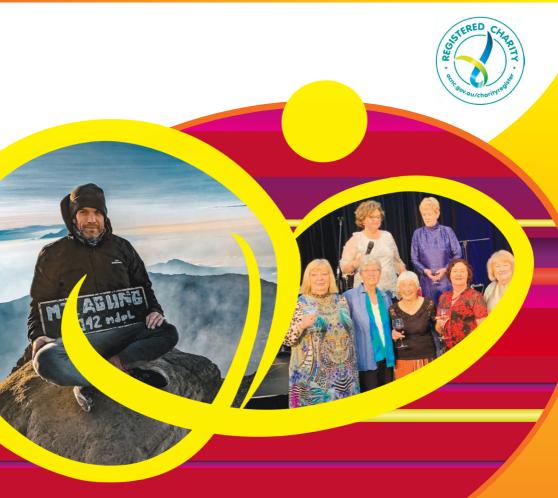


June 2023

Journal

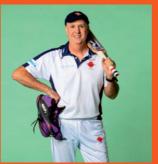
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NOTICE BOARD

Notice of NSW Stoma Ltd AGM

Saturday 18th November 2023, 10am via Zoom

For more information, including election of directors go to:

https://www.nswstoma.org.au/about-us/agm/

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	
Simpla Nightstand Plastic	380431	each	\$14.50	\$16.00	
Ostomy Scissors (curved)	9505	each	\$8.00	\$9.50	
Hollister Leg Bag	9632	each	\$8.50	\$10.00	
Urostomy Drain Tube Adaptor	7331	10	\$30.00	\$33.00	
Odour Be Gone Hos-Togel	3300	each	\$34.00	\$38.00	
Odour Be Gone Hos-Toma No Smells 500ml	10500	each	\$16.00	\$17.50	
Odour Be Gone Hos-Toma No Smells 120ml	10120	each	\$8.00	\$9.00	

A MESSAGE FROM THE CHAIRPERSON

hope everyone had a great Easter break.

We are now in the "living with COVID" stage and NSW stoma is managing well to keep your supplies coming in a timely manner and managing risks to keep the distribution of your supplies reliable.

It is great to be able to support and meet with members again as we have now recommenced our information days with a meeting in Queanbeyan recently. We were able to provide support to members during COVID with our zoom online monthly seminars which have been very popular, and we are pleased to continue.

Our board is working well, and the new members have added to the professional quality of the board. We will be having our annual strategic planning session soon with the board and General manger and do not anticipate major changes in the strategic direction of the organisation.

The main issues we will be undertaking for this year are a change to our main computer system that manages orders and distribution. Please be patient as the changes will be made over a few months during the middle of the year. The new system will be the one that all the other soma associations use in Australia and should be less expensive to run.

The main advantage of the new system that will be the online interface



for members that will allow you to see your past orders and products you previously ordered and reorder again without having to type in all the details again. We anticipate this will be much easier and more accurate for members to place orders.

We are still operating within budget and thanks to the support by donations from members can continue our extra support operations such as our resident stomal therapy nurse, information days and our online seminars.

Our government funding has not increased for many years despite substantial increases in operating costs, so it is a great achievement of our staff who continue to work hard under significant pressure to keep providing an efficient service to members.

In summary, we are under constant financial pressure but are managing the situation well with generous member support and a dedicated staff.

Keep well.

Allen Nash

Chair - NSW Stoma Ltd

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A message from Mary Egan, your General Manager

am so please to report that NSW stoma has been covid-free so far this year! I need to send out a big thank you to all those who helped us during December when most of our warehouse staff came down with Covid. For this to happen during our busiest 3 weeks of the year was auite a challenge. I want to thank everyone who stepped up to that challenge. Our brilliant office staff, board members and volunteers for pickina & packina orders and most of all our members for your patience and understanding with any delays in receiving your orders.

Our volunteer drive has been a great success and our numbers have grown to 15 regular volunteers at our Stanmore premises. These volunteers are working in reception and order collection, picking and dispatching orders in our warehouse and answering phones. Having a great team of trained volunteers makes us a more resilient organisation and if we get hit with Covid again, we will be even better prepared.

Our monthly zoom meetings for members continue to be well attended. Anne Marie Lyons (STN), Carol Quast (Ostomate & board member) and I love bringing them to you. If you haven't had the opportunity to join us yet, I do hope you will give it a try. If you have topics you want us to cover, we are keen to hear from you. If you want to know, chances are someone else will too.

We had the first of our Regional education days in Queanbeyan this vear. Attendees had the opportunity to meet with suppliers and see the latest products. Stoma Nurses, Anne Marie Lyons, Brenda Christensen and Heather Hill were joined by ACT stoma nurse, Olivia Dyriw for an excellent Q&A session. Anne Marie spoke about the different types of stomas and Brenda talked about hernias - causes. prevention & treatment. We all learn't a lot. See advert in this journal for the next day, being organised by Helen Richards (STN) in the Illawarra on 21st June. It should be another really informative day. We are then looking at another day in the Sydney region later in the year.

Thank you to all of you who contribute to this journal. The professionals who provide valuable information and the members who generously share their stories. This issue we feature 2 intrepid ostomates



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

including Luke who had his stoma surgery in Bali!

It's membership renewal time again. All memberships expire on 30th June each year, regardless of when you join. Our costs have risen considerably over the decades since we began. Unfortunately, our funding has not kept pace with those increases. In fact, we have had no increase in the handling fee we receive under the scheme (2.75%) since 2012. With dwindling revenue, it is becoming increasingly difficult to meet the costs of distributing products under the scheme and even more challenging to provide the additional support services many of our members rely on.

Therefore, the Board of NSW Stoma Ltd have reluctantly decided to increase the 2023-24 Membership fee by \$5 from 1st July. (If any member is experiencing financial difficulty and unable to pay this increase please contact our office on info@nswstoma. org.au.) This increase will assist us to continue our operations, providing you with the essential products you need to manage your stoma.

Our new member portal is well into development and we plan to

launch in the second half of this year. Members will be able to log in to their own account, review previous orders, re-order and top up postage balances. I know many of you will enjoy the convenience. For those of you who prefer to post your orders, don't worry. We will always accept your orders through the mail. Please be aware that it sometimes takes weeks for us to receive your order via post so make sure you allow lots of time for that.

I also want to thank all of you who generously donate to our organisation. Without this we wouldn't be able to offer all the additional support services we do. It is very gratifying to be able to help those members who need additional support from us.

Lastly, a big thank you to our board members who work hard to ensure we remain a strong, resilient organisation that everyone of our members can rely on for their vital supplies.

Warm Regards,

Mary Egan

General Manager, NSW Stoma Ltd



JUNE 2023



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250ml Pump Pack (1 per month) Product Code: # 1103

HOS-TOMA NO SMELLS

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45ml Dropper (2 per month) Product Code: # 1001





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Failte Mo Chairde (Hello my friends)

e have had Christmas and Easter since I last wrote! Where does the time go. I feel as I get older that time passes much more quickly!

We had our United ostomy education day In Queanbeyan and it was a great success despite lower than normal numbers. Our attendees were very engaging and judging by the evaluation forms completed they were happy with the content. I do encourage you to attend these days if possible as not only is it educational it is a marvellous way of meeting people who are in the same boat as yourself and sharing experiences.

I have just attended the 50 +2 AASTN (Australian association of Stomal therapy nurses) conference in Perth.

It was a truly wonderful conference, great content and a wonderful opportunity to network with like minded people.

Interesting to note how other associations work, sharing knowledge, noting what researches are in progress, particularly the hernia management and minimising the risk of hernia formation, I will be following these

researches closely and will keep you posted.

600 people attended.

There were 15 countries represented and I've attached a photo of their representatives proudly wearing their national costumes.

A quote from the conference that struck me was from the Chancellor of the university of Notre Dame (where the conference was held) the honourable Chris Ellison who said a nurse told him "save one life and you're a hero save one hundred and you're a nurse"!!

Thank you to the Conference organising committee for all their time and effort to produce an exceptional conference.

Finally my clinic is fully open now, do make an appointment if you are having issues and cannot see your regular Stomal therapist, my hours of work are in this journal and on the website.

Slan agus beannacht Bye and blessings Anne Marie Lyons STN



The line of representatives from 15 countries,



AASTN Conference Perth 2023



■ Some of the life members in attendance: Carol Stott, Lorrie Gray, Heather Hill, Ros Probert, Keryln Carville, at the back Mary Jo Kroeber, with Fiona Bolton out outgoing President.



Heather Hill, Anne Marie

A Fiona Le, Ian Whiteley, Heather Hill, Jess Yanlan Lin and Anne Marie - all Concord trained STNs.



From left: Dee Coulton (Gosford Private), Jenny O'Donnell (John Hunter), Mary Cuzner (Central Coast), Karen Cole (JHH), Emma Cutugno (JHH), Cecilia King (Newcastle Private), Deb Day, Jean McCarroll (Port Macquarie), Renae Bootland (JHH), Annika Leyshon (Maitland).



Jenny O'Donnell and Karen Cole



Anne Marie & Brenda Christiansen.



Leakage

lease note: Leakages can occur for a number of reasons. Following surgery your abdomen and your stoma are swollen, your Stomal Therapy Nurse (STN) will help you choose the correct product to suit your shape at that time.

When you are discharged you will have a follow up appointment to see your STN and this is a very important appointment for remeasuring your stoma, checking your contours, checking how you like your pouch, is it sitting well, does the filter work well for you along with many other reasons.

As your stoma shrinks in size (usually 4-6 weeks before it is the size it will remain) and your abdominal swelling reduces, you may start to have some leaks.

How to try and be on top of leaks early is when you remove your pouch look at the adhesive backing to see has the faeces managed to undermine the pouch, if it has contact your STN and she will advise.

Some STN give ostomates accessories such as stomahesive powder, paste or seals (rings) this is done for a few reasons:

- 1. You may live remotely and a long way from help from a STN
- 2. Your STN may not have an outpatient's clinic
- 3. Your STN may only work part time and may not be available the day you need her, in this case your STN will have explained what the products are for and how to use them



(Very important to note if any of these products have been ordered on your first order and you do not use them, please do not continue to order them)

You may be cutting the opening too large and need to reduce the size of the opening, this may result is reddened skin around your stoma.

A change in output from your stoma can cause issues with leakage. If the change in output continues for a number of days it is important for you to seek medical advice.

Over time you may gain or lose weight, this can lead to leaks as pouch not suiting contours

Again over time you may develop a parastomal hernia which changes your contours and increase the size of your stoma leading to leakage.

Whatever the reason for the leakage the important thing to remember is you do not need to put up with it.

Anne Marie Lyons STN

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Stitched up in Bali by Luke McConaghey



Top of the world - Mount Agung, highest peak in Bali, before the fall...

s the Pandemic subsided, I revenge-travelled to Bali on a one-way ticket. Aptly named, the "island of the gods" offers many spiritual paths: the hedonistic worship of beach party life in Seminyak, the yogic way (or are kinky tantric workshops more your speed?) in Ubud, the digital nomad mecca that is Canggu.

I contemplated these options as a young woman emptied a bottle of jelly into my anus, then changed my diaper. No: I was not at a kinky tantric workshop. I was marooned in Bali's largest and oldest hospital.

She displayed a typical nonchalance throughout the profane act; a trait that makes nurses excellent at their

job... and eminently dateable (or so I imagine). The 2022 World Cup played from an old wall-mounted screen. At half-time, Korea and Uruguay were drawn at nil-all. I'd been nil-by-mouth for a week, and would remain so for another two.

This was *not* how I'd imagined my Bali adventure would conclude.

Problems had begun when I'd vomited all over my surfboard, paddling off the black sands of *Batu Bolong* beach. The moment passed like a sun shower in wet season: apparently a mild case of "Bali belly", or some swallowed seawater. But I was spooked. My tummy bore an old souvenir of medical trauma: a zipper line from groin to navel. As a teenager

I'd been bedridden for days following abdominal surgery, drawing comics in hospital to preserve my sanity.

Should I have visited a doctor? Tellina someone "Got a bad feeling" in pigeon English, with no further symptoms, seemed pointless. But sometimes you need to trust your gut, start a half-baked conversation, be the dumbest person in the room and see what happens. I call it a "license to ill".

Gavin de Becker wrote that fear is a gift: our primal instincts are honed, trustable, and ignored at our peril. I would soon learn this the hard way. Two weeks later, I took a Goiek to the nearest clinic after vomiting all morning. They swiftly sent me onward to Nusa Dua's Siloam Hospital in an ambulance.

The diagnosis following a CT scan: pancreatitis? That didn't make sense.

Pancreatitis is a lifestyle disease for overweight alcoholic octogenarians. I was a fit, (mostly) cleanliving 40-year old. They suggested I meet Doctor Muliawan, a specialist, at Sanglah Hospital, in Bali's provincial capital Denpasar, for further examination. Ambulance 2, Hospital 2.

Despite being referred, I was deposited in triage. The large hall reflected the character of the city around us: chaotic, loud, overcrowded. Patients were Tetrised into wall-towall beds, including one poor old man directly in front



I thought we already defused this back in 1995



Not flight-ready - post-surgery observation in Sanglah





LIMITED

Stitched up in Bali by Luke McConaghey (continued)



Apparently my view of hospitals has not changed much in 27 years

of the single shared toilet (which had no seat, toilet paper or working flush).

After a long wait, I was introduced to a nasogastric tube. In Australia, local anaesthetic is used when inserting NGTs into the nasal passage, down the throat, and into the stomach. The doctor on duty instead rammed it in without so much as a "How's your mother?". NGTs are used to remove excess fluid from the gut. This one had the desired effect... immediately and violently.

"Whoa! It's green!"

He wasn't wrong: I was soaked chestto-waste in my own verdant gastric juices. But doctors are like airline pilots: you really don't want to ever hear them surprised... then you know it's bad.

Six hours later and shirtless, I was moved to an inpatient room.

It's difficult to explain Sanglah without invoking zombie apocalypse tropes. Old curtains partitioned four narrowly separated beds in an otherwise bare concrete cube of a room. My nearest roommate was moaning as if he might

"turn" at any moment (and perhaps he thought the same of me). He was connected to a large contraption that beeped constantly with a volume that ensured any sleep was out of the question. Sanglah remains the only medical facility in which staff asked if I could buy them supplies: after the diaper incident, the nurse suggested I buy more in the store downstairs, because they had run out.

Describing pain is like enumerating every alcoholic beverage you drank at that house party: morbidly intriguing for you, and nobody else. Suffice it to say that I was in a lot of pain. Later, I was on a lot of morphine... and in a lot of pain. Meanwhile, Dr Muliawan and his team had not found much insight into my condition.

The entire enterprise seemed ironically antagonistic toward health. Imagine the last place you'd want to be when ill. You're imagining Sanglah. And my deficit of local language added insult to my unknown injury.

After a short eternity of several days, I was moved to a private room. Quiet. Natural light. Meanwhile, my parents had realised this was serious before I had, and dad had flown in. With allies and space to think, I could plan my evacuation to Australia and its free, world-class healthcare.

The primary challenge was getting onto an aeroplane. Airlines require passengers to be "flight-ready" to board. You can be unwell, but you must be able to get to your seat – and eventually, out of it – somewhat independently and in one piece. That was becoming a challenging requirement for me.

I continued my ongoing battle with



The living dead - inpatient ward in Sanglah

the medical system, and now also my insurance company. Travel insurance a necessary evil: without it, you're trapezing across the globe without a safety net. With it, you have a net... with huge holes. As they say in Indonesia: "Trust in Allah... and tie your camel" (Side note: Safety Wing is either deeply incompetent, a scam, or possibly both. Consider this my one-star review).

Finally, Dr Muliawan advised surgery. It still wasn't clear to me what was occurring. Even the name of the procedure, "exploratory laparotomy", sounded like "open him up and have a stickybeak" to me. It was a terrible idea... and it was the best idea I'd heard all week.

Within hours, I was prepped for surgery and drifting into unconsciousness. My prison break had failed before it had really begun. I woke up alone in a bright room. Too cold to be Hell. Heaven? Too ugly. A painfully loud medical device confirmed that I was still among the living, More specifically, I was sharing a long observation ward with seven other patients.

As my vision sharpened, I looked down to assess.

My guts were exposed.

Between drugs, fatigue and the relief of survival, I failed to register horror, instead shaking my head in mild bemusement and commenting to nobody:

"That is not flight-ready."

It sat to the right of a freshly stapled line ascending crookedly from the groin and detouring around the belly button. A shiny flesh blob,

bright red as if furious about being transplanted out of its warm home to this cold, noisy room.

I could relate.

continued on page 24 🖾



I'm told this is a fairly medically accurate diagram









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Stitched up in Bali by Luke McConaghey (continued)



The World Cup saved me from diabolical daytime TV the second time around

This was the worst possible way to learn what a stoma was.

The operation had been similar to my teenage misadventure, and complicated by misdiagnosis and miscommunication. Dr Muliawan had opened my abdominal cavity to find it full of necrotic faeces (an excellent metal band name, btw). Both bowels were perforated and he had removed part of the small bowel.

The cause: adhesions. Australian surgeon Dr Peter Stewart explains:

"Whenever the abdominal cavity is subjected to trauma, scar tissue forms internally: a natural immune response. Imagine a spider's web. Adhesions were forming since your appendectomy as a child. Right now, new adhesions are forming, replacing the ones removed during surgery. Every now and then, they form in just a way as to twist or kink a part of the small bowel. And you've been catastrophically unlucky twice in a row."

I would meet Dr Stewart in weeks to come. Until then, I would remain largely uneducated about my prognosis and my new friend.

When you're really stitched up, the worst thing someone could say is "Look on the bright side", "Whatever doesn't

kill you makes you stronger" or "Have you looked into ThetaHealing?" (that last one might be more of a Bali thing). Positive platitudes stop working as motivational fuel at some point: when you're shitting out of a second belly button, you need something stronger. Instead of positive mental gymnastics, you need a mental breakdown (if only for a day, or a week, or two). You need sto(m)ic philosophy. There is an honest beauty in embracing the dark moments. Mark Manson called it the "reverse rule": accepting the negative is itself a positive experience. Misadventure is permissible: some scenes in life can just be for cinematic value.

And being unwell isn't easy... but it is simple. Everything not immediately pertinent had been cut away: an Occam's scalpel. I set tiny goals — drink; sit up; meditate — and moved forward minute by minute. I reminded myself that beyond that simplicity was a world so deeply layered that I couldn't see far ahead... and that I didn't have to. I'd been surprised to end up here, but I could be surprised again. Recovery could be slow, then fast. Life is logarithmic and it's a reason to be optimistic.

Days later, a hot breeze hit me as I was wheeled out of the observation room.



This was even worse in Bali, with its amazing sambal-soaked cuisine

An open-air maze of covered walkways through small courtyards comprises much of Sanglah. Loitering visitors ogled a very lost bule, and I squinted back as my eyes adjusted to the natural light. I was promptly back in my World Cup room.

Recovery was slow, then fast. I was discharged twenty kilograms lighter and held together by staples and glue. I had a few short days to get flight-ready.

The last leg of the journey was not short of drama. Dad and I headed to DPS airport amidst flight-cancelling earthquakes.

I'd arranged to receive airport assistance, and was granted a wheelchair on arrival. Although I could now walk, the wheelchair sent a useful message: "We will ignore all social etiquette". As we jumped queues and skipped checkpoints, my initial embarrassment subsided and I settled into my privileged role. Kneel before me, able-bodied peasants!

I wondered if my first business class experience would be wasted on me in my current condition. But it seemed essential. Was I truly flight-ready? I was lie-prostrate-for-six-hours-ready. I suspect the battlezone that is cattle class on a red-eye flight might have been the death of me. And the extra personal space was very welcome when, several hours out from Sydney airport, my stoma appliance — my only one — started leaking.

One of many reasons to be grateful for Australian healthcare: extensive ostomy support. True osto-mateship! Less so in Indonesia: I'd left hospital with one spare appliance, long since used. I went to the bathroom partly to patch



Recovering at home with friends

myself up, MacGyver-style, but mostly to hide. I eventually failed on both counts and opened the door, to be greeted by a throng of impatient passengers, legs crossed in bladder distress.

On landing, I rolled swiftly to the airport clinic. No ostomy gear there. After a final long drive home, I met a stoma nurse who cleaned me up and, horrified by my lack of education, gave me a veritable library of reading material, covering every conceivable facet of the ostomate experience. It even covered sexual activity and made very explicit that one should never have sexual intercourse with the stoma! That's one brochure you won't see in conservative Indonesia.

Life remains difficult to predict.
When will the stoma be reversed?
When will adhesions strike again (if ever)?
Dr Stewart is preparing me a one-page
"game plan" to present to ER in case
of emergency — a real license to ill.
Perhaps I should get it translated into
all major world languages... but I'm
grounded for now, with time to think.
How can I come out of this better
than before? I don't have the answer.
But the question might drive me to
interesting places.



Travel with a stoma by Shona Gawel

ir travel as an ostomate shouldn't normally be anything too out of the ordinary. Make sure you have your supplies as part of your carry-on, wear comfortable clothing it's long-haul and staying as hydrated as possible are tips that most people, ostomate or otherwise would be comfortable with.

However, as I and several other NSW Stoma members have experienced recently, the new 3D body scanners installed during 2022 at several Australian domestic airports are creating a little bit more of a headache for us!

The 3D computed tomography machines (technical term – in my head, the big metal tube things!) use nonionizing wave images to scan, looking for items under clothing. You are asked to stand in them and raise your hands while it scans you through, rather than the older ones where you walk through.

While this is great from a safety perspective, it does mean that for ostomates used to being able to travel through security scanning discretely, it can now be rather a different experience.

On my first encounter, suited and booted as I was travelling for work, after the scan I was asked to lift my blouse up in the middle of the airport by the security personnel. That's right, in front of work colleagues and gawking members of the public. The other option was to be taken to a private room for a search.

I chose the private search... while the two female staff members were courteous and professional, I was shocked and humiliated.

Being in a tiny, cramped room and asked to lift my top in front of complete strangers while they patted down my appliance was confronting.

I was also travelling with staff I manage who aren't aware I am an ostomate and wanted to know what came up on the screen and why I was taken away.

I've heard stories from other ostomates who have experienced the new

scanners and also found the experience difficult and I empathise whole-heartedly. Living with a stoma is nothing to be ashamed of but it's also absolutely our right to decide how, when and if we want to share the information with others.

As someone who travels weekly for work and has now experienced these scanners in airports across Australia (what an odd travel blog I could write!) while I don't have anything revolutionary to share with you, here's some ways I've been managing:

Be aware; knowing the scanners will pick up my appliance it's not a rude shock.

Communicate with the security staff. As I enter the scanner now, I let them know quietly I have an appliance and it will show up on the screen.

Know your rights... request a private room and a female or male attendant.

Give yourself additional time. If the scanner does pick up your appliance, it can take longer, particularly if the airport is busy.

Acceptance! The staff are just doing their jobs to keep us safe. I've had some absolutely lovely people including one who was an ostomate themselves and apologised that I had to go through the process. I was advised I could request to use the older scanner but to be honest, I haven't tried that and a bit loathe to.

Pride. Keep your head up and remember that being an ostomate makes you a tough, resilient person and if they picked that up on the scanners, we'd be setting them off loudly!

At NSW Stoma, we are going to be communicating our concerns about the new scanners and ostomate treatment, so if you have an experience you'd like to share please do get in touch.

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

Guidelines for returning to normal activities after abdominal surgery

Article by **Sarah Lawrence**,
Exercise Physiologist

Follow for at least 6-8 weeks after surgery

General guidelines

- To protect wound healing, avoid lifting, pushing or pulling objects more than 2-3kg.
- Over time, you may be able to slowly increase how much weight you can lift.
 For now, go slow.
- Learn new ways to stand and sit, while avoiding holding your breath or straining your abdomen.
- Take care of your personal hygiene including daily washing to reduce the risks of wound infection

- Begin a light walking exercise programme
- Allow yourself time to rest in the day and slowly resume normal activities and hobbies
- Avoid kicking or pushing heavy objects with your legs or feet
- Consider using an abdominal support garment. Speak to your stoma nurse for correct garment selection

and use

A support garment can help keep your stomach muscles relaxed and provide support while you heal. This is important in the early stages of recovery.





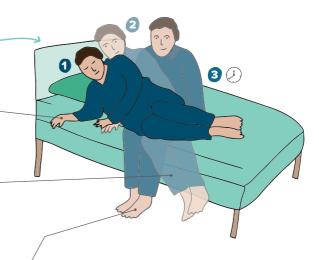
12

Getting in and out of bed

GET OUT OF BED

Use a "log roll" method to get out of bed.

- 1. While lying on your bed, draw your knees up and gently roll onto your side.
- 2. Swing your legs off the edge of the bed whilst at the same time using your arms to push yourself up into a sitting position. Try to keep your stomach muscles as relaxed as possible use the momentum of your legs to help you to come up to a seated position.
- **3.** Sit on the edge of the bed for a moment to regain your balance before standing or walking.



GET INTO BED

Reverse the process for getting out of bed. Sit on the side of the bed near the top third of the bed. Lower yourself onto your elbow and swing your legs up at the same time, ensuring your stomach muscles stay relaxed.

From here you can comfortably roll onto your back, keeping your hips and knees aligned.

Standing up from a bed, chair, or toilet

- Bring your feet in close to you, with your feet hip-width apart.
- 2. Lean forwards from the hips keeping your back straight
- **3.** Keep your stomach relaxed the whole time by remembering to breathe. Push through your legs to stand up.

To sit down, perform this process in reverse, bending at the hips as if taking a bow and slowly lowering yourself onto the chair.

Avoid sitting on low or soft surfaces. An over-the-toilet frame may be helpful in the short term.



Dressing and showering

- Avoid wearing overly tight pants or clothes that may constrict uncomfortably around your abdominal area
- Avoid narrow waistbands that cut directly over the top of your stoma or wound
- Have someone assist you with your first few showers until you feel comfortable with your safety. Use a shower chair if necessary.

- Use a shoe horn if necessary to avoid straining when putting on shoes
- Sit down to put on trousers and socks
- When stepping into a raised bath or shower, reduce abdominal strain by bringing your heel to your bottom rather than lifting your knee towards your chest.

Exercise and other activities

- Don't be afraid of exercise.
 Although you need to be cautious in the beginning, abdominal strength and whole body fitness can be regained through a graduated exercise program.
 Early exercise will support your whole body health, assist recovery and may prevent other complications.
- Ask your doctor about a referral to a Physiotherapist who has experience with Pelvic Health and Continence.
- Begin exercising initially with 5-10 minute walks outside or walks inside or around your house (depending on your fitness and energy levels). Build up by a few

- minutes each week once you feel comfortable at this level.
- Be aware that you may grow tired more quickly than you used to. It is better to walk short distances two or three times a day rather than attempting a long walk and getting stranded half way.
- Maintain good hydration, especially if you are out in the sun, and be aware of signs of electrolyte imbalances.
- Avoid high impact activities for 6-9 months including activities such as jumping, jogging or four wheel driving until you have recovered sufficient abdominal healing and strength.



THE THE



Exercise and other activities...

- Be aware of physically strenuous tasks you may have taken for granted before surgery. This includes activities such as vacuuming, cleaning, mowing or simple things like opening jar lids. These are not advised for at least 12 weeks. Don't be afraid to ask for help. If possible, arrange to have some help at home in your first 6-8 weeks after surgery.
- Talk to your doctor or stoma nurse about safely returning to driving. You may need to be off certain pain medications and have suitable strength to qualify for driving. When cleared for driving, test your abilities with a short drive around the block, potentially with a supportive

- passenger. Ensure you can move your legs quickly and easily in case emergency braking is required.
- You can slowly resume sexual activity dependent on your abdominal healing, energy and comfort levels. Talk to your doctor or stoma nurse if you require further information.
- Avoid lifting children or grandchildren.
 Hugging a child whilst sitting is a safer option.

Remember...

- Be patient with yourself and respect your body's healing processes.
- ✓ Be careful of any strenuous tasks within the first 12 week period and then gradually resume further activities and exercises.
- Be kind to yourself. Seek support where needed.
- Be aware that it is normal to feel emotionally unsettled (frustrated/ stressed/anxious/depressed) as well as mentally and physically tired after major surgery. Remember that help is available from your care team.

INTRODUCING

The **NEW** Omnigon Support Garment

KomfortLite Support Belt



SUPPORT LEVEL

Rating 3 – MODERATE SUPPORT

SUITABLE FOR

- After surgery
- Wear during light exercise
- To help prevent or to support a small bulge

With handy pockets to help you grip the belt, hold it against your body, and pull the belt together.

The comfort level for the KomfortLite support belt was beautiful, the fabric is very soft and felt smooth and delicate on the skin.

JESS @ownyourbag

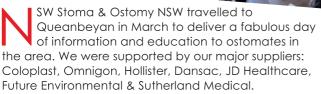
Available to order now through your association





Queanbeyan Information Day





Stomal therapists, Anne Marie Lyons and Brenda Christensen discussed types of stomas and everything you need to know about hernias. Olivia Dyriw & Heather Hill joined them for a really interesting Q&A session. Carol Quast and Renee Constantin spoke about their own experiences as ostomates.

A big thank you to everyone who attended.
Feedback from the day was very positive with most people saying it was a really helpful and informative day. I hope you enjoy some of the pictures from the day.











JUNE 2023

My Ostomate journey – John Burgess





▲ Hervey Bay Whales QLD

◀ The Great Ocean Road

▲ Near the Great Ocean Road

i, My name is John and I have a permanent colostomy bag due to bowel cancer in 2011. I have been living and travelling around Australia in my caravan since 2012. I sold my home to buy the car and van.

I've seen some amazing scenery and wildlife and have no intentions of stopping any time soon .

I've spent time in all states and Territories with the exception of the N.T. and W.A. If not for covid in 2020 I would have already been there. I'll be heading off to the N.T and W.A for 2024. I'd love to go and see Uluru, and one day, maybe next year, cross the Nullabor.

After finishing work due to a lower back injury suffered at work... then getting bowel cancer, I decided to sell up everything and go travelling.

I went to Africa in 2016, 2017 and 2019. It was always somewhere I wanted to go and I finally got there.

I enjoy seeing painted silos, water towers and street art. I've seen a lot in Vic and some in QLD, SA and NSW. I've been whale watching in Hervey Bay QLD, and love all the wildlife I see along the journey

I've been up and down the coast of QLD to S.A. and inland. I've been to Lightning Ridge and Bourke. I enjoy all different places.

I took up photography and take photos of anything interesting I see. A few of my favourites are military stuff, trucks, birds of prey, whales and dolphins

The colostomy bag does not prevent me from doing things. It is part of me but not a hinderance. I also go kayaking and swimming. It hasn't prevented me from doing anything to date.

Enjoy life and get out and see it! John



Gunnedah Silos



The entrance to the Sernegti



John and a friend



DONATIONS

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.

The last few years have been hard for many of our members, with the pandemic, fires, floods and a myriad of other challenges. 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 October 2022 to 31st March 2023:

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 October 2022 to 31st March 2023:

Vicky Anderson Margaret Caskey Shirley Davis Alan Armstrong Cesare Cescon Lancelot D'Costa Nordano Baraghini Robyn Chidgey Bronwyn De Aldi Allen Beumer Marika Chrisostomou Andrew Divola Chris Clark Roberta Drake Colleen Bidgood Kenneth Bolton Patricia Clark Mavis Edwards Geoffrey Booth Lawrence Leslie Coble Michael Eyre Robert Booth Michael Codling Tring Farren-Price Peter Faull Peter Braathen Christopher Collison Tracy Brett Beryl Colston Lesley Frendo Kathleen Broadfoot Trevor Cook Charlotte Gallagher Katherine Gauci Irmaard Cairns Joan Cronk Robin Gibb Robert Campbell Peter Daffy

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Tracy Yeung

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 Master Locksmiths' Association Key. 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.







LIMITED



You and your support network are invited to attend:

2023 ILLAWARRA OSTOMY INFORMATION AND TRADE DAY

Date: Wednesday 21th June 2023

Time: 9:15am – 2.00 pm (registration, tea & coffee 9:15 - 9:45, Junch 12 -1)

Cost: \$15 per person – cost includes light morning tea and lunch

Venue:

Figtree Anglican Church Auditorium 4-10 Gibsons Road, Figtree (Parking and entry via back car park, wheelchair friendly venue)

The day will include:

Stomal Therapy Nurse presentations

Guest presenters including:

Physio, Dietitian, Stoma Buddies

fashion, Ostomy associations, Ostomy companies, Trade displays Raffle: bring your spare change...

Key Note Speaker: Petrea King Quest

for Life Foundation

RSVP prior to 9th June 2023 to the following address, including details as per below

By Email:

richardsh@ramsayhealth.com.au

By Post:

Helen Richards CNC STN

6 South – Wollongong Private Hospital 360-364 Crown Street, Wollongong NSW 2500



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.

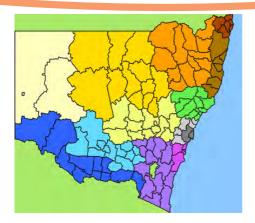
The meeting is hosted by Anne Marie Lyons, our Stomal Therapy Nurse, Carol Quast, NSW Stoma Director & Ostomate, and NSW Stoma Manager, Mary Egan. To attend please email: **customer.service@nswstoma.org.au** and we will send you a zoom invitation on the day of the meeting. You need to register your interest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

NSW OSTOMY SUPPORT GROUPS





stomy 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.

Contact: 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





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: 10 am-12noon, Wednesday 15 March, 14 June, 13 Sept, 13 Dec 2023

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: 16/2/23, 20/4/23, 15/6/23,

19/10/23, 7/12/23

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

Afternoon tea provided - RSVP essential for catering purposes.

JOURNAL

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 buildina)

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: 2023 TBA

Contact: Your Stomal Therapy Nurse Everyone is welcome. 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.

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 and friends are welcome to attend meetings

Where: Aruma, 175 Queen St, Grafton **When:** Bi-monthly – 2nd Tuesday of month **Contact:** Gary Tobin Ph: **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 Avenue, Sawtell

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

Contact: Mandy Hawkins STN:

(02) 6656 7804 or

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

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 7/3/23, 6/6/23, 5/9/23, 28/11/23

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 2023 TBA
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 & 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:** 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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