

December 2022

Journal

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8.30am - 3.30pm

Friday 8.30am - 1.30pm

For current information go to:

nswstoma.org.au

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NOTICE BOARD

CHRISTMAS CLOSING

We will close at 12pm Friday 23rd December, 2022 and re-open 8.30am Wednesday 4th January, 2023

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

Code	pack size	Member Price	Non-Member Price				
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7331			\$10.00				
	10	\$30.00 	\$33.00				
3300	each	\$34.00	\$38.00				
10500	each	\$16.00	\$17.50				
10120	each	\$8.00	\$9.00				
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A MESSAGE FROM THE CHAIRPERSON

t is good to see that we are getting back to normal operations even with COVID still lingering.

Having an opportunity to meet face to face with members at our recent information day in the Newcastle region was a pleasure after a long break in offering this support to members.

I would like to thank our General Manager Mary Egan and our staff have done a great job of continuing to provide quality service despite the difficulties of managing through COVID. It has not always been easy, but they have managed the difficulties well.

The board has continued to ensure that NSW Stoma maintains a high standard of governance and stays in a sound financial position. We are still performing well financially despite no increases in the level of funding from the Federal Government. Member donations have helped to allow us to continue providing extra support to members such as information days, our Journal, stomal therapy nurse support etc. Thank you, members, for your ongoing support.

The board will have two members retiring at this AGM Ken Batten and Kingsley Liu. A great thank you to Ken who has made a great contribution to ensuring the good governance as a board member and Treasurer.

Kingsley has been a valuable board member as a lawyer providing legal support. He has generously offered to continue to volunteer to provide valuable and much appreciated pro bono legal support to the board after leaving.

We will also have three new board



members joining us this year: Ian Niccol, Graham Lawson, and John Hickey. Ian Niccol was appointed as Treasurer and brings valuable experience as a qualified accountant with his own accounting firm.

Graham Lawson brings valuable experience having held several senior positions in health administration and John Hickey has held senior positions in education.

Members can feel confident that we have a strong board who are committed to members service and support as well as ensuring good governance going forward.

As we continue to grow our membership, we will at some point soon need to consider our premises as we are getting close to capacity. This will be one of the issues the board will be considering over the next year.

The other major change over the next year will be the need to covert our primary computer system to the SAMS system that is utilised by most of the other Stoma Associations which will come with a very good member interface to make ordering supplies easier for members.

Overall, I am pleased to summarise our position as having a growing membership, sound finances, with sound governance policies and procedures in place.

Allen Nash

Chair - NSW Stoma Ltd



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A message from Mary Egan, your General Manager

s we come to the end of another challenging year, I am happy to report that we have resumed all pre-covid services – and added a few more as well. On the bright-side, Covid has taught us new ways of doing things and we are better equipped to assist members remotely.

Zoom has allowed us to offer member meetings to anyone with a computer – no matter where you live. While these meetings started as a way to tell new members about their association and how we can assist them, they have grown with a much broader agenda and range of topics. With something to offer everyone, our audience continues to grow. If you haven't joined our monthly meetings yet, I urge you to give it a try.

Our clinic is open at our Stanmore premises on the 1st 3 Thursdays of each month and can also be accessed by phone and email. Wherever you are, you can access a stomal therapy nurse. This is an essential service to those members living remotely and to any member who doesn't have a regular STN they can call on. We do urge members to see their nurse, at least annually, even if you aren't

experiencing problems, to review your product usage.

What a joy it has been to bring back our face-to-face Education & Information Days. Along with our sister association, Ostomy NSW, we ran 2 days this year. The first in the Newcastle region and the second in Sydney. You can read more about this on page 24. We aim to run 3 days per year, 2 in regional areas and 1 in Sydney. I hope to meet you at one of these days soon.

The Penn Foundation are continuing their support for our STN Scholarship and we will announce this years winners in December, 2022. The aim is to encourage nurses to undertake the stomal therapy qualification and increase the number of stomal therapy nurses available to our members, particularly in remote areas, but also in Sydney. With a shortage of nurses everywhere, it's essential we provide this support.

Volunteers play many important roles at NSW Stoma: on our governing board, our reception, our warehouse and behind the scenes. If you have time and think you can help, go to: https://www.nswstoma.org.au/volunteers/. We would love to see you.

In the coming year we plan to bring you a new and improved online ordering system, with member login and access to your account balance and past orders to make ordering simple, fast and easy. There is a lot of work happening behind the scenes to make





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this happen, and I know many of you will appreciate the benefits this system brings. For those of you who want to post your orders, we will always offer alternative methods so that all our members are catered for.

We have had a couple of board changes in the last year. A special thank you to Ken Batten for his work on our board, taking on every role asked of him and giving 110% to everything he did. He will be a hard man to replace. Kingsley Liu and his legal expertise will also be greatly missed.

A warm welcome to John Hickey and Graham Lawson. You can read more about them on page 21. Our board are all ostomates, members and volunteer their time. We are fortunate to have such high calibre directors to ensure we remain an efficient, reliable and sustainable organisation, offering our members the best service we can. Thank you to all.

Warm Regards,

Mary Egan

General Manager, NSW Stoma Ltd



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**





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Failte Mo Chairde (Hello my friends)

he clinic has taken off like a train since the restrictions have lifted, I am well pleased.

It was wonderful seeing some new faces and old ones alike.

Thank you to my friend and colleague Donna for filling in for me when I went home for a visit, she said she really enjoyed helping all who visited and called.

We had a truly wonderful time at home in Ireland, England and Germany after a very bumpy start for myself catching COVID 2 days before I flew! Such is life I had a good rest and only lost a week of my 7 weeks.

We caught up with family and friends, made my brother's wedding, did Croagh Patrick for our sins! Packed lots in but had quality time with all. (see photos below) the scenery photo is from my home town in the bog of Allen (Derryounce), final photo Glendalough County Wicklow a must visit place.

I was sad to pay only a flying visit to the Education day at Canterbury

leagues club, but it was worth the visit as I had a lot of questions from my talk from many of you and was only too delighted to answer them. It was a wonderful turn out and great feedback on what topics you wish covered in future.

Your feedback is essential for these education days and for our zoom meetings so keep them coming.

Gosh, I need to wish you all a blessed Christmas and I hope the new year brings plenty of good luck, (Irish of course!) happiness and good health to enjoy it all.

Slan agus beannacht (bye & blessings) Nollaig shona dhuit! (Merry Christmas to you)

Anne Marie Lyons STN









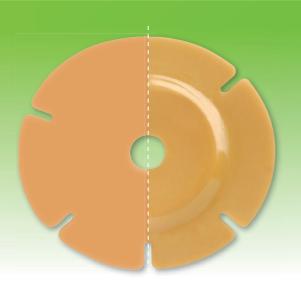




JOURNAL

DECEMBER 2022

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Electrolyte imbalance/dehydration

This is more relevant to people with an ileostomy and urostomy

- Common signs and symptoms:
- Dry mouth
- Tingling/cramping in hands or feet
- Dizziness
- Tiredness
- Weakness
- Nausea and/or vomiting

What you need to do to minimize the risk

- Drink 2 litres of fluid per day, water, tea, coffee, cordial, oral rehydration fluids (gastrolyte, hydrolyte etc.) a mixture, remember when the weather is hot and humid you will need to increase your oral intake as you lose a lot of fluid sweating.
- You can have a beer or a wine, everything in moderation.
- (Be aware, tea, coffee, alcohol are diuretics (increase water output) so moderation is very important.
- Keep a cold jug of oral rehydration solution in the fridge, it's more palatable when cold. Sometimes water is not enough as it does not contain minerals which are lost during sweating, such as salt.
- Gatorade and powerade are high in sugar, stick to the below simple recipe or oral rehydration solutions.

 Below is a cheap recipe to make, to replace fluids and minerals lost during hot days and hard exercise. (1)

Try the APPLE JUICE RECIPE:

240 mls. Apple juice 480 mls. Water Half a teaspoon salt

Bleeding around your stoma:

It is always a worry when you see blood anywhere, especially from your stoma.

Stomas themselves are very vascular and can bleed quite easily, but the bleeding does not last long, it can be as little as spotting or soak a gauze.

When you change your bag and notice some bleeding, examine your stoma and ascertain where it is coming from, it will come from a few different areas, from the stoma itself, from the skin around the stoma or from the inside of the stoma internally as such (2).

If the bleeding is from the stoma itself this is very common, put some pressure on it and it should stop almost immediately, if it persists apply some iced water to the stoma, (do not apply ice directly onto the stoma as this can cause ice burns), if it persists for more than 10 minutes ring your stoma nurse, GP or present to emergency.

If you have bleeding around your stoma on your peristomal skin this can be caused by a poorly fitted stoma pouch, faeces undermining the pouch and sitting on the peristomal skin and causing erosion, contact your Stomal therapist for assessment.

Bleeding around or on your stoma can also be from friction if the appliance opening is too small for the stoma, again see your stoma therapist for assessment.

If the bleeding is coming from your stoma and into your pouch, this can be an internal bleed and needs assessment by your GP or present to Emergency

1. Prepared by the Australian Association of Stomal Therapy Nurses Inc. Education and Professional Development Committee,

www.stomaltherapy.com

 https://www.oakmed.co.uk/helpadvice/advice-articles/stoma-bleedingwhats-cause-for-concern-and-what-isnt/

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My Journey – by Rosemary Wattle



ello to all readers. I sincerely hope you are all well. What follows is my story which led

me to having what was supposed to be at the time, a temporary colostomy. Thanks to Matthew who inspired me with his story (June 2022 edition).

In 2012 I found out that I was born with a very rare muscle disease named Central Core Disease (CCD) and was told that in my family of four girls, two of us would have it.

There are two types of the disease, that being progressive and the other is stable. Unfortunately, I have the progressive type and my next sister down in the age line has the stable type. My twin sister and youngest sister have both escaped the disease.

I mention this because the muscle disease affects every muscle in my body except the heart, and so with me, all of the smooth muscle in my abdomen has been affected and right from birth I have had bowel problems. I am now 69 years of age and until 2019 I literally was living a life of hell with my body.

I was misdiagnosed several times over the years with various neurological diseases, with each doctor saying the disease they misdiagnosed me with was responsible for my bowel problem; diseases such as MS and Myasthenia Gravis. No medication helped with the weakening of the muscles and in 2012 I found a Professor of Neurology in Queensland who stopped at nothing to find out why I had the problems I had.

She had me undergo a muscle biopsy whereby a huge chunk of muscle was removed from the right thigh and tested

for every muscle disease you could think of. It was the last test they did on what little bit of muscle they had left that confirmed I had CCD and that my muscles were wasting.

Since 2012 I have had three operations on my bowel and also wear a permanent SPC, i.e. Supra Pubic Catheter.

As a baby, my mother told me I gave her one dirty nappy a week but my twin sister gave her four or five a day.

When I was two years old my parents and me and my twin sister visited my grandmother so my parents could watch The Outer Limits on television while my sister and I played with my grandfather's train set which took up a whole room.

Some people say that one cannot remember much before the age of three but I have a high IQ, have studied Medicine and Pharmacy and was once told my IQ was there from the day I was born along with my twin sister. I do remember from before the age of two years and certainly remember that night because for a two-year-old what took place was traumatic.

Everything was going fine until suddenly I developed stomach pains. My grandfather didn't hesitate to call his doctor immediately. What happened next was I had an enema but back then it was done with a very long rubber hose and soapy water. Yes, it worked, it worked extremely well, but oh so painful. That was just the beginning, and years later my dad told me that at that time I had not used my bowels for six weeks.

Over the years I visited the hospital many, many times but it wasn't until 2019 I met a surgeon who told me that my bowel was extremely oversized in diameter and was no longer working effectively being about 5 times the diameter it should

have been. So, in November 2019 after being admitted through Emergency at Wollongong Public, my surgeon's Registrar came to me and she mentioned that her "boss" was recommending a Loop Stoma.

I was operated on that morning and because I have CCD I cannot have the usual paralysing agent with the anaesthetic, so they had to clean the theatre of all gasses, so I went into a clean theatre.

It does have its advantages. Having CCD, I am at risk of Malignant Hyperthermia with some paralysing agents so whenever I go to hospital now, I am always first on any surgeon's operating list.

So, in mid-November 2019 I had my first operation beginning at 8.00am in the morning and I woke in ICU around 1.00pm, no pain, no anything. My sisters came to visit, and I was feeling good. We were laughing and joking around when my surgeon popped in to check on me. She was surprised to see me so alert, laughing and enjoying myself and best of all pain free.

However, that did not last long. I was in a glass room in ICU and enjoyed a light dinner. At 10.00pm that night I am sitting up in bed, arms folded, looking up watching TV when suddenly, a few doctors and nurses came rushing into my room followed by a cleaner with bucket and mop.

I found out later that a young nurse had walked past the glass room I was in and saw a fountain of blood coming from my left side, so she pushed the emergency button on the wall outside of my room.

My bed was laid flat, and the CPR cord pulled on the air mattress so I was completely flat. My surgeon's Registrar came around to the left side of my bed and put her fist in my side. I asked her what was going on and she said "If you

are game, look over the side" which I did and the doctor's estimated at least

half my body's blood volume was on the floor, possibly more.

Transfusions were started and they worked on me for six hours until 4.00am the following morning.

Eventually they stopped as the last bloods taken showed my haemoglobin was still only 55 and no matter how much blood they transfused, it didn't go any higher.

My blood pressure was 20/10, so low that doctors then decided to call my family and the surgeon.

My twin sister and brother-in-law arrived first looking very grim, but then my youngest sister arrived with her partner and being a nurse went to the monitor and found my blood pressure to be low and heart rate very slow, so she took it upon herself to make me laugh and her partner joined in making me laugh but oh it hurt.

The surgeon arrived at 5.00am and first went to the monitor declaring "Well that's a damn sight better than what I was told on the phone" and then turned to me and asked how I felt and of course I told her I felt tired, and she then asked me if I would like some sleep and told my sisters to go home and get some sleep. Apparently, my youngest sister knew what she was doing when she made me laugh. I later found out my blood pressure had risen to 90/50 after watching and listening to my youngest sister's carry-ons done ever so funny.

So just after 5.00am I found myself back in surgery only to wake in the same glass room in ICU to be told by my surgeon that everything had gone just well.



My Journey - by Rosemary Wattle (continued)

I expected to go home in 4 days but my magnesium levels bottomed out and so I had an infusion every day until my levels were satisfactory which took three weeks to achieve. I finally went home a month after my admission via the Emergency Department.

It was expected that the surgery would be good for 2 years and my surgeon left the loop stoma as is and I returned to the aged care home I was living in at the time, but 2 years I did not make.

I had to return to the surgeon because my stoma grew to the size of a tennis ball and stuck out so far that a group of ladies at the aged care home where I used to live, thought I was pregnant so about 10 months after the first operation I went back to the surgeon who did a colonoscopy first before deciding on what to do.

The results were not too promising, and the surgeon was worried about a few things, those being the size of my bowel and the fact she had removed one of the largest polyps she had ever seen. It had a base of the diameter of a fifty-cent piece and was multilayered standing about 5cm high so she said my descending colon would have to be removed as I had a mega colon plus a 20cm tear in my very fraaile abdominal wall. A bookina was made for 12th August 2020 to be operated on at a private hospital, however my stoma which was as large as a big orange, prolapsed and I was taken to the public hospital where a surgeon came down to emergency and was able to put it back in place, only for it to happen again 2 days later and so back to emergency.

Eventually I was admitted to a private hospital on 12th August 2020 and when I came to after surgery, I learned that my transverse colon was so bad having been affected by Inflammatory Bowel Disease

that it had to be removed and a 25cm tear in my abdominal wall was repaired at the same time. I was supposed to go home on day 4 after surgery but my blood pressure was 199/99 and so I was sent to the Cardiology ward for one-on-one treatment. However, I was put into a private room and only when my surgeon came to see me after three hours was something done.

I'd never had high blood pressure before and apart from throwing up I felt okay but my surgeon was worried and had me sent to ICU, however on the way down to ICU, I suffered a Myocardial Infarct and by time I reached ICU, two doctors were waiting for me. A central line was inserted into the right side of my neck. With about eight inches of bowel left I had managed to get a blockage and so I had to swallow a nasogastric tube inserted as I sat up in bed, not really feeling like someone who had just suffered an MI. I then went into Atrial Fibrillation, and I continue to take heart medication to this day. I spent 9 days in ICU and another week or so back in a private room.

My surgeon was so happy with the outcome as was I, but I now have a massive hernia at the stoma site. The surgeon didn't want to see me for 5 years, but as my abdominal wall is so thin, I now have an appointment in two months.

Even though I have a colostomy and soon maybe an urostomy, as I have a slow growing cancer in the bladder associated with Non-Hodgkin's Lymphoma, nothing has ever stopped me doing what I like.

I used to live in aged care as there was no other place for me at the time. The muscle disease has left me in a wheelchair, and I went into aged care at the age of 59. I now live in Supported Income Living with two other ladies with disabilities in a purpose-built house for

disabled people and I am supported by NDIS. Despite being disabled I don't see myself as being disabled and I now volunteer at the aged care home where I used to live, two days a week, and they are full days too not half days.

As I write this, I am lying in bed with Covid.

With all the things I have wrong with me I never complain as I don't see a use in complaining. No one likes a complainer and so I have adopted a positive



outlook on life. Being in a wheelchair that I can operate does have its advantages. I can beat everyone else from point A to point B and not tire myself out.

One of my positives is that I take people and things as they come, and I can still enjoy life. I encourage everyone in

a similar situation to accept the changes to their bodies. Matthew was very encouraging in his story of his life and is now doing what he likes best.

Introducing our newest board members

Graham Lawson

raham has a Masters of Commerce (Professional Accounting) and a Bachelor of Commerce (Honours Economics/Law) and has 30 years experience working within the public health system in Corporate Services Management and major project management.

Graham was moved to nominate for

the Board following his experience in the NSW Stoma Member Information and Education days.

Graham is passionate about equity of access to services.



John Hickey

John's background and passion is in education where he has been involved for 40 years, beginning as a secondary teacher in 1983. For the past 25 years he has held leadership positions in schools in Sydney and Melbourne as a Deputy Principal and Principal. He currently works in the area of teacher formation, development and leadership in a range of schools across Australia.

John holds a post graduate master's degree in educational leadership and

is strongly committed to the support and development of young teachers as future leaders. He became an ostomate in 1987 as a result of bowel cancer surgery and is very keen to assist Stoma NSW as a Board

d supporting this

member as a way of supporting this organisation that has supported him for 35 years.







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For fast and easy adhesive release:

- Reduces painful skin stripping and skin irritation
- Quickly removes adhesive residue
- Feels silky and smooth, no residue left behind

Product Codes*

SKIN BARRIER							
SILESSE™ Sting Free			New ESENTA™ Sting Free				
420797	SILESSE™ Skin Barrier Pump Spray 28 ml (1x1PK)	•	423286	ESENTA™ Skin Barrier Pump Spray 28 ml (1x1PK)			
420790	SILESSE™ Skin Barrier Spray 50 ml (1x1PK)	•	423288	ESENTA™ Skin Barrier Spray 50 ml (1x1PK)			

ADHESIVE REMOVER						
NILTAC™ Sting Free		New ESENTA™ Sting Free				
420788	NILTAC™ Adhesive Remover Wipe (1X30 PK)	•	423281	ESENTA™Adhesive Remover Wipe (1X30PK)		
420787	NILTAC™ Adhesive Remover Spray 50 ml (1x1PK)	•	423289	ESENTA™ Adhesive Remover Spray 50 ml (1x1PK)		
420798	NILTAC™ Adhesive Remover Spray 150 ml (1x1PK)	•	423290	ESENTA™ Adhesive Remover Spray 150 ml (1x1PK)		

^{*}Included on SAS





United Ostomy Associations of NSW Education and Information Day



SW Stoma Ltd & Ostomy NSW Ltd are proud to present the return of our Stomal Therapy Education Days in 2022.

These days provide an opportunity for members to meet and support each other, meet representatives from your association, meet suppliers, listen to presentations from experienced stomal therapy nurses and more. All members, their families and carers are welcome.

We held 2 days this year. The first, in June, at Club Macquarie just outside Newcastle. What a wonderful Day! After more than 2 years of Covid restrictions we were finally able to meet in person and hold an Education and Information Day. The event also coincided with National Stomal Therapy week. More than 130 members and







friends joined us for the day. Feedback from the day was overwhelmingly positive, with one member commenting: 'Until today I felt so alone with my stoma. Now I feel like I am part of a family'. The day was all about the members and there was lots of opportunity to ask questions and meet other members.















The second day was held at Canterbury League Club in South-Western Sydney with 125 members & friends attending, and again feedback was very positive. Members were really keen to talk to the suppliers about their products and meet other ostomates.





A huge thank you to our STNs, Lee Gavegan and Anne Marie Lyons, who generously give their time and share their extensive knowledge. We could not run these days without them.

Another big thank you to Carol Quast,



whose time and effort in arranging the day, and then speaking on the day about her own experiences as an ostomate, is so valuable. Her tips and tricks for living with stoma should not be missed.



I also want to thank Mathew Boyd-Skinner for speaking at our Sydney day. Mat, you are an inspiration to us all.



These days are made possible by all the major

suppliers attending and supporting us financially. Without their support we would not be able to hold these events. Thank you to: Coloplast, Convatec, Future Environmental, JD Healthcare, Liberty Medical (Dansac & Hollister), Omnigon and Sutherland Medical, Ainscorp & AMSL.







It is so lovely to meet so many of our fabulous members. Those I talked to on both days were so positive about their

experience with the day, saying they found it very useful and informative and it was great to meet other ostomates too and hear their stories.

We are really looking forward to delivering more of these days in 2023 so watch our website for our next



Education and Information Day, hopefully coming to a venue near you shortly.



My story of A ROAD LESS TRAVELLED

G'day everyone

y name is Warren Bell and I have just turned 73. Early in 2009 I had radical surgery for the removal of my prostate. That same year in August I decided to retire and do other things.

I have always had a passion for motorcycles and for most of my life I commuted and rode for pleasure.

In August 2010 a mate and I decided to organise a ride in Northern Vietnam from Hanoi to Sapa. During this adventure I found that the prostate surgery had severely affected my core strength. The goal on my return was to get as fit as I could be for my next trip.

July 2011, as with so many things in life stuff gets thrown at you that alter your plans. While visiting my daughter, who was living in Bangkok, I came down with what I thought was a bladder infection, coffee coloured pee. I seemed to recover but while riding my motorbike locally early September that year I had to apply the brake suddenly. When I got off the bike to go to the toilet there was blood in the urine. It was only eight weeks to my son's wedding. So I talked to my GP and I discussed options with my Urologist which would allow me to be at the wedding. I ended up with an Illeal Conduit and was released from Strathfield Private 4 days before the wedding. I didn't dance but my 80 year old father certainly made up for that.

Now I have had two major surgeries in the same core strength area which presented some problems. However, with the help and encouragement my family, the amazing medical and



specialist nursing staff at Strathfield hospital, my physio, and with lots of hard work I was back on the bike in just over six months, albeit only locally. My next step was to work out where I could go that was off the beaten track.

I am a self funded retiree and admit that travel can be expensive. To overcome a large part of the expenses I stay just on the outskirts of major cities and commute into town by motorcycle, local train or bus. For long distance overland travel I look for schedules which allow me to depart around check out time and arrive around check in. I love and do lots of walking and hiking. Buy food at local delis and supermarkets helps and makes a great lunch somewhere on the road or train. I also obtained a part time job commencing 2011 that I retained until 2019.

Then with guidance and great advice from Anne Marie on options to manage long distance travel the first trip was planned for June 2014, two weeks road / rail and 7 days motorcycle. It was to be my first time in Europe and I only speak English, except for a few essential words of French and Italian. After visiting Paris, oh lala, and the Loire valley, with two friends they drop me



2014 pinch myself childhood dream the Colosseum.

at Annecy. From there I catch a train to Turin in Italy to meet my son in laws cousin and spend a few days with him walking and exploring the Alps north of Turin. What an experience train travel is in Europe, it is the best. After Turin I head to Modena to pick up a motorcycle. From here I plan to explore roads to Pisa, Lucca and Portovenere on Cinque Terra, all on S roads, paper maps, addresses and instructions written on paper, never a toll or freeway. Everyone I meet is so helpful and friendly to this bloke, who cannot speak their language, and is at times so completely lost with only a general idea and an address of where the agri accommodation might be.



2015 en route Augerien.



2016 Florence.

This gave me the taste, the challenge of planning and getting around the complete unknown. I was addicted. So 2015, I receive an invite to good friends 50^{th.} in his home village Augirein which is in the French Pyrenees and I jump. Mates had hired bikes from a place in Frankfurt so I went with their recommendation; routes were sorted by looking at past Tour de France routes. Only B roads planned unless these are blocked by snow, or collapsed tunnels.

A few months before I set off in June a good mate from home said he would like to accompany me on the trip, better still someone to get lost with.

Although Greg likes a GPS what could go wrong. Again we were to do two



2015 party starts in Augerien.



My story of A ROAD LESS TRAVELLED (continued)



2014 Lake Como hike to abandonded castle.



2016 Siena.



2016 Turino family friends.



2016 Pisa.

weeks road and rail then this time two weeks on motorcycles. We arrange to meet in Bologna and then catch a train to Frankfurt Germany visiting of course the museums of BMW, Porsche and Mercedes. After the we collected our motorcycles in Frankfurt for a 4,000km odyssey through the most amazing scenery you could ever imaging. We ended up with so many hilarious stories I could go on for ages. Patisseries in France, sometimes two a day, someone leaving their passport on a counter and asking me later where it is, GPS units searching for satellites as you approach a round bout and, with the same make, model GPS, with the same avoidances and settings one GPS telling one to go left the other straight ahead.

September 2016. It has always been on my bucket list to visit a few places in Europe, The Colosseum in Rome (2014 and 2018), Versailles 2015 and Auschwitz. So immediately on our return we started planning for a trip in 2016 and decided to ride from Milan over the alps to Lake Garda then to

Krakow via Stelvio Pass, Czech and Hungary to visit Krakow and Auschwitz. We returned through Austria, the Dolomites and Lake Como. In 2017 we travelled from Milan through Slovenia, Croatia, back to Italy and Florence. From there we headed into the eye of a fierce electrical storm on the way from Sienna to Monterosso al Mare and trying to go over a pass on the Apennines of 1,800m by the time we reached 700m our temperature garages were at 7°C and visibility was the edge line of the road. We turned back to the Tollway

In 2018 I decided to do something different and travel by train. Landing in Rome to visit the original port of Rome, Ostia 7BC-9AD, then Naples, see Herculaneum; catch a local train to Caserta for largest Royal palace ever built in 1752. From Naples I caught the train to Sicily, from there back to Bari and onto Matera.

At the places I visit I always try and squeeze a swim in. Portovenere in 2014 a late afternoon swim, 2015 Banyuls sur Mer we had a sunrise swim in the Med.







2022 HIke to Florence Falls.



2022 exploring with grandkids, Canberra.

2016 we were not near the sea and 2017 the weather beat us, In 2018 I swam at Taormina beach on the coast of Sicily and then had the Pope do a quick drive by of my accommodation in Palermo.

I do also love local travel and since receiving my clearance to ride again in 2012 have not missed a week without venturing out on the bike. I believe it helps reflexes, balance, perception and fitness.

In 2020 my trip to France and Spain to ride from Barcelona to San Sebastian via the TET through Spain and back via France was cancelled due to Coved. I did Nyngan, Wilcannia, Broken Hill, Wentworth, Balranald and Yanga National Park instead. In the last twelve months our group did a ride to Kempsey up through Armidale via the upper reaches of the McLeay River, further onto Gunnedah, Boggabilla, Goondiwindi and returned via Narrabri, Bathurst and lots of rain from Lithgow. We enjoyed some of the most spectacular scenery you will ever find. Late June 2022 I have just returned from my first trip to Darwin. In Litchfield National Park I swam in Bluevs Pools and under Florence waterfall. It was difficult to get to, it was hard owing to the crowds, but it was so worth the effort and warm. Next year I might return on the bike, or in the car.

Travellina like this has given me the view that if you want to you can. Long distance travel requires lots of planning, calm and patience is paramount; most important thing is NOT to lose it if you make a mistake. Travelling with a months worth of supplies can be dauntina. I take as carryon luggage the number of days plus ten percent with a leg bag for long haul flights and bike trips. Once I left my supply bag on a train at Rome Termini when the train I was taking had a carriage 3 and further down a 3B. I had boarded the first but my seat was in the second. When I made it to the correct car realised my supplies were in the first. Quick footwork required.

I hope my story provides some inspiation for you to get out and try things.



2022 dusty ride



The Hidden Disability

hile it can easily become something that we can't stop thinking about, an ostomy is often kept hidden from the masses. However, as airport travel safety procedures increase and become more hi-tech, many ostomates and those with other disabilities worry about the public scrutiny they may face. Thankfully, to take a little pressure off, the sunflower lanyard has become a globally recognised symbol for invisible disabilities.

Launched in 2016 in the UK, the sunflower lanyard scheme helps staff to identify passengers who may need additional help while travelling. A hidden, non-visible or invisible disability includes those which are not immediately obvious such as autism, chronic pain, speech, sight and hearing loss as well as disorders which significantly impact day-to-day life.

At Sydney airport, any passenger who would like to identify that they have a hidden disability can collect a sunflower lanyard at the Airport Services Centre located on Level 3 (Administration) at T1 International airport or from the

Ambassadors information desk on Arrivals level at T2 Domestic terminal. It is important to locate these desks prior to passing through security.

On a recent interstate trip, I personally collected a sunflower lanyard at the Domestic Terminal. The Information Ambassador manning the desk at the time asked no personal questions or for me to prove my hidden disability, he simply passed on the lanyard and directed me to the sunflower symbols at security. While not a fast-track access through security or passport control, you will notice a sunflower image directing you to a specific assistance line and makes staff aware that you may need additional help, time or support through different processes such as security, scans, passport control and boarding.

Walking through the airport, part of me was quite conscious of the lanyard hanging around my neck. Thankfully, just like having a stoma, no one looked twice at the green lanyard or questioned why my young, healthy looking family was by-passing lines of waiting passengers, perhaps we looked like airport VIPs!

Unfortunately, some of us have had negative or embarrassing experiences at airports, being questioned about "hidden bulges" on our bodies following the new security scanning procedures or being asked to lift clothing and be patted down. When your stoma bag is detected on the scanner, according to

the Australia government guidelines, you are not required to expose your ostomy to security staff, nor do you need to remove your clothing or let them touch it. Most procedures will ask you to rub your own hand on the outside of your clothes. I've made it my practice to point out my stoma upon entering or immediately exiting the



scanner so that I can remain in control of the situation and to keep the conversation discreet, especially when travelling with companions or colleagues who are not aware of my stoma. As I mention my "medical device which is attached to my stomach", I gently pat my bag so they're aware of where it is.

Fortunately, I have had mostly

positive experiences moving through security, but like many ostomates, there is the odd occasion where I was met by a staff member who was not educated or trained. One such experience saw a staff member repeatedly demand for me to lift my shirt, remove my bag and for them to look inside. I was adamant that wasn't going to happen, the staff member was adamant it was, people were looking as I did in fact lift my shirt and my blood was boiling with both embarrassment and anger at the situation. Eventually, a manager came hustling over and promptly apologised and diffused the situation, but the memory still causes panic each time a pass-through security.

It is our hope that in the future, all staff will be provided more thorough and sensitive training to help passengers remain comfortable and safe while completing the necessary checks discreetly.

It's also helpful to keep in mind that you can request to not go through a whole-body scanner at the airport, however you will need to comply with some sort of full-body search as





passengers refusing any screening will not be allowed to pass through screening points or board their flight. While you may wish to request a certificate from your association or medical professional to explain that you have a stoma and will be travelling with medical supplies, as of 2012, the Australian Government has outlined passengers are not required to carry any such letter but to notify the screening officer prior to the start of the scan to aid in the process.

A stoma shouldn't stop you from travelling, and a successful trip comes down to preparation, the more we know of the process, the easier it will be! And of course, practice makes perfect, so book those holidays!



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 April 2022to 30th September 2022:

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 Nov 2021 to 31st March 2022:

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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 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.









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/

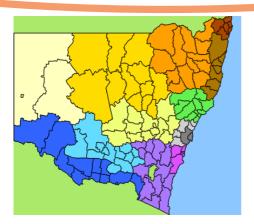
or just email volunteeer@nswstoma.org.au and we will send it to you.

Andrew Hollo, our fabulous volunteer who works every Monday and Thursday in our warehouse. Thank you!



NSW OSTOMY SUPPORT GROUPS





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

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

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

email: info@nswstoma.org.au

For current information on support groups please go to:

https://www.nswstoma.org.au/ becoming-a-member/support-groups/

NSW STOMA LTD MEMBERS SUPPORT GROUP ZOOM MEETING

All members, carers & friends are welcome to join our monthly Zoom meeting at 6pm on the first Wednesday of every month (except January). Hosted by Anne Marie Lyons (STN), Carol Quast (Director & ostomate) and NSW Stoma Ltd manager, Mary Egan, this is designed

to give information about the services we offer and provide some explanation of the Stoma Appliance Scheme and how to place orders. To attend please email: customer.service@nswstoma. org.au and we will send you a zoom invitation on the day of the meeting. You need to register your interest for each meeting you wish to attend.

WOMEN'S OSTOMY SUPPORT GROUP

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

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

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

Contacts: San Cancer Support Centre (02) 9487 9061

email: 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

email: 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 6th Apr, 1st Jun, 3rd Aug, 5th Oct, 7th

December 2022

Contact: The group is hosted by Tracy McMorrow (Stomal Therapy Nurse) and Fiona Le (Stomal Therapy Nurse) RSVP for catering and up-to-date Covid-19 restrictions. You must be double vaccinated to attend.

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: 15th Dec 2022, 16/2/23, 20/4/23, 15/6/23, 17/8/23, 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.

NORTHERN SYDNEY AREA

All Ostomates, friends and supporters welcome.

Where: Jacaranda Lodge, Sydney

Adventist Hospital,

185 Fox Valley Road, Wahroonga

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

Contact: San Cancer Support Centre on

(02) 9487 9061 or

email: cancersupport@sah.org.au

PENRITH AREA

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

Where: Sydney Medical School,
Outpatients Department,
62 Derby Street, Kingswood
(opposite Nepean Hospital Emergency
Department at roundabout, Outpatients

is at left hand side of building)

When: 15th Dec 2022

Contact: Naomi Houston (Stomal Therapist) on (02) 4734 1245 or email: 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 but must be double

vaccinated to attend

RSVP in case of Covid update and

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

email: Lisa.Clare@health.nsw.gov.au Kate Rycroft 0432 251 703 or email: 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: Check with the group organisers for advice on scheduled meetings.

Contact: Gary Tobin 0400 675 277

COFFS HARBOUR

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

Where: Sawtell RSL Club, First Avenue,

Sawtell

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

Contact: Mandy Hawkins STN:

(02) 6656 7804 or email:

Mandy.Hawkins@health.nsw.gov.au

HASTINGS MACLEAY

Where: Port City Bowling Club, function room, 4 Owen Street Port Macquarie
When: 10am - 12pm Third Wednesday of every second month Feb, Apr, Jun,

Aug, Oct, Dec

Contact: Neil 0427 856 630 or

Glennie 0410 637 060

MANNING / GREAT LAKES

Where: Venue TBA

When: 10.30-12pm approx.

1st Wednesday of every 2nd month **Contact:** Karla MacTaggart STN

(02) 6592 9169

NEWCASTLE REGION

NEWCASTLE DISTRICT

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

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

Hamilton

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

Contact: Geoff Robinson 0411 221 193 (Jan)

ILLAWARRA / SOUTH COAST REGION

BOWRAL

Where: Bowral Bowling Club, 40 Shepherd Street, Bowral

When: 1pm – 3pm Tuesday 6th Dec 2022,

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.

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



NSW OSTOMY SUPPORT GROUPS

ILLAWARRA

Where: Education Room, Figtree Private

Hospital, 1 Suttor Place, Figtree
When: 10am-12pm, Wednesday.

 15^{th} Dec (Xmas luncheon. Venue to be

advised).

Contacts: Helen Richards CNC STN Wollongong Private Hospital

phone: **(02) 4286 1109**

email: richardsh@ramsayhealth.com.au

Julia Kittscha CNC STN Wollongong

Hospital mob: 0414 421 021

email: 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 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 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 email:

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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