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Monthly Issue:

3 Boxes

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HOURS OF BUSINESS

Because of the reduced incidence of community transmission of COVID-19 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	Andrea Cross
TREASURER	Ken Batten
OTHER DIRECTORS	Carol Quast Andrea Cross Ian Murray Eugene Tomczyk Renee Constantin Kingsley Liu

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The reader is strongly advised to first obtain appropriate medical advice from an STN or GP before trialling any products advertised in this publication. No advertisement published in this Journal shall be taken to constitute an endorsement of products contained in that advertisement, either by the Editor, this organisation, or any government department connected with the Stoma Appliance Scheme.

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NOTICE BOARD

New website

www.nswstoma.org.au

We have launched a new website. Please take a look and let us know what you think. We are still working on an online ordering portal. Watch this space for more information.

Pick-up times

Please see our website for up-to-date information and times.

www.nswstoma.org.au

Onsite Stomal Therapy Clinic

Onsite Stomal Therapy Clinic is now open for business on the first 3 Thursdays of every month. Appointments are essential.

Email or text Anne Marie Lyons STN

Mob: 0468 582 951

Email: stomanurse@nswstoma.org.au

Products for Sale

Product	Code	pack size	Member Price
Rediwipes Silk Wipe	ARS3033	100	\$10.00
Micropore 1"	1530-1	1 roll	\$2.00
Micropore 2"	1530-2	1 roll	\$3.50
Metal Nightstand	NIGHTSTAND	each	\$45.00
Simple Nightstand Plastic	380431	each	\$13.45
Hollister Leg Bag	9632	each	\$7.80
Urostomy Drain Tube Adaptor	7331	10	\$30.15
Odour Be Gone Hos-Togel	3300	each	\$33.79
Hos-Toma No Smells 500ml	10500	each	\$15.84
Odour Be Gone Hos-Toma No Smells 120ml	10120	each	\$8.00
Ostomy Scissors (curved)	9505	each	\$7.50

A MESSAGE FROM THE CHAIRPERSON



I have recently taken over the Chairperson position on the NSW Stoma Board after the last Annual General Meeting.

I would firstly, like to thank Carol Quast the previous Chairperson for her dedication to *NSW Stoma* members she demonstrated while in the Chairperson role. She is continuing as a member of the board and will be focussing on member communications.

We have continued in 2021 to have to deal with changing Covid restrictions and border closures coming and going. This has affected delivery of supplies both from suppliers and to our members. Our dedicated staff have managed to keep the timely flow of supplies to members despite these conditions.

We have also taken advantage of the technology available to keep providing services to members including our Stomal Therapy Nurse Anne Marie who is now providing consultations online (see our website for details). Other initiatives are to use Zoom to provide new members meetings to support and provide information to new ostomates at that difficult time soon after they have their stomas.

The NSW Stoma board has determined that these on-line services will be ongoing, as they not only allow us to continue to provide services to members during the Covid crisis, but allow members in more distant locations in the state to have access to our member services.

We are still hoping to restart our regional information days later this year as this face-to-face event is still very useful to members as well. It allows members to meet other ostomates, talk to Stomal Therapy Nurses and inspect products that the suppliers bring to the sessions as well as hear useful talks that are very relevant to their situation, living with a stoma.

One of our board members has left the board as she had to move interstate. Sallyanne Lerota made a significant contribution to the board while she was a member bringing much expertise particularly in risk management. We wish her well and really appreciated her participation while she was on the board.

Volunteers assist us in improving our services to members within the limited funding under which we operate. We are still looking for volunteers and if you have some time to assist please contact our General Manager.

We have had the Department of Health spring on us a significant change in the way we claim our refunds from Medicare for providing ostomy products to our members.

This change came to us on short notice and required much effort of our staff to make the changes required



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Adapts
to form a mirror
image of the
peristomal
contours



Contact us today to try a FREE sample from our Aurum Convex with Manuka honey range!

A MESSAGE FROM THE CHAIRPERSON (*continued*)

while carrying on ensuring no disruption to members orders. The system changes were completed on time but there is ongoing work resulting from the changes such as getting up to date Medicare numbers from all our members.

There has been no news from the Department of Health on the tender process they started with an *Expression of Interest* to run the Stoma Appliance Scheme which is what *NSW Stoma* does as a not-for-profit association, run by ostomates. It has created much concern as to what will happen to this vital scheme for ostomates. We have been cooperating with the peak body for stoma associations, the Australian Council of Stoma Associations (ACSA) which has been coordinating actions to provide a more efficient and cooperative

approach between stoma associations aiming to provide an improved service to members overall and to strengthen the system we have i.e. a not-for-profit service run by ostomates.

Thank you for your patience, as members, while we cope with significant system changes, Covid and other disasters and thank you to all our staff who have managed this change with a high level of efficiency.

We have a great team of staff and a committed board that I look forward to working with over the coming year as we hopefully emerge slowly from the Covid and other crises we are now leaving behind us.

Keep well.

Dr Allen Nash

Chairperson of NSW Stoma Ltd



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.

A message from the General Manager

As I write this, dancing and singing are now allowed in NSW! While the vaccine roll out is slow, I am buoyed by the lack of community transmission of the virus and look forward to the rest of 2021 with a reasonable amount of optimism. To all of you who have suffered in the floods, I wish you a speedy clean up and recovery.

Because of the lack of community transmission, we are gradually opening up our doors. For those of you picking up your orders we will advise pick up times via SMS when we let you know your order is ready.

We have re-opened the on-site clinic on the 1st 3 Thursdays of the month. Anne Marie Lyons, our fabulous Stomal therapy Nurse (STN), is available from 11am to 1pm on those days. (Appointments are essential). For those of you who can't make it to Stanmore, Anne Marie will continue to offer advice via phone and email. This service remains free to all our members.

Thank you to all who filled in our survey last November. You can read the full report on our website. As a direct result of that survey we have made a number of changes. I wanted to highlight one of those. We have begun a zoom meeting for all members once a month. This is particularly aimed at new members but all are welcome and many find it useful even if they have been with us for many years. Hosted by myself and Anne Marie Lyons, our STN, we give an overview of the role of NSW Stoma, a brief explanation of the Stoma Appliance Scheme and why seeing your stomal therapy nurse is essential! If you would like us to cover other topics please email customer.service@nswstoma.org.au

We have launched a new website and added lots of new resources, including an up-to-date list of Stomal Therapists in

NSW and much more. We also have a list of Ostomy support groups in NSW and if you're involved in one and would like us to publish information about your group, please contact us. We are keen to get your feedback too so please use the contact page to let us know what you think and add any other suggestions that will help you manage your stoma.

Our survey showed that many of you want an online ordering platform to place your orders. This is definitely in the pipeline so keep an eye on our website and we will get it up and running as soon as we can.

We are looking at resuming our regional education days this year so please keep an eye on the website for updates. I know how important these days are to all of you. It's a great opportunity to meet other ostomates, gain valuable information from the STNs and other guest speakers. All the suppliers display their products and are there to answer all your questions too.

We are looking for volunteers in a variety of roles, from packing boxes, reception duties, data entry and more. If you have time, can get to our Stanmore premises and would like to help, we would love to see you. Volunteering can be such a rewarding thing to do and full training is provided. See our website for details and how to apply.

A big thank you to all our volunteers, with particular thanks to Eugene Tomczyk who has manned our front door and pickups nearly every Friday this year and ostomate Paula Garrod, retired graphic artist, who so generously volunteers her time to put this magazine together for us. I also thank our volunteer board of directors who give so much of their time.

Mary Egan
General Manager, NSW Stoma Ltd

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Eliminate bad odours

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neutralises mal-odours, doesn't just mask them.

HOS-TOMA NO SMELLS

neutralises mal-odours from urine, faeces, vomit and toilet smells

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is for hospital, medical, ostomy, continence and use in the home

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1Litre # 11000

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500g # 3300



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



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ODOUR PROBLEMS? Problems with GAS or Pancaking?

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

Product Code: # 1 203

HOS-TOMA NO GAS

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

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

Product Code: # 1103

HOS-TOMA NO SMELLS

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

Product Code: # 1001



WIN

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HOS-TOMA No Gas #1103,

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Your opinion is important to us. It is the customers who use the products that help us in the development of current and new products for Ostomates.

Send your comments on the "Customer Feedback Form" included with the products, or email them to: health@futenv.com.au

Entries close 31st July 2021

Failte Mo Chairde (Hello my friends)



I am back in the clinic now since the 25/3 so I'm looking forward to catching up with you and helping you whatever way I can.

Please ring or email me or call the office for an appointment, also remember if you are popping in to pick up supplies and did not make an appointment please wait and ask to see me and we will take it from there.

We also started a Zoom meeting for new members and long standing ones if they wish, it is a touch base and guide you through the ins and outs of the association and how it all works, and who to go to if you have concerns regarding your stoma.

It is the first Wednesday of each month, details are in the journal, so feel free to join in.

We decided on an evening meeting as we are aware many of our members work and evenings would suit better.

Today I thought a short article on swimming and exercise with a stoma would be of benefit to most, its general, but I do hope none the less helpful.



Hope this journal finds you all well and looking forward to a covid safe time ahead.

Well 2020 was a very trying year for most but for me it was one of the happiest!

Greg and I finally got married after 19 years together! Connor our son was best man!

It was one of the best days of our lives. Highly recommend it.

Let's celebrate National Stomal Therapy Awareness Week – 14th to 20th June 2021



Stomal Therapy Nurses

Stoma • Wound • Continence



Helping Solve the Stoma Puzzle

Specialising in the management of patients with faecal and urinary diversions, Stomal Therapy Nurses can help you with all aspects of stoma management.

To find your local Stomal Therapy Nurse visit

www.stomalththerapy.com

An initiative of the Australian Association of Stomal Therapy Nurses. Poster proudly sponsored by Liberty Medical, distributors of Dansac and Hollister products.

A nationally-designated week in June which acknowledges and supports persons living with a stoma in our community and recognizes the health professionals and other support organisations involved in their care.

For more information go to https://stomalththerapy.com/awareness_week.php

Swimming and exercise with a stoma



Swimming and exercise with a stoma

Once you feel confident about your stoma in private, you can show this confidence in public.

You do not need a special stoma bag to go swimming, though some ostomates like to wear a smaller bag or a stoma cap whilst they are in the water.

Some find a secluded beach away from everyone and go pouchless!

Here are some helpful tips:

- For Colostomy and ileostomy pouches – cover the filter with the little stickers you find with your pouches (although most filters are waterproof now).
- Empty your pouch before you swim.
- Change your pouch if needed (1/2 hour prior)

- For our ladies - wear firm fitting 1 piece costume a patterned print can disguise your pouch (and many other things!!!)
- For the gentlemen wear high waisted board shorts, an abdominal support band or a rashie.
- For others ... they are just not fussed and sport their pouch for all to see, it's your choice.

Getting fit after stoma surgery

Getting fit and being more active actually is the key to a faster recovery and a better quality of life in the long run.

With time, there is every chance that you can expect to return to your pre surgery fitness and beyond.

The physical benefits of exercise are important for everyone, but for someone

with a stoma, maintaining a healthy weight and keeping your muscles strong are important for helping prevent parastomal hernias from developing.

- If you're new to exercise altogether it can be harder to get motivated, so build up slowly and seek advice from a fitness trainer or physiotherapist.
- Walking is the ideal choice for everyone it can be as gentle or as brisk as you wish.
- After your surgery, walking will get your system moving and help you recover quicker.
- Take things step by step to begin with and build up slowly, perhaps aiming to go a little further each day or every couple of days.

- When you're fully recovered, walking longer distances and more briskly is a great way to stay fit.

Remember exercise to have fun and stay healthy not just to lose weight.

Web sites to browse and find all the information you need regarding your stoma

<https://www.coloplast.com.au>

<https://www.dansac.com.au>

<https://www.convatec.com.au>

<https://www.salts.co.uk>

<https://www.hollister.com>

<https://www.omnigon.com.au>

*Slan agus beannacht
(bye and blessings)*

Anne Marie

Anne Marie Lyons STN

Information is out there just ask.

The image displays three brochures against a dark grey background. The top brochure is red and white, titled 'Sports and fitness with a stoma' from the 'Lifestyle series' by Hollister. The middle brochure is white and orange, titled 'Getting fit after stoma surgery' by Dansac, featuring a person sitting on an orange exercise ball. The right brochure is green and white, titled 'Keeping on the move' by SALTS, featuring a wooden post with a stoma icon in a field.

Meet the Members of Ostomingle



Ostomingle, a support group for young ostomates in Sydney, has seen ostomates from all walks of life and aged from 18 to their 40s come together with one mammoth shared experience. One of our members, talented Marketing Coordinator Eliza Palo recently spoke candidly about her life as an ostomate.

1. Tell us about how you came to have a stoma

In November 2019, when I was 23 years old, I suffered severe stomach pains at work. At the time I didn't think anything of it because I rarely get sick. I'm the type of person to brush off and push through my pain, but this was very different. Later that day I went to emergency, I waited for hours where the nurses gave me morphine to help with the pain until I was finally admitted.

While I don't remember much from that night I do remember being surrounded by close friends and family. The next day I woke up in the ICU with many cords, a breathing tube down my throat, not being able to speak or move. It was very

traumatic physically and mentally to process what had just happened.

I went from having severe abdominal pain to waking up in ICU with the end of my small intestine sticking out from my stomach. Many ostomates are able to plan and prepare for their surgeries, but because of the severity of my situation, I couldn't even consent to having an ileostomy. In the span of two days, I had two major operations. The doctors found that I had an Ischaemic bowel which meant the blood flow to my intestines was decreasing, as a result, a blood clot or Deep Vein Thrombosis (DVT) spread to my large bowel.

Recovery was very difficult. I was hospitalised for over one month trying to recover from the two major surgeries. Many setbacks came my way, the doctors found a partial bowel obstruction from the adhesions (scar ring) internally. Which resulted in another surgery to remove the obstruction. At this point I wanted to give up. I was depressed, physically and mentally drained. I was preparing myself to die if I didn't make it through. But thankfully after the third surgery the recovery was uphill. After further investigations from the doctors they came to a diagnosis the blood clotting was hereditary from my mother.

2. What would you say has changed the most between your life before and now living with a stoma?

What has changed the most now living with my stoma is my appreciation and perspective of life in general. Prior to my stoma I really took my health for granted, I was the type of person to brush things off especially when it came to my health

and wellbeing. I felt invincible and ignorant to the fact that nothing bad could happen to me. I've learnt to listen to my body and take care of it. Without your health you can't do anything. Health is wealth!

The good thing about having a stoma is the convenience of shitting in a bag, which is honestly so much easier! It's taught me to eat much slower and chew my food properly. The bad thing about having a stoma if I'm being completely honest is the itchiness around the stoma bag, my skin gets super irritated sometimes. Farting through my stomach was very weird to begin with, when I get gassy my bag turns into a balloon and sometimes even results in my bag leaking with shit everywhere.



3. As a young woman, how has having a stoma impacted you mentally and the relationship you have with yourself and with others?

Having a stoma has significantly impacted me mentally especially during the early stages of acceptance. Emergency surgery was such a traumatic experience for me, everything changed instantly. I couldn't mentally prepare myself for my ileostomy, neither did I know what it was. I was heavily depressed for the first couple weeks, I was ready to give up and honestly it put me in such a dark space mentally.

As a young woman, body image post surgery was difficult to even look in the mirror. I had so many battle scars on my stomach, arms and legs. I despised how my body looked, and resented my stoma because of how it made me look and feel.



Meet the Members of Ostomingle (continued)

Over time my mental well being with myself and my relationships has improved. My boyfriend has supported me from the beginning and is so accepting, understanding, patient and kind towards my stoma journey. Especially those days where I felt unattractive, ugly and weak, he really has accepted my condition and loves me even more for it.

As for my other relationships, joining ostomingle has aided my mental health in so many ways. Talking to people who share and relate to the same experiences is very comforting especially when you think you're alone, you're not.

4. Have you ever felt judged or self-conscious about your stoma? Do you have any advice for new and old ostomates struggling with the same feelings?

Definitely! First experience I recall feeling judged was my first trip to the beach post surgery. Building up my confidence

to rock a bikini with my ileostomy bag out for everyone to see was nerve racking. What I've found is that people will look once and that's it. Especially in the beginning stages of my ileostomy journey I did not feel comfortable in my own skin. The scarring, bruises, and stoma from my 3 surgeries changed my body significantly. I was ashamed and really hated my stoma to begin with. Over time I learnt to love my body and stoma because it saved my life. If you're struggling with self confidence, it helps to reach out to people that have shared the same experiences, it puts your mind at ease.

Remember what you're feeling is normal and okay. You are not alone - don't suffer in silence, talk to people and reach out. Daily affirmations are important to build your confidence. I am worthy and beautiful, I believe in me.

5. Could you share your best and worst memories or experiences with a stoma?

My best memory would probably be doing outdoor activities such as swimming, skiing, and hiking for the first time post surgery. I had doubts that having a stoma would restrict me from doing certain activities or eating foods, but it hasn't stopped me from living my best healthy life. The best experience would have to be sharing my story online that has connected me to ostomates online around the world and through Ostomingle group here in Sydney.

Worst experience would have to be the first time my bag leaked. I woke up to the smell of shit all over my bed. It was a real shitty situation.



6. Do you have any "next steps" regarding your stoma? why/ why not?

Yes, the next step for me is the j pouch surgery which will connect my small intestine to my rectum so I will be able to go to the toilet the "normal" way. My doctor recommended I have the J Pouch surgery. I've spoken to many ostomates with similar experiences, i've heard many positive stories. Currently still on a waiting list to have my surgery sometime this year. I love my stoma and the experiences and lessons it's taught me. Although I'm really scared for the next chapter, i'm mentally and physically prepared for what's next.

7. What is the most valuable tip, hack or piece of advice that you've learnt/ were taught about living with a stoma that you can share with everyone?

My advice is to give yourself time to feel comfortable with your stoma. You are in charge of your own feelings, and you know your body better than anyone else. My stoma nurse said it's good to name your stoma and form a bond with it. I call mine Sheila the Stoma. What you're feeling and struggling at first is normal, I truly believe time heals everything. Give yourself time to gain that confidence back, educate yourself, speak to fellow ostomates and find comfort talking to people who understand you and have been through the same experience. Find products that work for you. Take advantage of free sample products online, I did through coloplast. It takes time to love yourself, but once you do embrace and own it! You are beautiful, sexy, and worthy!

Next Ostomingle event will be on Saturday June 5 2021



ostomingle

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, ask questions and learn from one another.

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

FOR FURTHER INFORMATION:
www.ostomingle.com | ostomingle@gmail.com

Farewell and Thank you Sallyanne Lerota

Retiring Director June 2019-December 2020

The Board of Directors of NSW Stoma Ltd would like to thank recently retired director Sallyanne Lerota for her service and contribution to the organisation, particularly in 2020 during the pandemic.

Prior to retirement from work Sallyanne was generally engaged by the financial industry. Her roles in the last 10 years of work were concentrated on partnering with business stakeholders, implementing and maintaining governance frameworks for their boards and executive groups she reported to. This included presenting governance reporting to government organisations such as APRA (Australian Prudential Regulation Authority).

The sorts of organisations she worked for included the Commonwealth Bank, GE Capital, Standard & Poors, ANZ Bank, Shell Australia, KPMG and many more.

Upon being elected to the board, Sallyanne took on the role of Secretary for the following six months. It was a quick introduction to how the board worked, and she worked hard on getting the governance structures up to scratch.

During 2020 Sallyanne was able to draw on her past working experience to help NSW Stoma design and manage risk plans associated with the Covid-19 pandemic, and any other disaster. The organisation successfully implemented the Disaster Plan and Business Plan under Sallyanne's guidance, allowing us to continue to operate during the worst of the Covid-19. Her knowledge and expertise was incredibly useful to



the board at such a time of global crisis, and helped us keep on top of all the logistical issues in delivering appliances to members.

Whilst on the board, Sallyanne also designed a skills matrix to guide the board in working out where the gaps were at board level. Subsequently this enabled the board to recruit two new directors last year, Renee Constantin and Kingsley Liu, with communication and legal expertise.

Sallyanne was also a member of the IT Committee, working closely with other directors.

Originally from Victoria, Sallyanne has moved back there with her husband and beloved dog for work and family reasons.

We shall miss Sallyanne's acute interrogation of each agenda item and her quick wit, willing contribution and wish her all the best in Melbourne.

Andrea Cross
Secretary
NSW Stoma

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*Coloplast, Review, Global Ostomy Life Study, 2020

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 **Coloplast**

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confidence to do
the things you love



Introducing

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ALL BODIES ARE DIFFERENT. Esteem[®]+ Soft Convex combines flexibility with a shallow convexity, and is designed to conform well to the body and be comfortable to wear.

Flexible Convexity: conforms to the body and helps improve the pouch seal by minimising leaks

Easy-View Window: for accurate positioning and observation

Filter: designed to help minimise odours and ballooning

Safe Seal Clipless Closure: designed to make emptying and cleaning easy*

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Tips for taking better care of peristomal skin



Do

- Change your pouch routinely.
- Gently remove the base plate from top to bottom – people find an adhesive remover helps.
- Clean the skin around the stoma with a wipe soaked in warm water.
- Dry your skin thoroughly before applying your next pouch.
- Inspect your skin every time you change your base plate.
- Apply a skin barrier spray/wipe if required.
- Check the hole cut in your base plate is the right size for your stoma.
- Apply the base plate securely around your stoma ensuring there are no gaps or folds in the base plate.



Don't

- Use soap or other solutions to wash skin.
- Over complicate your pouch changing routine.
- Wait for your pouch to leak before changing it.
- Pull your pouch off too quickly.
- Ignore any changes in the skin around your stoma.

Are you experiencing peristomal skin problems now?

Don't try to manage skin problems on your own. Seek help from your Stomal Therapy Nurse or contact ConvaTec Customer Care on **1800 335 276** or email connection.au@convatec.com

THE RIGHT ACCESSORIES CAN MAKE ALL THE DIFFERENCE

Whether you are looking for better skin protection or added security to your ostomy system, you can feel more comfortable with the right combination of accessories.



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Always read the instructions for use and follow the directions for use.

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Ben Selinger- A patient perspective – 45 years an Ostomate



In October 1976 I was given the contact details a jolly English woman living close to Oxford UK for a chat and the opportunity to ask a few questions. Why?

"My ileostomy arrived during the war; my bag was fashioned from a metal biscuit tin with some glue provided for attachment". It seems that you, like me, will be fitted with the current rubber reusable bags and scientist developed double-sided adhesive pads...luxury!"

I had no idea about ileostomy bags, their history and more importantly, their application.

Going back eleven years (1965), in my mid-twenties, I was diagnosed with ulcerative colitis. You will know the signs. A bit of diarrhoea, a trace of blood in the faeces, (hopefully just haemorrhoids), but after a colonoscopy...little doubt.

And of course the bloody diarrhoea gets worse with time. And eventually becomes semi-continuous. You soon know every public lavatory in town and nervously plan trips with that in sight. Today there is a government toilet detection app. Luxury.

From a Sydney Uni students' songbook....

*"If you're ever down in London,
and you have no place to go
And you cannot find a spot to
sit you down,*

*For a penny on deposit you can
hire a water closet*

*And a season ticket costs
but half-a-crown.*

*There's a gent's convenience at the
corner of Waterloo*

And a ladies' one a little further down,

*If you've an aching in your heart
we get a penny for a fart
We own every public lavat'ry in town."*

So "Clancy of the overflow" and I became attached at the Radcliffe Infirmary in Oxford UK and a "lead pipe" of a colon thrown out. Radcliffe is a very old hospital that is often used in a movie set that requires a 19C ambience.

Dated may be the décor, but dedicated were the staff. And clever. To get me out of bed post-op, they said they were short staffed and I needed to take around the trolley with the hot tea and Bonox™. When I said I was crook, the nurses needed a translation from the South African surgeon (bless him) who was used to Oz-lingo. "No, he won't steal your valuables".

The heavy rubber, (ex truck inner tube?) cleanable, reusable bag had a complex adhesion system. I recorded the instructions faithfully on a Sony Walkman (tape player/recorder) until confident (months later).

There was lots of advice.

- "Cheer up, better a semicolon than a full stop"
- "Care you don't lose the plug down the toot! We'll give you a few spares"



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Ben Selinger- A patient perspective – 45 years an Ostomate (continued)

- “No-one can smell the appliance like you think they can and anyway if you are still worried, get a perfume that can compete”.
- “As for the rumbles, learn to cough synchronously”.

Most importantly,

- “ You can live with the ileostomy, or it can live with you. Choose the latter and you will inevitably have an occasional accident (leaks, detachments) but your lifestyle and outlook will be far more positive.

“Never leave home without spares!!!!”.

Of course, getting an ileostomy was the expected long-term outcome for ulcerative colitis (and Crohns disease) and thus comes as a relief of symptoms. For an unexpected cancer diagnosis, it comes as a shock. Internal pouch options were not considered safe at this time.

Exploring the now wider food possibilities was a matter for experiment.

And that means occasional failures (blockages) are inevitable. These led to emergency hospital admissions that generally meant a generous injection of pethidine, (now banned because it is **so** nice), followed by an overnight stay. I had one or two in an ICU... in 45 years!

It is therefore very important to consider and balance with the added positives.

Swimming, surfing, tennis, City to Surf walk (running?...never was for me).

With electronic devices most us (oldies) stick with what has worked OK for us, instead of regularly exploring the more versatile newer products that may suit our changing body better. The secure feeling of our current appliances does lead to an understandable reticence for change.



But in this case, not a good idea.

Yes, the instinct is to 'let sleeping appliances lie' but the (free) stoma nurse's role is to explain the advantages, reduce the angst and monitor the transition.

Fast forward late October 2020. Got a sudden bout of very liquid diarrhoea but with no abdominal discomfort but severe aches and body pains. Unusual! Viral?

I tried to keep up the fluids. My stoma swelled and our fab stoma nurse Anne Marie L. reassured me that it would settle down when the fluid output did (it did). But the other symptoms got worse. My GP then picked up an atrial (heart) flutter. Never ever had a heart issue.

Bundled into an ambulance with sirens screeching through Bondi Junction to St Vincents Hospital. A 100 joule electric zap reset the heart.

It was fortunate that the electrolyte stress from severe dehydration exposed a problem in a symptomless heart.

What a wonderful ambulance and public hospital system we have, along with dedicated amazing staff.

I re-read the article “Hydration is so important to ostomates”, Ostomy Australia, Dec 2009 p 30. So when the hot weather returns...remember this lesson.

Ben Selinger

DONATIONS

Thank you to all our wonderful members who have given so generously throughout the year. As we approach the end of another financial year, I'm again asking you all to dig deep and give what you can to support us. We need your support.

As a registered charity our primary focus is to support our members by:

- raising the standard of care and wellbeing for all ostomates
- providing you with information, education, encouragement and emotional support through our website, journal and our regional and urban information & education days
- funding a free clinic for members with our Stoma Nurse on site (and by phone during Covid)
- representing you and advocating on your behalf to the government, both federal and state.

Also, from time to time a member may find themselves in dire financial circumstances, even homeless, and need extra support from us in the form of subsidised membership or other needs.

Despite rising costs and increased pressure on our sparse resources there is no increase to annual fees this year. I know many of you have had a particularly hard year with the pandemic and fires and floods,

as well as challenging personal circumstances. Instead, we ask those of you who can afford it, to consider a donation to NSW Stoma so that we can continue to offer our vital services and increase that support to the benefit of all our members.

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 would like 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. So, we need your donation.

Donations to NSW Stoma Ltd are tax deductible. Please consider adding an additional amount to your annual membership renewal. We would also like to acknowledge and thank our donors in our journal, so please tick the box if you are happy for us to do this as acknowledging you and your donation can encourage others to donate too.



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The names of those of you who have given us permission are listed below, in alphabetical order by surname:

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The NSW Stoma Clinic (free to members) is open from 11am to 1pm at half-hour intervals on the second and fourth Thursday of each month in the private room at our office in Unit 5, 7-29 Bridge Rd Stanmore. Our lift has wheelchair access. Members with an ostomy problem may phone to organise a free consultation.

Anne Marie is also available for phone and email consultations.

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NSW & ACT – DIRECTORY (continued)

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THE NATIONAL PUBLIC TOILET MAP

A Project of the National Continence Program (NCP)

www.toiletmapp.gov.au

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

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

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



WHAT DOES THE TOILET MAP DO?

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

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

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



HOW DO I USE THE TOILET MAP?

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

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

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

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

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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.

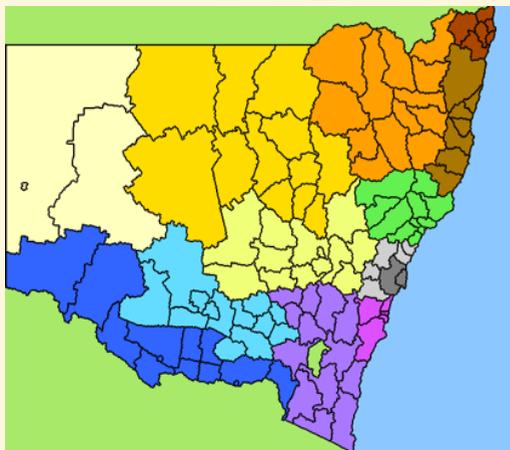
To apply download our application form here:

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

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

*Eugene Tomczyk who has been volunteering every Friday this year so that our members can collect their orders.
Thank you!*





OSTOMINGLE - YOUNG OSTOMATES SUPPORTING EACH OTHER

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

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

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

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

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: 10-12noon, 5th May, 7th July

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



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 journal please email your details to:

info@nswstoma.org.au

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
support@sah.org.au

NSW OSTOMY SUPPORT GROUPS

LIVERPOOL AND CAMPBELLTOWN AREA

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

When: 1.30-3pm Thursday- 17th June, 30th Sept, 2nd Dec

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

Afternoon tea provided - RSVP essential

NORTHERN SYDNEY AREA

All Ostomates, friends and supporters welcome.

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

When: Contact San Cancer Support Centre on (02) 9487 9061

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 26 Feb, 23rd April, 25 June, 3 sept, 26th Nov 2021

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

Naomi.Houston@health.nsw.gov.au

RAMSGATE

The Stomal Therapy Nurses from St George Public, St George Private, Kareena Private, Hurstville Private and Sutherland Hospital's together would

like to invite you to attend a stoma support group for ostomates and their families.

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

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

Contact: Your Stomal Therapy nurse for details. (02) 9504 8000

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.

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Where: Sawtell RSL Club, First Avenue, Sawtell

When: 2.15pm-3.45pm – 8th Apr, 10th Jun, 12th Aug, 9th Dec 2021 (COVID restrictions pending – please confirm before attending)

Contact: Mandy Hawkins STN: (02) 66567804

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 9169

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: to be advised

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.

Where: Moruya Hospital, River Street, Moruya

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

Contact: Trena OShea (02) 4474 2666

ILLAWARRA

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

When: 10am-12pm, Wednesday, 14th Apr, 9th Jun, 11th Aug, 13th Oct,



NSW OSTOMY SUPPORT GROUPS

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 0414 421 021

office: (02) 4255 1594

julia.kittscha@health.nsw.gov.au

SHOALHAVEN

Where: Nowra Community Health Centre,

5-7 Lawrence Avenue, Nowra

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

When: 24/02/21, 2pm. Nowra Showground Pavilion.

30/06/21, 2pm. Ulladulla Civic Centre.

25/08/21, 2pm. Nowra Showground Pavilion.

24/11/21, 2pm. Nowra Showground Pavilion.

08/12/21, 2pm. Ulladulla Civic Centre.

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

4th March, 1st Apr, 6th May, 3rd Jun, 1st Jul, 5th Aug, 2nd Sep, 7th Oct, 4th Nov, 2nd Dec 2021

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

Brenda.cristiansen@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

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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Stoma
Skin
Soul



Feeling comfortable
in your own skin

Lauren, Stoma Advocate



NovaLife TRE ostomy barriers are designed to help keep your skin naturally healthy

- Stay in place, yet easy to remove
- Help absorb stoma output and perspiration to protect your skin
- Help protect the skin from digestive enzymes by maintaining the right pH level of the skin



Flat • Soft Convex • Convex • 2 Piece

For more information about NovaLife TRE skin barriers and to order a free sample, please call Customer Care on **1800 880 851** or visit **www.dansac.com.au**

Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions.

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Sudocrem 30g tube
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An effective skin barrier for all skin types



babyU Nappy Bags 200pk



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Ocean Flushable Toilet Wipes 40's
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 Suitable for hands and body and Rinse Free