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HOURS OF BUSINESS

With the vaccine rollout, we are gradually re-opening our premises. Opening hours are published on our website and written notices are placed in all orders. Thank you for your patience during this exceptional time.

For current information go to:
nswstoma.org.au



DIRECTORS

CHAIRPERSON	Allen Nash
SECRETARY	Renee Constantin
TREASURER	Ian Niccol (non-director, volunteer)
OTHER DIRECTORS	Carol Quast Ian Murray Eugene Tomczyk Ken Batten Kingsley Liu Shona Gawel

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NSW Stoma Journal is printed by:



Graphic designer: Paula Garrod
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NOTICE BOARD



Xmas Closing

We will close on Friday 24th December 2021 at 12pm until Wednesday, 5th January 2022.

Pick-up times

For information on pick times and our Covid Plan please go to:
nswstoma.org.au

Onsite Stomal Therapy Clinic

We hope to open early in 2022 but watch our website for up to date information.

Email or text **Anne Marie Lyons STN**

Email: stomanurse@nswstoma.org.au **Mob:** 0468 582 951

Products for Sale

Product	Code	pack size	Member Price	Non-Member Price
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Simple Nightstand Plastic	380431	each	\$13.45	\$15.00
Hollister Leg Bag	9632	each	\$7.80	\$8.45
Urostomy Drain Tube Adaptor	7331	10	\$30.15	\$33.00
Odour Be Gone Hos-Togel	3300	each	\$33.79	\$37.00
Odour Be Gone Hos-Toma No Smells 500ml	10500	each	\$15.84	\$17.50
Odour Be Gone Hos-Toma No Smells 120ml	10120	each	\$8.00	\$8.50
Ostomy Scissors (curved)	9505	each	\$7.50	\$8.00

A MESSAGE FROM THE CHAIRPERSON



What a challenging year! We have all had to deal with managing the risk of COVID for our particularly vulnerable ostomate community. It was good to hear from you (NSW Stoma members) via the ACSA survey which reinforced that a large majority of you have a high regard for the way your associations managed the pandemic.

NSW stoma staff have applied great effort to get supplies to members in a timely way despite the delays and extra costs involved in compliance as well as difficulties with Australia Post delivery delays.

There was much relief felt all around from the Health Department's potential tender for the whole Stoma Appliance Scheme being cancelled. It has been hanging over us all for some time now. This means that the distribution of stoma products will remain in the hands of not-for-profit associations run by ostomates like NSW Stoma.

I look forward to the coming year with hopefully a more stable environment that will give us all a chance to take a breather and give us time focus on further improving our service and support to our ostomate community throughout Australia.

I have had much positive feedback that the World Ostomy Day webinar held on the 2nd October was very much enjoyed by the participants. It was great to be able to connect with ostomates around Australia in this time of isolation

due to COVID. NSW Stoma took the lead in organising this webinar.

We have had one of our NSW stoma Board members leave recently. Andrea Cross made a great contribution to the board in assisting in further developing the standards of governance at NSW Stoma and her work was much appreciated.

There is a new board member joining the board. Shona Gawel is most welcome as she has skills in communications which complements the skills of current board members.

We also have a new voluntary Treasurer, Ian Niccol, who is a Chartered Accountant (a rare find) and who is also most welcome. All the board are looking forward to working with him over the next year.

NSW Stoma is now the largest Stoma Association in Australia, and we look forward to continuing to provide the best service and support for members that we can moving forward into the next stage of the COVID situation.

Keep well.

Dr Allen Nash
Chairperson of NSW Stoma Ltd

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A message from Mary Egan, your General Manager

2021 has been another challenging year as we continue to deal with the pandemic. With the vaccine roll out, we are now transitioning back to pre-covid conditions. At NSW Stoma we continue to take a very cautious approach. Even though our staff and on-site volunteers are fully vaccinated, Covid-19 is transmissible and it can shut us down. Our emphasis will continue to be on the continuation of our operations and supply of essential supplies to all our members. Our Pick-Up service has resumed and in 2022 we look forward to opening our doors and offering face to face services.

Apart from a few months in the 1st half of the year, our on-site clinic has remained closed. Anne Marie Lyons, our fabulous stomal therapy nurse, has continued this vital service via phone and email. While this has given many more of you access to this service, we acknowledge it can't take the place of a face-to-face service. We intend to reintroduce this as soon as we feel it is safe to do so, while continuing to offer the phone and email service. All NSW Stoma members have free access to this clinic.

We have really missed delivering our regional education/information days over the last 2 years and we now look forward to resuming these in March 2022. Keep an eye on our website for details about this and all our services. We initiated our monthly zoom meetings this year, with a focus on new members, and these will continue in 2022. Everyone is welcome to join us on the 1st Wednesday of every month (except January). To register, just email customer.service@nswstoma.org.au If you have suggestions for topics you

would like us to cover, we'd love to hear from you.

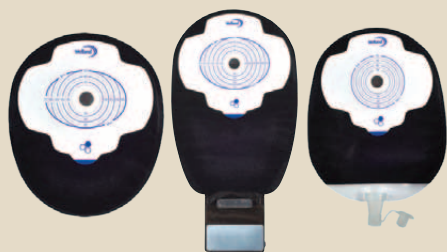
We were really proud to initiate and take part in the World Ostomy Day event on 2nd October over zoom. It was wonderful to work with all the other associations, particularly Ostomy NSW, to bring this event to ostomates all across Australia. See the full report from Carol Quast, NSW Stoma director, later in this issue.

During the last 12 months we have finished upgrading our internal software systems, giving us much greater stock control and automated purchasing. We upgraded our website and added online ordering and payments. While the new website has provided us the ability to make changes and update our communications quickly and easily, there is so much more we want to do. In 2022 we hope to add a much more interactive experience for our members, with the ability for members to securely log in and retrieve their order history, repeat orders, place new orders, as well as view and update account balances. For those of you who prefer to deal with us by post, phone and email, we will continue to offer those channels in their current format. We understand that many of our members do not own or have access to computers and we will always accommodate alternative modes of communication and ordering.

We received a huge lift in donations this year with so many of you prepared to help support your fellow ostomates. What a wonderful community we have. The pandemic has also meant a big increase in the number of members requiring our



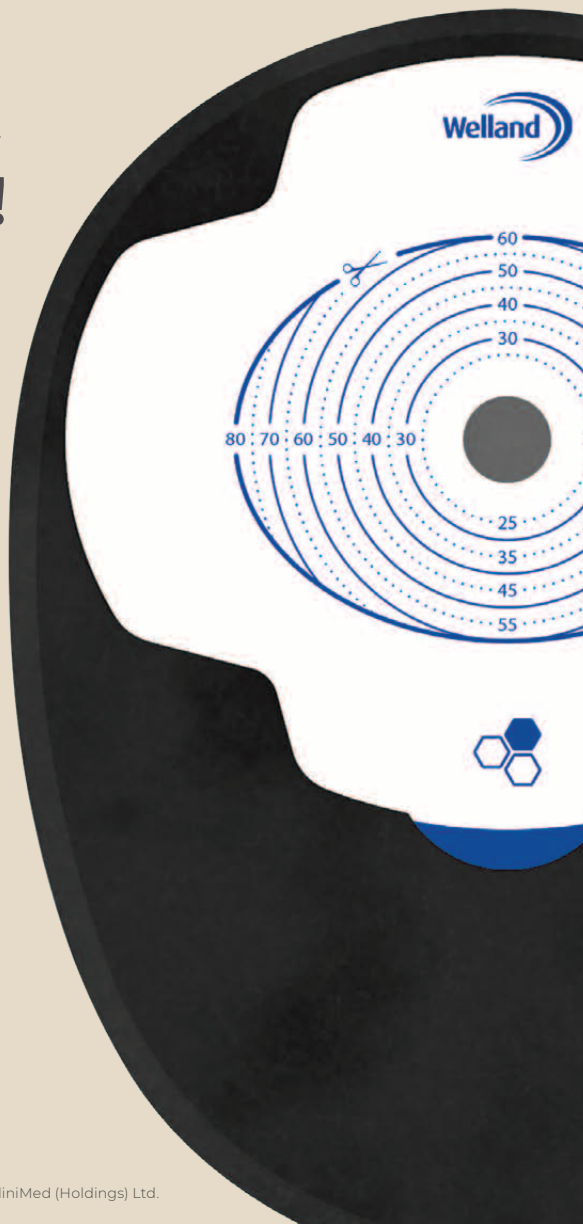
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support with membership and postage fees. It is so rewarding to be able to assist those who really need it right now. Your donation allows us to do so much more than distribute products. It funds our stomal therapy service, our information & education meetings, financial support for Support groups, our website and now our Stomal Therapy Nurse Scholarship. We know how vital it is that all our members have access to an experienced Stomal Therapy Nurse and we recognise the growing need for services across NSW. We now offer a scholarship to registered nurses wanting to complete their Stomal Therapy training. It costs approx. \$12,000 (of their own funds) for a qualified nurse to complete the additional training required. Their services are essential to us as an association and to all our members individually. In order to encourage as many nurses as possible to undertake the required training we can alleviate some of their financial burden by offering this scholarship.

I would like to take this opportunity to thank our volunteers who give so much of their time to assist us deliver our services. Eugene Tomczyk continues to give up his Fridays to assist with member pick-ups and other office duties. Eugene also sits on our board. Paula Garrod generously gives her own time and skills to pull together our journal twice every year and also assisted us on World Ostomy Day with our flyer to advertise that event. Su Wun Harris has also made a huge contribution assisting with our pick-up service. I also need to thank our wonderful volunteer board of directors. Without them NSW Stoma would be a very different place. We are so lucky to have so many talented and hard-working board members. Allen Nash, our Chair, gives so

much time, energy and thoughtfulness to our governance. Carol Quast, looks after member communications and participates in our zoom meetings, regional education days and was the driving force behind our World Ostomy Day event. Ken Batten takes on any role asked of him and in the last year has served as treasurer and secretary and sometimes both at once. Renee Constantin is tireless in her efforts to improve the lives of all ostomates. She is the founder and convenor of Ostomingle, has now taken on the role of Secretary with us, and became a mother this year! The list of accomplishments of all our board are too numerous to mention but I want to thank all our directors for all they do.

We also farewelled Andrea Cross from our board. Andrea made such an impact on our governance and made a real contribution to many of our board policies. You will find a special tribute and thank you to Andrea in this issue. We were fortunate enough to welcome Shona Gawel to our board. Shona brings a wealth of communications experience. You can read more about her later in this issue too. We also have a new volunteer treasurer. Ian Niccol, a chartered accountant with many years' experience, has volunteered to fill the role of treasurer. Ian has very generously given us his ostomy journey and we bring that to you in this issue as well.

If you are interested in volunteering we would love to hear from you. Find more information about this on our website here: <https://www.nswstoma.org.au/volunteers/> I wish you all the joy of the season and a very happy, Covid-free 2022!

Warm Regards,

Mary Egan

General Manager, NSW Stoma Ltd



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Entries close 31st March 2022

Failte Mo Chairde

(Hello my friends)



Trusting this letter finds you well.

Another crazy few months we have had, all I can say is all those jobs I put off and had no time to do are finally done!! There always has to be a positive side, sometimes we have to look very hard!

Well my phone has been as busy as ever and I look forward to seeing some of those people I have had the pleasure of helping in the flesh someday.

We had to cancel our ostomy education day yet again, better luck next year hopefully.

Where would we be without zoom? It has filled a huge void for many of us.

Our zoom information hour for new Ostomates has proven to be a great success, we will continue with this service on the first Wednesday of the month from 6-7pm, I cannot stress the importance of your feedback on these evenings, it is the only way we can improve the service.

We had our world ostomy day on the 2nd October (zoom) and it was very well attended by over 250 people.

Our wonderfully funny/entertaining MC Luke Escombe set the scene off to a great start with some very amusing tales to say the least. Luke is an ostomate himself and an ambassador for Crohn's colitis Australia. He is also a singer, a comedian, a children's story book writer and most of all a dad (I think this is the job he prefers most!)

I presented an 'A-Z of living with a stoma', which was well received and I

intend to present the same at the next zoom meeting.

Margaret Allan a Nutritionist presented a very informative session on the benefits of hydration for all Ostomates, again well received with a lot of questions online.

Anna Minchin an exercise Physiologist gave some wonderful practical information on exercising with a stoma.

Dr Allen Nash President of the ACSA presented feedback form the ACSA member's survey, very interesting findings and very well received.

Many other people were behind the scenes working tirelessly to ensure it was a fun and yet informative day, thank you to all.

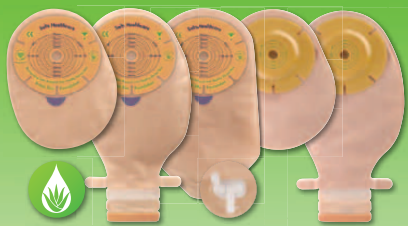
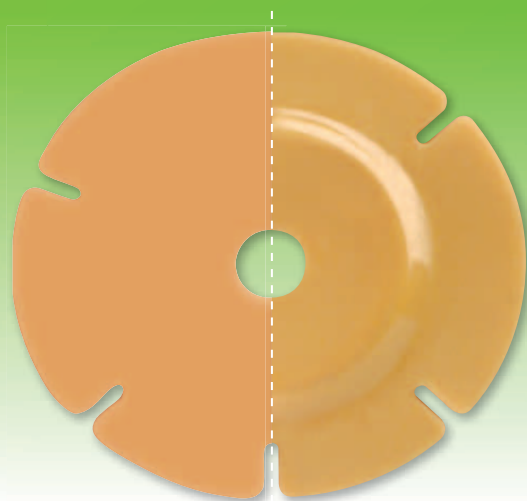
You will be able to view the world ostomy day via the web site.

As this is our Christmas journal, I do wish each and every one of you a happy and blessed Christmas and I hope the New Year is full of good fun, good food, good wine, good friends and most of all good health to enjoy it all.

Nollag sona daoibh (happy Christmas all)
Slan agus beannacht (bye and blessings)

Anne Marie
Anne Marie Lyons STN

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What is Vitamin B12?

Also known as cobalamin, vitamin B12 is an important water-soluble vitamin that is needed for the production of red blood cells, tissues repair and proper nervous system functioning. B12 Cannot be made by the body. Instead, we must get it from our diet (animal-based foods or fortified foods) or supplements. [1]

B12 absorption:

The absorption of B12 starts in the mouth. Vitamin B12 binds to the protein in the foods we eat. In the stomach, hydrochloric acid and an enzyme called pepsin remove B12 into its free form. Once in its free form, vitamin B12 combines with another binding protein called intrinsic factor so it can be absorbed further down in the small intestine (ileum -last part of the small intestine).(2) The liver can also store a five year supply in reserve.

What happens if I don't have enough?

Vitamin B12 deficiency can lead to a number of health conditions including:

- Anaemia- not enough red blood cells
- Neuropathy – nerve damage
- Neurological disorders.

What causes vitamin B12 deficiency? Groups at risk:

Vegetarians/vegans

As vitamin B12 is found in animal-based foods (dairy, eggs, meat, poultry) and is not found in plant foods, strict vegetarians and vegans are at high risk of deficiency, especially if they don't eat fortified foods (e.g. cereals) with B12 or use a supplement. [3, 5].

Exclusively breastfed infants of women who consume no animal products might have very limited reserves of vitamin B12 and can develop vitamin B12 deficiency, sometimes very early in life [6]. The infant's deficiency can be severe, especially if the mother's deficiency is severe or caused by pernicious anemia; sometimes, the mother's own deficiency is clinically mild and not recognized. Undetected and untreated vitamin B12 deficiency in infants can result in neurological damage, failure to thrive, developmental delays, and anemia [3, 4, and 7].

Older adults

Reduced levels of the enzymes (pepsin) needed to break down protein, and reduced levels of stomach acid (hydrochloric acid) mean that B12 absorption is reduced in older people. Up to 20% of the population over 50 may have a vitamin B12 deficiency [9, 10].

Helicobacter pylori a common bacterial infection that causes inflammation of the digestive track, can reduce the absorption of B12 from food [9].

Individuals with pernicious anemia

Pernicious anemia is a rare autoimmune blood disorder caused when the body does not make enough red blood cells due to the lack of vitamin B12. It affects the gastric mucosa (stomach cells) that make intrinsic factor (a binding protein) and results in gastric atrophy (loss of muscle tissue) [1, 11]. This loss of parietal cell (cells in the stomach that secrete hydrochloric acid) maybe due to destruction by the body's own immune system.

Gastrointestinal disorders

Stomach and small intestine disorders, such as coeliac disease and Crohn's disease, may be unable to absorb enough vitamin B12 from food even if they eat enough to maintain healthy body stores [2, 3, 12]. While vitamin B12 deficiency rates are higher in people with coeliac disease [3], the evidence for Crohn's disease is mixed [12,13 ,14]

Gastrointestinal surgery

Gastrointestinal surgical procedures, such as weight loss (bariatric) surgery or surgery to remove all or part of the stomach (gastrectomy), can cause a complete or partial loss of cells that secrete hydrochloric acid and intrinsic factor [15, 16]. Thus, these procedures reduce the amount of vitamin B12, particularly food-bound vitamin B12, that the body absorbs [15,16]

People with ileostomy or Urostomy

Some people with an ileostomy or ileal conduit (Urostomy) may experience a decrease in their level of vitamin B12. This is because the part of the small intestine that absorbs vitamin B12 may have been removed from the digestive system during surgery. [8]

How do I know if I'm deficient?

Signs and symptoms:

Vitamin B12 deficiency can develop slowly over time. Typical symptoms include:

- strange sensations, numbness, or tingling in the hands, legs, or feet
- difficulty walking (staggering, balance problems)

- tiredness, fatigue and weakness
- light-headedness and breathlessness
- pale, jaundiced skin
- rapid heart rate
- bruising or bleeding easily
- disturbed vision
- upset bowel
- anaemia
- a swollen, inflamed tongue and mouth ulcers
- difficulty thinking and reasoning, or memory loss
- Changes in mood.

If you are concerned you have one or more of these symptoms please see your GP to discuss.

Best sources of vitamin B12

The best sources are animal products including red meat, poultry, seafood, eggs, milk and milk products. Foods fortified with B12 that are available include some breakfast cereals, soy milks, yeast spread and vegetarian meat substitutes, including soy-based burgers and sausages.

What about supplements?

It's recommended that those who can't consume or absorb enough B12 through their diet should use supplements. Your doctor will be able to order a blood test to check your B12 levels in your body and recommend the most appropriate form of supplementation – oral or in some cases it may be necessary to receive B12 injections especially if an area of your small intestine (terminal ileum) has been removed or damaged,



What is Vitamin B12 (Continued)

If a diagnosis of vitamin B12 deficiency or anaemia is confirmed, treating the condition is relatively straightforward and involves taking regular vitamin B12 supplements in the form of injections, tablets, sublingual, patches or nasal spray.

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Introducing new NSW Stoma Board member



NSW Stoma recently welcomed new board member Shona Gawel. Shona has extensive experience in communications and has a passion for digital technology. Shona's experience includes communication roles in both Australia and the United Kingdom, working on projects that have spanned agriculture, infrastructure, the charity sector, and industry associations.

Shona has been a member of NSW Stoma for a number of years and is passionate about being a positive ambassador for those living with an ostomy. Working full-time and with a family, Shona understands that some days can be more of a challenge than others and appreciates the role NSW Stoma plays in supporting members. Shona is keen to help the organisation grow its online profile and to help share

the many positive messages that the ostomate community has.

In her spare time, Shona enjoys running (slowly) and also recently took up playing soccer at the age of 40! Shona would like it pointed out though that she is not sure her ability could be defined as "playing soccer" so much as "being on the field while soccer is played around her".



NEW MEMBER SUPPORT GROUP ZOOM MEETING

A new initiative from NSW Stoma Limited

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.

Whether you are a new member or have been with us for some time you are welcome to join us. The meeting is hosted by Anne Marie Lyons, our Stomal Therapy Nurse and NSW Stoma Ltd 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.
(except for the month of January 2022)


Ian Niccol – A patient perspective



Early 2013, I remember sitting in front of my gastroenterologist telling my doctor that my stomach issues were because I had spent a couple of weeks at my mother in-laws place, that I was trying to use the bathroom as sparingly as possible for the fear of receiving embarrassing looks. I thought this had thrown my system out of whack. But after explaining my symptoms, my doctor calmly told me that it sounded like I had ulcerative colitis, which my sigmoidoscopy proved correct.

Over the course of eight years, I went through every possible treatment, right through the standard medications, steroids, medicated enemas, biologics

(that were on and not on the PBS), faecal transplants, and the experimental removal of my appendix. Each treatment showed a slight improvement and then would revert into a flare. To top this all off, because of my constant flares, I developed an anal fissure, and the only relief was a Botox injection.

At this point, my doctor told me that my only option was to have my large bowel removed. I thought well if that is the case, then I'm going to live a little, ease up on my diet, e.g. add back some gluten, enjoy some red wine, and just go out and enjoy life. For whatever reason this seemed to work, and I was in remission for about 2 years. That all ended very quickly and painfully earlier this year. *continued page 24* 





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1. Maria Teresa Szewczyk, MD, PhD; Grazyna Majewska, RN, ETN; Mary V.Cabral, MS, FNP-BC, CWOCN-AP; and Karin Holzel-Piontek, RN: The Effects
of Using a Moldable Skin Barrier on Peristomal Skin Condition in Persons with an Ostomy: Results of a Prospective, Observational, Multinational Study,
Ostomy Wound Management 2014;60(12):16-26. 2. Consumer sampling survey, N=61, ConvaTec Inc., February 2021, data on file. October 2021 O615



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By the time I had my colectomy & ileostomy, I had lost 22kgs, I was so frail that I couldn't walk unassisted, and spent almost 2 months in hospital.

As a new ostomate, there are a couple of things on my healing journey I thought I would share with my fellow “new” ostomates and I thought would be useful for anyone needing this surgery:



Exercise

Recovery after surgery is slow and painful. But it does get better! For the first two months, I did very little and as someone who was active at the gym, this was frustrating. During this time, I had one goal, can I make it to the end of my street and back – a small cul-de-sac. Gradually, I got there. The third month following my surgery, I started off with very light exercises. The first sign of pain or overdoing it, that was enough – I would never push it.

Halfway through the third month, something clicked, and my body started to heal quickly. With the right support devices, I was able to be more active, do weights, ride my bike, work in the garden and importantly, play with my boys.

Wearing a bag

I always research and try different products. My stoma and my stomach have continued to change following surgery and what worked well initially doesn't always work or fit me now. I've

made a point of trying different types of bags (grab a sample for free from suppliers). I have purchased support belts from overseas, which have been great providing me with the confidence to do anything.

At the beginning, I was very conscious of preventing leaks during sleep that I would wake every couple of hours to empty my bag. Over time, I got used to going longer where I now only empty it before bed.

Not very often, but leaks happen. I now understand when this is happening. Eg, when output feels like it is staying around my stoma and not draining to the bottom of the bag.

Food

Some food and drink make output watery. I counter this by eating starchy foods, eg, white bread, pasta, banana and even jelly babies. Check with your doctor when you can start eating some of these foods post-surgery, but I will have a banana before coffee and jelly babies before a glass of wine.

JOURNAL

DECEMBER 2021

I stay away from nuts and corn kernels and always chew more than I used to. Just recently, I got lazy and suffered a blockage which lasted about 4 hours. I managed to work the blockage through massage and drinking fruit juice. Lucky, as I thought I was heading back to hospital.

Mental awareness

Some days I am down on myself because I am wearing a bag, but as time passes these days are becoming fewer. I have managed to get my life back, and I no longer look at places of interest, shops etc as available toilets.

I follow Mr ColitisCrohns on social media, a great ambassador for all ostomates alike and I regularly stay in touch with my stoma nurse – she was there at the beginning and continues to be, helping me with ordering new and different supplies.

One thing I realised is that I am not alone in this and that there are more people than I realised who are ostomates.

It's also important not to go on this journey alone. My wife was with me every step of the way and she also had many questions to assist her on this journey together.

In hospital, I spoke to a nutritionist, a psychologist, my stoma nurse, my doctors, and a fellow ostomate on a regular basis. I had so many questions and everyone was so helpful. To that end, the NSW Stoma website is a great site to obtain a lot of this information. As I am dedicated to knowing more and assisting where I can, I recently volunteered to assist the NSW Stoma Board as treasurer and am excited to join the team to continue the great work for members.



In Memory of Margaret Samuels

2020 is a year that the whole world will certainly remember due to the pandemic and its' associated challenges. For me, these challenges were heightened by the passing of my wonderfully inspirational, stoic, kind and cultured mother. She died on March 22nd aged 95 years.

Mum spent her 95th birthday in hospital and as my brother Roland recalled after a young doctor outlined mum's next 3 months of life by telling her "if the cancer in your bowel doesn't kill you then the blood clots on your lungs will" she said: "Well, that's not such a great birthday gift but I've had a good run, haven't I, a good run."

Overall, my mother did have a good run. After being awarded Dux of Dubbo High School, Margaret was granted a scholarship to train to be a teacher at Armidale Teacher's College. From there, she taught at Trangie, Bourke and Dubbo Primary and High Schools. Her teaching career came to a stop after she was diagnosed with Crohn's Disease in 1964.

Mum married, had four children, eight grandchildren and one great grandchild. She was a dedicated grandmother who sort to inspire her grandchildren with an appreciation of poetry, art, music and literature. This quest to cultivate went even further and Mum spent many years with a small group of community members, working tirelessly to promote dance, theatre, fine arts, embroidery, flower arranging, gardening, music, literature and much more in the city of Dubbo, in the central west of NSW.



To quote Kent Buchanan, the Curator of the Western Plains Cultural Centre, "I can confidently say that without Margaret Samuels, Dubbo would not be the sophisticated city it is today."

In her quest to cultivate a predominantly staunch sporting town, Mum and her committee from around 1975 pushed and pushed for Dubbo to have an Art Gallery and Theatre. This finally eventuated and her involvement spread over the next 45 years. She was a Volunteer, Guide, Advisory Board Member and during this time, she established some wonderful friendships. She spent many days at the Gallery and in a way, it became her second home.

My mother had a quest for knowledge. She loved the Saturday Sydney Morning Herald, studied literature at the U3A up until she was 93 years of age when it was a bit too much reading a book each week, and would attend a concert, play or see a good film whenever she could. I remember when I was living in the small Victorian town of Castlemaine and when Mum arrived from Dubbo after enduring an 11-hour train trip, she said a quick "hello" and then was off to attend one of the events of the Castlemaine Arts Festival.

I hope I have captured the essence of my dear mother. She truly was inspirational in so many ways. One of the ways, which she kept very much to herself, was the fact that she had overcome 2 forms of cancer: cervical and bowel cancer, and, had lived with her colostomy for approximately 50 years. Although privately, this caused her some angst, it in no way stopped

her from living life to the full. She loved to travel, enjoy the company of friends and family, garden, walk, embroider, do the flowers at her local Church, occasionally swim and as already stated, be on the Advisory Committee for the Dubbo Cultural Centre and volunteer as a Gallery Guide. Her colostomy did not stop her from enjoying herself on so many levels. My only regret is that I wonder if she kept up to date with the latest possibilities for bags, odour killers, skin care that are now available, as these may have improved her experience. Since I lived interstate from Mum, I am sorry that I wasn't there to assist her with this and ensure that she received the

continued support from the excellent stoma therapists that helped her along her journey.

Despite living with her colostomy for nearly half of her life, she hated when people discussed her health issues and made it clear that it was none of their business. Although this could have been a generational thing, I feel that the burden, if it was one to her, could have been shared with her loved ones. When I read about the support networks available now, I think this is wonderful.

Katie Stewart (Samuels)

Thank you to Andrea Cross – Director of NSW Stoma from June 2019 to June 2021

Andrea joined and was voted onto our board in June 2019 and had an immediate and positive input in raising the education and quality of governance on the board.

She served not only as a Director but also as Vice Chairperson and Secretary during her time with us.

Andrea organised for all directors to be participants in a Not For Profit, BetterBoards Governance Conference in July 2020 and she kept us updated on important governance issues throughout her directorship.

She attested to making our members remain uppermost in our decision-making, whilst making changes that protected the organisation into the



future. She was part of the sub-committee in developing our strategic plan for NSW Stoma.

Andrea was also involved in and worked tirelessly with our General Manager in putting together our Risk Management and Covid-19 Plan at NSW Stoma.

Andrea resigned because of personal reasons and we will miss her enthusiasm and eye for detail. She has had such a positive input on the board of directors and was a critical friend at meetings.

Thank you once again Andrea from the whole board.

Carol Quast (Director)



World Ostomy Day

Saturday 2nd October 2021 by Zoom Webinar

During one of our NSW Stoma Board meetings, a possible World Ostomy Day event was discussed and the board decided we needed to commemorate this event here in Australia and raise awareness and educate ostomates, their carers and families. We felt strongly that this should be an Australia wide event, free and open to all members around Australia. We wanted to acknowledge that we are part of a wider community and the need to support each other is important.

We put together a sub-committee and then called out to all Ostomy Associations in Australia to join and help organise an event to celebrate and support ostomates Australia Wide.

Our organising committee had representatives from each state and I want to thank them all for their support and contribution, especially Mary Egan, Renee Constantin (NSW Stoma) and Stephen Lardner (ONL) who organised so much more behind the scenes.

What eventuated was a free, fun and informative webinar. Convatec, Coloplast, Hollister, Dansac and Omnigon sponsored the event which allowed us to make this special event happen. We wish to thank each of these companies who made the day so successful in reaching out to our wider community.

We had 418 registrations for the day and 251 active participants (not including the presenters). What a wonderful turn out!

We engaged Luke Escombe, musician, singer, songwriter, entertainer, comedian and Ambassador for Crohns and Colitis Australia as our MC for the webinar. His comments, songs and entertainment on the day struck a wonderful balance of wit, comedy and ethos.

Our program:

Dr Allen Nash, president of ACSA gave a short opening address and shared results from the ACSA Members Survey at the end.



We were delighted to have four experts in their fields address subjects that are always important and close to the heart of many ostomates.

Thank you to: -

- ♥ Ann Marie Lyons, Clinical Nurse Specialist, Stomal Therapy Nurse "The A-Z of Living with a Stoma"
- ♥ Margaret Allan – Nutritionist, from Nutrition for Ostomates "Hydration: The benefits for ALL ostomates"
- ♥ Dr Vicki Patton – Stomal Therapy Nurse "Why I should see a Stoma Nurse"
- ♥ Anna Minchin – Exercise Physiologist – from Balanced Bodies Lifestyle Clinic "Exercising with a Stoma"

At the end we gave away ten \$100 visa lucky door prizes to participants and those have already been posted off to the lucky winners.

A few comments from the zoom chat and emails:

- ♥ *Happy world ostomy day everyone. It's our day to shine!*
- ♥ *Thanks to the organisers for the informative webinar*
- ♥ *Hey hey hey, good job Luke*
- ♥ *So good! Congratulations everyone! Fabulous day!!*
- ♥ *Great presentation learnt lots, you're fantastic Luke*

- ♥ *Support is amazing.*
- ♥ *Thanks for such a good webinar. Its so lovely to hear from people with lived experience. I'm studying a master of public health so its exciting to see survey data*
- ♥ *I did indeed enjoy the webinar. There was lots advice even persuasion regarding drinking lots of water and what you can still do with a Stoma. I particularly liked the presentation of the ECU research by Vicki Paton from which I learnt a lot about what other people use to keep their bag in place etc. Also, the comedian Luke gave an entertaining but balanced presentation.*
- ♥ *Thank you for organising a great program. Hello from Australian Association of Stomal Therapy Nurses Executive.*

What a success!!! The webinar exceeded our expectations and the feedback was so positive, thank you all for attending.

You can watch a video of the whole event by going to our website (nswstoma.org.au) and clicking on the link on the home page. I hope you enjoy it as much we enjoyed bringing it to you.

Keep safe,

Carol Quast

Chairperson, Committee,
World Ostomy Day

THE FINEST COMPLIMENT – by Gayle Dean



Some years ago, I trained as an ambassador / speaker for the National Breast Cancer Foundation. My bio at the time said :

“My name is Gayle. I am a wife, mother, stepmother, mother-in-law, and grandmother. By profession, I am a teacher. My life is full and interesting – I am never bored. I am a multiple cancer survivor – every day I live is a gift. I'm not afraid of cancer – to me, it is simply an enemy to be beaten”.

All of the above still rings true today. But since 2016, there's something important to add :

“I am an ostomate – I have a colostomy bag for life”.

My first cancer diagnosis was in 1991. I was 38, a single mother raising 3 young children. After a mastectomy and 6 months of heavy chemotherapy, I was

declared to be clear and well. But in 1996, during a routine checkup, cancer was found in my remaining breast. Thus followed another mastectomy. Then in 1999, a diagnosis of uterine cancer required that I have an immediate radical hysterectomy.

When I think back to those traumatic 1990's, I am honestly in awe of the courage and resilience of my children, the sensitive support of my parents, and the relentless commitment that my church friends had to praying. Most of all, I am thankful to God – without my Christian faith, I could never have stayed strong.

16 years went by – I married my wonderful Peter, gained 2 lovely stepchildren, saw my 3 children make happy marriages, and had 10 gorgeous grandchildren added to the family. Then in 2015 came the unthinkable news... a routine examination showed that I had a tennis-ball-sized pelvic tumour, a rare and inoperable cancer poised to wreak havoc.



I endured 9 weeks of concurrent radiotherapy and chemotherapy, which killed the cancer (thank God!) but left me with irreversible rectal damage. My stoma operation happened in March 2016, after many months of struggle – when I was wheeled out of the operation, my Peter said I smiled at him for the first time in 6 months! This amazing man had never stopped believing that I would get well.

Today I live normally, I am well most of the time, and my stoma fits into my lifestyle. I can't say it's a friend, but it has freed me from pain, and I manage it with confidence. My husband says that he often forgets I have a colostomy bag – for me, there could be no better compliment!



DONATIONS

A huge thank you to all our members and supporters for your generosity. In May we sent out the call for your support and your response was amazing. We received \$74,019 in donations in May & June alone. Some of you choose to remain anonymous but your generosity and philanthropy are noted. Your support for your fellow ostomates has made a huge difference to the support we are able to offer those less fortunate. The pandemic has seen an increase in those of you needing our financial support.

We know how vital it is that all our members have access to an experienced Stomal Therapy Nurse and we recognise the growing need for services across NSW. We are now able to offer a scholarship to nurses wanting to complete their Stomal Therapy training. It costs approx. \$12,000 (of their own funds) for a qualified nurse

to complete the additional training required. Their services are essential to us as an association and to all our members individually. In order to encourage as many nurses as possible to undertake the required training we want to alleviate some of their financial burden by offering a scholarship. I would particularly like to thank the Penn Foundation whose generous donation of \$10,000 has made this possible.

Your donations have continued in the current year with many of you adding a donation to your order each month. 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.

Donations to NSW Stoma Ltd are tax deductible.

The names of those of you who have given us permission are listed below in alphabetical order by surname and include donors from 1st May to 31st Oct 2021:

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THE NATIONAL PUBLIC TOILET MAP

A Project of the National Continence Program (NCP)

www.toiletmapp.gov.au

© Commonwealth of Australia 2001 - 2013

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

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

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



WHAT DOES THE TOILET MAP DO?

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

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

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



HOW DO I USE THE TOILET MAP?

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

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

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

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

The National Public Toilet Map is also available on:-

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

MASTER LOCKSMITHS' ASSOCIATION KEY (MLAK)

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

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

MLAK FACILITIES

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



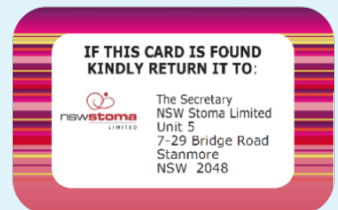
NEED TO USE A WHEELCHAIR ACCESSIBLE TOILET?

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

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

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

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



VOLUNTEERS WANTED

Ever thought of volunteering?

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

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

Whatever your skills, full training is provided.

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

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

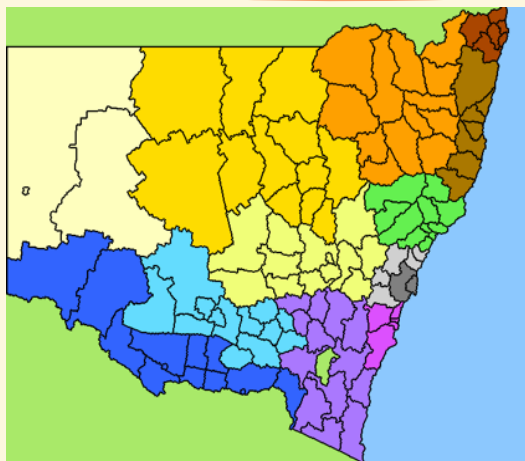
To apply download our application form here:

<https://www.nswstoma.org.au/volunteers/>

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

*Eugene Tomczyk, our
Friday volunteer.
Eugene assists with our
pick up service and
sits on our board
as a director.
Thank you!*





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

If you are involved in a support group and would like us to include information about your meetings in this listing, please email your details to:

info@nswstoma.org.au

Due to Covid-19 Restrictions, many meetings are currently cancelled.

Contact your group for more information.

NSW STOMA LTD NEW MEMBER SUPPORT GROUP MEETING

Whether you are a new member or have been with us for some time you are welcome to join our monthly Zoom meeting at **6pm on the first Wednesday of every month**. Hosted by *Anne Marie Lyons* and **NSW Stoma Ltd** manager, *Mary Egan*, this is designed to give information about the services

we offer at NSW Stoma and give some explanation about the Stoma Entitlement Scheme and how to place orders. If you would like to attend please email:

customer.service@nswstoma.org.au

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

WOMEN'S OSTOMY SUPPORT GROUP

This group is 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: to be advised

Contacts: San Cancer Support Centre(02) 9487 9061

support@sah.org.au

OSTOMINGLE - YOUNG OSTOMATES SUPPORTING EACH OTHER

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

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

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

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



NSW OSTOMY SUPPORT GROUPS

SYDNEY METROPOLITAN AREA

BANKSTOWN AREA

The Stoma Therapy Nurses from Bankstown Hospital would like to invite you to attend a stoma support group for ostomates and their families.

Where: Revesby Workers Club Functions Room, 2B Brett Street, Revesby

When: 10am-12noon, 2022 dates to be advised

Contact: Clare Jacobs on 0400 921 901 or aucldo@coloplast.com
RSVP for catering

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: Heritage Auditorium, Campden Hospital, Menangle Hospital, Camden

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

Contact: Diane, Erin Wagner or Lu Wang (STNs) (02) 8738 4308

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.

Contacts: San Cancer Support Centre on (02) 9487 9061

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PENRITH AREA

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

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

When: 2pm. 2022 dates to be advised

Contact: Naomi Houston (Stomal Therapist) on (02) 4734 1245

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, (02)9504 8000

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

Contact: Your Stomal Therapy nurse for details

NORTH COAST REGION

TWEED DISTRICT

Where: South Tweed Sports Club starting

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

Contact: Lisa Clare STN 0755 067 540;
Alex Gibson 0412 302 358;
Kate Rycraft 0432 251 703

GRAFTON AND DISTRICT

Where and when: contact Grafton Community Nursing Centre for information

Contact: Stoma nurse (02) 6641 8200

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

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: 2.15pm-3.45pm 9th Dec 2021 (COVID restrictions pending – please confirm before attending)

Contact: Mandy Hawkins STN:
(02) 6656 7804

Mandy.Hawkins@health.nsw.gov.au

HASTINGS MACLEAY

Where: Room 4, Port Macquarie Public Health Campus, Morton St, Port Macquarie (Old Hospital)

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

Contact: Neil 0427 856 630 or
Glennie 0410 637 060

MANNING / GREAT LAKES

Where: Skills for Life Building, 5-9 Elizabeth Avenue, Taree (wheelchair accessible)

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

Contact: Karla MacTaggart
(02) 6592 9469

NEWCASTLE / CENTRAL COAST REGION

NEWCASTLE DISTRICT

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

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

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

Contact: Geoff Robinson 02 4981 1799 or
Maree Dives 02 4971 4351

CENTRAL COAST

Get-togethers include an information session and company representatives presenting products.

Different venue each meeting.

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

Contact: Stomal Therapy Sessions
(02) 4320 3323

ILLAWARRA / SOUTH COAST REGION

BOWRAL

Where: Bowral Bowling Club,
40 Shepherd Street, Bowral

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

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

EUROBODALLA

All from the NSW South Coast region are welcome.

Phone clinics only during Covid-19 times.



NSW OSTOMY SUPPORT GROUPS

Where: Moruya Hospital, River Street, Moruya

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

Contact: Trena O'Shea (02) 4474 2666

ILLAWARRA

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

When: 10am-12pm, Wednesdays. Check with the group organisers for advice on scheduled meetings. 15th Dec (Xmas luncheon. Venue to be advised).

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

Office: (02) 4255 1594

julia.kittscha@health.nsw.gov.au

SHOALHAVEN

Where: Nowra Showground Pavilion, West St, Nowra

Also: Ulladulla Civic Centre, 81B Princes Highway, Ulladulla

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

Nowra: 2022 dates to be advised

Ulladulla: 2022 dates to be advised

Clinic – Ulladulla Community Health Centre, cnr South St & Princes Hwy, Ulladulla.

2022 dates to be advised

Contact: Brenda Christiansen (02) 4424 6321 or 0422 006 550 or

Brenda.christiansen@health.nsw.gov.au

WESTERN NSW REGION

BATHURST

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

Virtual meeting

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

Contact: Thulisile Moyo on 0408 769 873 or **Thulisile.Moyo@health.nsw.gov.au**

BROKEN HILL

Where: Broken Hill Hospital, Conference Room, 176 Thomas Street, Broken Hill

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

Contact: Tamdra (08) 8080 1333

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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Feeling Comfortable In Your Own Skin



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nswstoma

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