts: Mathew Sebastian & Erin Wagner, Stomal Therapists, Liverpool Hospital **(02) 8738 4308** or Mariam Mellor (Coloplast) on **0400 921 901**
Everyone is welcome. Plenty of car parking. Tea/coffee and finger food provided. RSVP 1 week prior for catering purposes.

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 2024 Dates: 11th Dec (Xmas lunch – venue TBA)

Contacts: Helen Richards CNC STN Wollongong Private Hospital phone: **(02) 4286 1109** or email:

richardsh@ramsayhealth.com.au

Julia Kittscha CNC STN Wollongong Hospital mob: **0414 421 021**

email: **islhd-stomaltherapy-NIHG-SIHG@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 email: **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 2023 TBA

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Contact: Your Stomal Therapy Nurse
Everyone is welcome, but must be double vaccinated to attend. RSVP required by ACT Health to comply with COVID numbers and restrictions.

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: Stomal Therapy on 0408 769 873

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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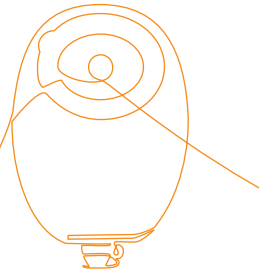
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1. Dansac data on file, LN-06224,07/22.

2. When compared to Nova urostomy pouch.

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