

# Ostomy

A U S T R A L I A

Volume 30  
Number 2  
August 2021

Print Post Approved  
PP 100008088  
ISSN 1329-959X



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**An open Letter to STN's  
from an ileostomy patient  
Are you having fun?  
My ostomy pregnancy**

# My ostomy pregnancy

By Kate Murray



Kate and Alex, and opposite a recent picture of Alex just before starting kindergarten preschool.

When I made the decision to undergo stoma surgery in 2010, after suffering through years of painful surgical procedures, I had no idea where it would lead me and how my life would change, but nine years on I am proud of how far I have come and what I have achieved.

Because of my decision I am happy and healthy, I am now a qualified RN helping others in the same situation and more recently have had the opportunity to share my story across several different settings including national conferences, education days and support groups. Perhaps my greatest achievement, however, was becoming a mum to my beautiful little boy, Alexander, something that may never have been possible without my stoma.

So, what is it really like being pregnant with an ostomy? The most important thing to remember is that having a stoma may not necessarily be a contraindication of pregnancy. I had done a lot of research into pregnancy

with an ostomy including a sit-down with my gynaecologist who after some routine testing advised I should be able to conceive naturally. With that said, both my husband and I were a bit shocked and surprised when we fell pregnant within a couple of months of trying.

My first trimester was relatively easy – I had no morning sickness, I was able to continue working normally and my energy levels remained unchanged, so much so that I was able to continue training at my local F45 studio gym. I was also barely showing, so it was easy to hide, but there were also no major changes to my stoma or the need to make any changes to my current appliances.

Unfortunately, my second trimester was not as straight forward. At 16 weeks, I suffered a complication – an intestinal obstruction likely caused by an expanding uterus and often associated with increased maternal and foetal mortality. I was gravely ill and needed

two life-saving surgeries to successfully treat an ischemic bowel. I left hospital two weeks later with a re-fashioned stoma and a 20cm wound right down the middle of my abdomen which needed daily dressing changes. I was incredibly lucky to have a very skilled medical team who fought so hard to keep both me and the baby alive and to this day, I am unable to explain how I survived such a life-threatening health crisis.

I spent much of my third trimester trying to comprehend what had happened to me and it would take several more months to regain my strength physically, mentally and emotionally. I was monitored and scanned weekly by my wonderful obstetrician and given strict orders to stop work and rest as much as I could to allow my body to heal itself. I also needed a lot of support mentally and once a week I would sit down with a psychologist who helped me process my feelings. Even though I am naturally petite, it took weeks for me to develop the typical 'pregnancy belly' mostly because of the trauma my body had been through. From that perspective, I was lucky because my stoma only expanded by a few millimetres, and as a result, I had no leaks and was able to continue using the same appliances by cutting the openings a little wider.

Whilst most women with an ostomy can have a normal birth and delivery, I opted for a scheduled caesarean section primarily for my safety and the safety of my child. My obstetrician was ecstatic when I made it beyond 28 weeks, then 32, 34 and finally 36 weeks gestation, convinced that at any time I would go into premature labour given all the complications I had endured. Luckily for us, I was able to deliver on my preferred date, two weeks prior to my due date at 37 weeks and five days. Against incredible odds, on 11 December 2017, we welcomed a healthy little boy, Alexander Benjamin Murray born at 9.37am and weighing in at 2.6kg.

It was such an incredible relief to be able to finally hold our little boy, the culmination of an epic journey that almost cost both of us our lives. The recovery from the c-section was

uneventful and my stoma reverted to its normal size when I returned to my pre-pregnancy weight just a few weeks after Alex's birth. Like any new mum, I still had to navigate through the sleepless nights and exhaustion, the rollercoaster of postpartum hormones and the difficulties of breastfeeding a baby that had trouble latching, but if you were to ask me today, I wouldn't change a thing.

Alexander will always be incredibly special, a gift to this world and a survivor. Today, he is a highly active, healthy and happy three-year-old. He has and continues to meet all of his milestones despite my fears that there may have been some developmental delays because of the heavy doses of anaesthetic drugs and narcotic pain killers that were pumped into my body during my pregnancy.

He is already discovering that I am a little bit different and often looks at his stomach wondering why it doesn't look the same as mine. I never hide my ileostomy from him and as he grows up,

he will learn to understand that his mummy is unique and that having a stoma has been life-changing, but not in any way life-limiting.

For any woman contemplating pregnancy with a stoma, I would recommend firstly seeking advice from a medical team including your stomal therapy nurse. Secondly, the power of social media is an undeniable force in today's society allowing us to connect with other ostomates around the world. What I found most useful was being able to connect with ostomy support groups through platforms such as Facebook where I was able to find other women to engage with for support.

Finally, pregnancy can be a daunting experience, but an incredibly rewarding one at the same time. Living with a stoma does not mean you can't enjoy a happy and healthy pregnancy and whilst my journey was a little more complicated, for me, having a child is the ultimate proof and reassurance of normality and is a reminder that anything is possible. ●



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## President's message



# Welcome

By Allen Nash

The most significant matter that occurred in the last quarter that affects all ostomates and Stoma Associations is the Federal Health Department Expression of Interest that was put out to canvas proposals for running the Stoma Appliance Scheme.

Currently the Scheme is run by voluntary organisations across the country that are managed by

ostomates. This structure has a huge advantage for ostomates as the distribution and related support is wholly focused on supporting ostomates and not in maximising profits. Having contact with all ostomates makes the ability to provide information and support possible. Our stoma associations also use donated funds and hundreds of volunteers to extend the support they can offer to ostomates and most importantly, they deal with ostomates with care and compassion.

Our system of distribution of products and support is one of the best in the world currently. As other countries, who predominately separate the stoma support associations from the distribution of products, are experiencing great difficulty in contacting all ostomates to provide support and information they need. This difficulty in communication means many ostomates miss out on vital information necessary to manage their stomas.

The Australian stoma associations have a track record of providing support and information to their member ostomates. The quality of the support provided has been evidenced by feedback surveys undertaken by many associations.

There is a real danger now if the Health Department proceeds to tender for the Stoma Appliance Scheme that it may be privatised. This will invariably

lead to the reduction of services and support to ostomates and a loss of the good working relationship between associations and ostomates.


The future is uncertain while the potential for a tender process proceeding hangs over us. However, we need to soldier on and keep providing the best support we can.

Because many of the stoma associations are moving toward online ordering and membership renewal etc, ostomates will be accessing the associations websites more and this gives a great opportunity to provide support and education through those websites.

There is also room in the future for possible further cooperation between associations in the development of educational material for the association's websites to maximise the support and information available to ostomates. As we all know, many of the ostomate community are frail and vulnerable and cannot access the internet so we will always need to have a multimedia approach to information provision and support.

As the new President of ACSA, I look forward to working through the changes that we face with the other members of the ACSA committee and to keep working with Government to ensure the Stoma Appliance Scheme works well for all ostomates. ●

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These contact details apply only to matters directly associated with Ostomy Australia. Email or Word documents are preferred, please include pictures if possible.

Published by:

Australian Council of Stoma Associations Inc.

Website: www.australianstoma.com.au

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Printing and Graphic design by:

Graphic Print Group

Graphic House, 10–14 Kingston Avenue,

Richmond, SA 5033

Phone: (08) 8443 8011

Cover photo by: Kseniya Resphoto

Source: Shutterstock

Advertising enquiries to: The Editor

Advertising & copy deadlines:

Issue	Deadline
April	1st February
August	1st June
December	1st October

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# Your say

## Letters to the editor

### Dear Editor,

There is a lot of talk about leakages, and I certainly had a few when my bag was new (September 2019). It was obvious the wafer wasn't sticking as well as it could and I came up with the idea of using a grain bag to heat it up.

After 40 seconds in the microwave, the grain bag sits on the colostomy bag while the old bag is removed and other preparations are made.

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**Rosemary Vanderlaan, NSW**

### Dear Editor,

**In reply to David Paterson, QLD**

Hello David, your question was how to contain the enormous rush to get to the toilet safely while prepping for a colonoscopy.

I had that problem too and solved it easily. At the time I was irrigating. To irrigate you wear a long cone shaped plastic sleeve, which reaches easily from where I sit, and dangles into the toilet. This sleeve is clipped onto the wafer you are wearing that would normally have your bag attached to it.

If I wanted to make beds or put out a load of washing, it was just a matter of folding up the end and clipping it closed (I'm sure the clips come with it).

It was an obvious move for me, when doing a preparation, to wear a sleeve.

I am sure your supplier could make one available for you, and if not, they will give you the phone number of the supplier and you could ask them for a sample.

It works well.

**In reply to Carl Bouwens, SA**

I hope Thor has settled in and is happy doing his job.

I have written in previously about 'what did I name my new friend?'. Long-time readers may remember.

I call mine the Baby. Why? To me it is obvious. I fed her, burped her, changed her, walked the floor with her, at times could have spanked her, and at other time, loved her.

I do hope my little bit of experience does help someone.

**Marion Chisholm, NSW**

### Dear Editor,

In response to the letter from David Paterson (volume 29 number 3)

Although not the same situation, I, too, found myself needing help after significant surgery. My output from pre-existing ileostomy had increased and consistency varied considerably hour by hour.

Hospital staff suggested I contact the customer service team of the company supplying my usual stoma items. Following some careful discussion, I was sent some high output bags to trial.

Marvellous.

They must have been at least double the normal capacity; a little bit awkward to wear but saved the overflow problem until a return to normalcy.

It seems worthwhile to contact the company direct for suggestions and advice.

**Isobel Davie**

### Dear Editor,

**In response to Elizabeth Kay (April 2021 journal)**

Hello Elizabeth,

I love Vanilla Blush products. They have several swimsuits. They are a Glasgow company so keep in mind the delivery times are slightly longer than local companies.

Their website – [vblush.com](http://vblush.com) – opens a world of underwear, swimsuit and hernia support options that are all beautiful and comfortable.

**Kirsty Evans**



### Dear Editor,

My name is Meagan Davey, I was diagnosed with Crohn's disease in 2007 and have been living with an ileostomy since 2011. I had complications after a proctocolectomy in 2013. I live with a chronic pelvic abscess and just a few weeks ago had fistula surgery. This year I must have another major surgery to drain my pelvic abscess.

It has been and continues to be a messy journey.

I wanted to give back to the Crohn's and stoma communities in some way and as a result, I have recently published my first book called *The Crohn's Diaries: A Book of Resilience* which I consider to be a trouble-shooting manual on living with Crohn's and its associated issues. It is my hope that my story can help others facing the challenge of living with Crohn's disease.



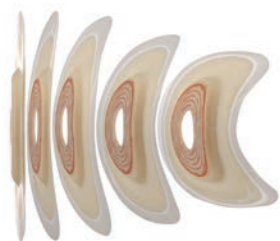
This book has all the tips and tricks that I've learned about stoma and skin management as well as sharing my story and other advice related to having a chronic illness.

Continued page 12

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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?

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In 2018, I walked the El Camino de Santiago with fellow ostomate and Crohn's advocate Melissa Lord and I've interviewed her in a section of my book where we talk about the importance of goal setting and looking after yourself to live your best life.

My book is available at most online major book retailers including Amazon, Fishpond, Barnes & Noble and Dymocks.

Meagan Davey

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# To my fellow ostomates

By The Gutless Wonder

How very important it is for me  
To enjoy this great camaraderie  
With Ostomates both young and old.  
To face the challenges, we must be brave and bold.

Humour is our most powerful weapon  
To live our lives without depression.  
Hearing so many stories that made me laugh  
Reduced my misery and confusion by half.

Col, Uri ad Ili are some stoma names we use  
But often more imaginative ones we choose.  
Many are clever, often an amusing one,  
And some of us just refer to it as a tummy bum!

So continue to look on the bright side of life,  
We can all achieve great things in spite of the strife.

Forget all those problems that always abound,  
Remember – a smile a day makes the world go round!

# Celebrating Volunteer Week at OAM

By Lindy McDonald



Our volunteers are more than volunteers.

They come 'to work' with a smile, a willingness to help and a desire to get the job done.

They want to give something back.

They want to make a difference to people around them.

## WHY THEY VOLUNTEER

To build on existing friendships or make new friends. Maybe with someone that has just started volunteering with us, it's to give them confidence or to join in and be part of our great team. Often, it's to help other ostomates, to 'pay forward' the benefit they received from our association, the Ostomy Association of Melbourne (OAM).



According to our volunteers, the rewards of volunteering at OAM are many and they encourage others to put their hand up to volunteer in their communities.

## WHY WE CELEBRATE VOLUNTEER WEEK

We love having an opportunity to give back to our volunteers and to acknowledge their achievements as they are an integral part of our success. Their dedication and hard work are reflected in the excellent feedback we receive about them and our association.

One word simply sums up our volunteers – **Amazing**

From all at OAM - we sincerely thank you and look forward to seeing you every week and especially during Volunteer Week when we can share our appreciation of you all.

As we say at OAM:

- Very good cooks
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# An open letter to STN's from an ileostomy patient

By Vivian Parry



major flare up and subsequently found myself receiving Infusions. The first infusion was deemed after three sessions to be unsuitable. The second type of infusion created serious side effects ... where to from here, I wondered. It was not long before I was ordered to have another scope. The result was life altering for me. It seemed I had an area of 'grave concern' and I needed to see a gastroenterologist surgeon to discuss my options. This outcome was my worst nightmare realised.

Being used to medical appointments I could not believe how fearful I became on the day of my consultation with the surgeon. I lost my favourite scarf on the way into the building and didn't even notice until I reached it hours later and it was gone.

The surgeon confirmed my specialist's opinion; my luck had run out, a pancolectomy resulting in an ileostomy was my fate.

I held off as long as I could to make my pre-operative Stomal Therapy Nurse (STN) appointment, I needed to go through all the emotions that came rushing to the surface: grief, anger, fear and self-pity. I had lost the UC battle and the price to be paid was, in my mind, a devastating loss of quality of life. The internet confirmed my worst fears and added new ones, appliances, leaks, restricted diet, blockages, dressing to camouflage the appliance, antisocial noises... on and on it went.

It all seemed so bad I decided to make the recommended pre-admission appointment with the STN to find out the true facts of the situation for myself.

To make the most of my appointment time I decided to write down my major concerns. I wanted to make sure I put forward all my queries because I knew in my case, having relevant information would help me through the ileostomy procedure. Looking back over my notes as I write this letter, I am a bit surprised how relevant for a 'stoma novice' my questions were:

After my op: will I be in acute care or back in my room? Will I have a catheter?

What shall I pack? I live on my own

and don't want to bother my friends with washing.

Other than on the internet I have never seen a stoma or the appliances; will I be able to change my own pouch before I leave hospital?

How long will it take for my stoma to decrease to its normal size?

What if I need to revise the appliances, who will I contact?

Blockages. I am 90% vegetarian who will give me guidance on diet, and will that be during my hospital stay?

Will I be given advice about skin care, how to deal with gas and odour? Will I receive advice on how to lie in bed, dress, have a shower or bath?

Will there be home visits, or do I call a community nursing service?

What I didn't write down but did reveal to the STN was my fear and dread of the procedure and my serious concerns about how my life would be into the future. I concluded with 'I don't want an ileostomy. I have tried every possible treatment over the years to avoid this outcome!'

'No one wants this operation', was the STN's only comment. Reflecting on that statement two years on, I believe patients deserve a more considered response. Her words were all I had to support me through the procedure.

'No one wants this operation'... How was I supposed to process that?

I believe this was a lost opportunity to provide positive support. Public hospitals provide counsellors. Private patients can gain referrals to trained counsellors. The question is 'How does the STN detect which patients need counselling?'

Never having sought any kind of therapeutic counselling in the past I regret not being offered counselling on this occasion. I feel my recovery would have been easier if, right at the start, I could have expressed my fears to someone trained to respond in a more valuable, effective and beneficial way.

## REFLECTIONS ON MY IN-HOSPITAL STAY

The following points are reflections on my in-hospital stay. My aim is not to be

critical but to point out the patient's perspective in a constructive way; potentially creating opportunities for STN's to rethink ways of assisting their ostomy patients.

## MEDICATION FOR PAIN RELIEF

My surgeon advised me on the morning after my procedure, I must maintain my pain medication schedule without fail. He explained if this routine was not strictly adhered to my pain would increase with little chance to return to my current relatively pain free situation.

I became distressed when my pain medication arrived significantly late or occasionally forgotten. I started setting the alarm on my phone to make sure the medication arrived within a reasonable timeframe; a responsibility I never thought a patient would have to deal with.

## FIRST APPLIANCE CHANGE

When it came to attempting my first appliance change (48 hours after the operation) I was not in great shape physically or mentally. The STN seemed to think a bit of bullying was a form of 'tough love' and she was short of time. I would have appreciated her understanding my medical and emotional condition. Seeing my stoma for the first time, swollen and angry looking with the accompanying drains, catheter, and drip on board, still shaky on my feet, a kind-hearted approach would have been invaluable.

I did appreciate being signed up to the Colostomy Association and having

the products explained, however for many post-op ostomates the ostomy situation seems quite surreal and the medication made it hard to concentrate especially after a major operation.

I came to understand how hard Ward nurses as well as STN's work, literally running from room to room to keep up with the demands of their nursing roles. I wondered how the hospital system could reorganise and prioritise duties more efficiently for both the staff and patient's benefit.

At the post-op meeting I appreciated the STN asking me, from my patient's perspective, if there was anything within her area of responsibility I felt could have been done differently or improved upon? I replied 'You could show more empathy and understanding'. She told me she thought she was doing exactly that. I offered 'if you could have taken five minutes, just once, to sit beside me and ask if there was anything I needed to know or was concerned about, I would have felt that connection'. Her reply, 'I don't have time'.

I left the hospital and arrived home to discover I couldn't remember the information I received at my initial consult weeks ago; essential advice on how I should sleep appropriately, keep my pouch dry in the shower and manage to avoid leaks.

I felt lost and alone with my swollen body complete with add on appliance; I felt socially unacceptable and embarrassed to draw attention to my situation. Not the best homecoming.

Understanding ostomates have no lived experience prior to their surgery I wonder at what stage in the hospital stay/ post op situation new ostomates could receive purposeful, encouraging advice to assist their transition out of the hospital space back to the reality of being home. (I was not advised of a possible community STN home visit to check on my progress).

My hope in writing this letter to you is that you have gained fresh insight into some of the important issues this ileostomy patient needed you to know. A bit of a reminder how incredibly difficult it is for your patients to be brave through the ostomy process.

I strongly believe you and your nursing colleagues can work through this information to bring about positive awareness and change.

Ostomy patients do understand their STN, and the Ward nurses have many patients to care for. We in turn have only one STN to guide us through this physically and emotionally challenging time in our lives.

Given support, empathy and understanding of our situation we would do our best to work with you to gain the most favourable outcome, for both our sakes.

Thank you for taking the time to read my letter it has been a privilege to share my thoughts and ileostomy lived experience with you. A huge Thank You from all your ostomy patients, we are ever grateful you have chosen caring for us as your career. ●

## Helpful tips for ostomates

### I would also like to share some valuable tips with my fellow ostomates

**Diary:** I have found keeping a diary noting the days I need to change my appliance, very helpful. It is not the 'early' changeover that causes problems; it's the 'late' changeover that can lead to day or night-time leaks because the adhesive no longer adheres to your skin. In each month I write K for keep and CH for change on each day of the month as a reminder.

**Shower:** Before I shower, I empty the pouch, roll it up towards my naval and secure each end with an elastic hair tie. Using a soft disposable shower cap (discount chemists sell packs of

eight for about \$5 and each cap last for weeks). I cover the rolled-up pouch bringing the elastic up to the top, twist and re-cover the area about three times until it fits securely. If any water does seep under the cap, it stays below the rolled-up area. After my shower I carefully remove the cap and dry the surrounding skin. Happily, the pouch stays dry.

**Product:** From my first solo home appliance change I had problems with left over adhesive residue on my skin. I knew it was important to have a clean and dry area to attach the new appliance to. The adhesive removal wipes didn't always do the job effectively and I was concerned

excessive rubbing would cause a skin irritation. By accident one appliance order replaced my wipes with a spray adhesive remover... Best mistake ever! One spray around the appliance edges and the pouch lifts off cleanly in one go with no residue left to remove. I then use the adhesive remover wipe to clean around the whole area. After a wash down with warm water I allow my skin to air dry. The other products I like are the Aloe seals used to create an added buffer against leakage and the flange extenders. The extenders assist the shower process by creating a larger adhesive area and they are a great line of defence and a visible early warning signal against leaks.

# Are you having fun?

By Margaret Allan

Margaret Allan advises both ostomates and the public on diet and health-related matters. She is the director of the consultancy Nutrition For Ostomates. To contact her or read more nutrition articles supporting the health of ostomates, go to [www.nutritionforostomates.com.au](http://www.nutritionforostomates.com.au)

That might seem like a silly question. You might be thinking “I’m an ostomate – how can I have fun?” However, the two don’t necessarily have to be mutually exclusive. As an ostomate it is important to still find joy in life, even if it is just in the little things.

Stomal surgery can be a very big deal. It can momentarily take the light out of life. And there may be major adjustments to make afterwards. It can seem as if you are being thrown a massive curve ball and are being challenged in a very profound way. You can feel overwhelmed and insecure about so many things, such as how to cope with the new circumstances, what your life is going to be like from now on and what the future holds. There can be a lot of uncertainty.

But these feelings don’t have to be permanent. You can learn to cope, you can make the adjustments, and you can find your way through the maze of uncertainty towards a new way of life that is still full of meaning and purpose. And this process can be made easier by having some fun!



## FUN IS INDIVIDUAL

The type of fun you have after stomal surgery may be different to what you did for enjoyment before you had surgery, but the concept is still the same – doing something that makes you laugh, feel lighter, lifts your heart and brings joy into your life. It is often said that laughter is the best medicine, and you can certainly cope better when you can laugh. Fun helps you focus on the present and enjoy the moment rather than dwelling on the past or fearing the future. Fun can provide some mental rest and a brief reprieve from the daily concerns or challenges. Fun helps you forget what is going on in your life and allows you to just indulge in a pleasant activity.

What one person experiences as fun may not be the same for others, and so the concept of fun is very individual. You may need to adjust or moderate your fun-filled endeavours for a little while after stomal surgery in order not to stress or strain your body whilst it is still recovering, but even then, you can still indulge in enjoyable pursuits. And whilst your body is healing you could also spend the time daydreaming of what you WILL do when your body is ready.

## SO, ASK YOURSELF: WHAT REPRESENTS FUN FOR YOU? FUN CAN BE SIMPLE

Fun does not need to be taxing or expensive. It doesn’t need to be a large-scale endeavour that requires a lot of time, energy or money. Fun can be free, and even if it only lasts five minutes can have a beneficial impact on your wellbeing. It can involve really simple activities such as:

- Sitting in a sunny spot reading a book or a magazine
- Having a coffee and a good chat with a loved one
- Chilling out watching a funny movie
- Singing along to your favourite music
- Sharing a joke with a like-minded friend

## Nutrition for Ostomates



- Going for a stroll in a pleasant environment, such as a park, the bush or the beach
- Visiting your favourite place
- Going on a picnic (at a venue with toilet facilities of course) or sharing a lovely meal with friends
- Floating away in a bed of delicious daydreams...

## THERE ARE MANY AND VARIED WAYS TO HAVE FUN. THE GOAL FOR YOU IS TO WORK OUT WHAT REPRESENTS FUN FOR YOU NOW, AS THE PERSON YOU ARE TODAY, AND THEN ENGAGE IN THAT ACTIVITY AS OFTEN AND FOR AS LONG AS POSSIBLE.

Aim to lighten your mood as much as you can. When you’ve had some fun, check in with yourself – how does it feel? Do you feel happier, lighter, more liberated? Do you feel that you can cope with your challenges a little more easily? If so, make fun a priority in your life and schedule some more light-hearted, joyful activities into your diary to keep up the momentum. After all, practice makes perfect!

I recently heard a blessing that contained the phrases:  
‘May you be at peace, may you be well, may you find loving kindness.’

I would add ‘May you also have fun!’  
Wishing you good health and happy days,

Margaret •

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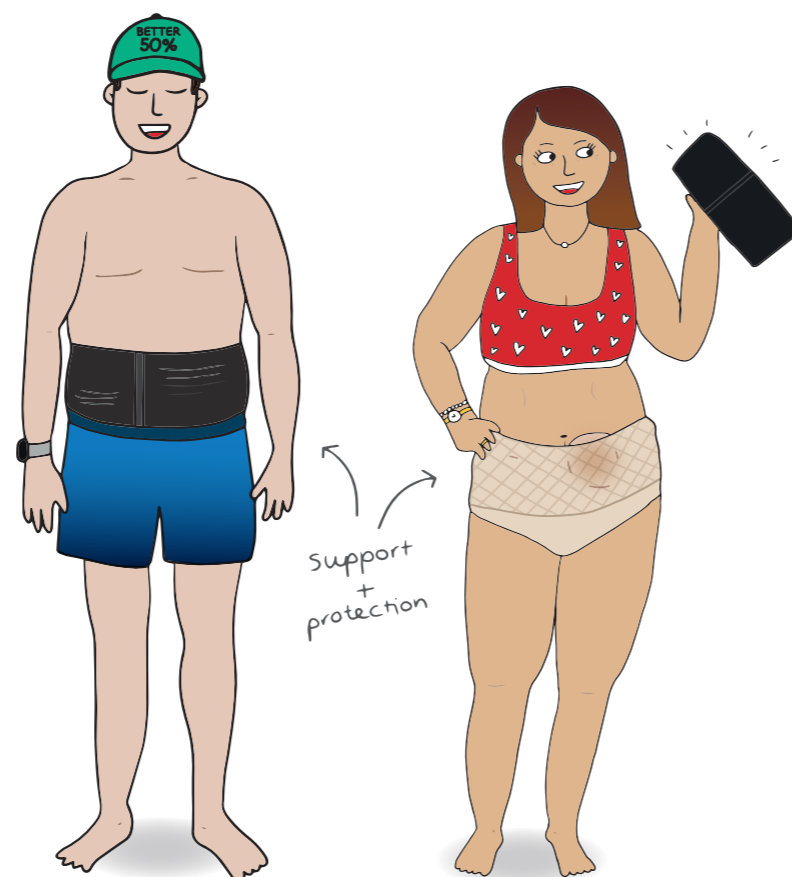
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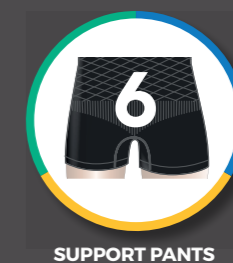
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A hole in Support  
Garments is not  
recommended by  
clinicians<sup>2,3</sup>

<sup>1</sup>: Colorectal Disease © 2018 The Association of Coloproctology of Great Britain and Ireland. 20 (Suppl. 2), 5-19. <sup>2</sup>: Thompson JM. A summary on parastomal hernias, February 2009. <sup>3</sup>: Thompson MJ. Parastomal hernia: incidence, prevention and treatment strategies, British Journal of Nursing, 2008 (STOMA CARE SUPPLEMENT); 17 (2), 16-20

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### RATING 4. INTERMEDIATE

Wear during daily activities  
(housework, shopping, golfing)

Support a more developed hernia



Support Briefs  
for Her

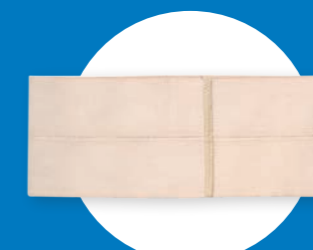


IsoFlex  
Support Belt

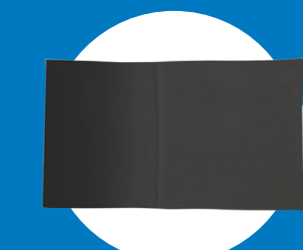
### RATING 5. FIRM

Wear during active work or sports

Support a more developed hernia



Total Control  
Support Belt



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# Tips and tricks for colostomy, ileostomy and urostomy

By Tyrrell, STN – NSW

Having a stoma is a life changing process. Yes, it is challenging, yes, it is hard to deal with, but with the help of a Stomal Therapy Nurse (STN) as an ostomate you will, over time, become confident in self caring for your stoma and be able to resume your previous lifestyle.

Everyone deserves the opportunity to embrace life to the fullest. In my 40 years of nursing, I have witnessed people who have had a stoma turn their life into whatever they wanted it to be. They have been able to resume their work life and exercise including swimming, golf, cricket, rugby, surf, ski (snow and water) and skydive. Many have continued with gardening and household chores. Women have still been able to give birth.

What I am about to share with you is the knowledge I have gained over 30 years of working as a STN. I have to thank my patients and my fellow STNs who have shared their 'tips and tricks' to better manage stomas, peristomal skin problems and appliance management.

When I first started working as a STN we did not have the wonderful pouches, accessories and skin technology that we are blessed to have at our fingertips today. We certainly have come a long way.

I have learnt many general tips and tricks over this time as well as specific tips for colostomy, ileostomy and urostomy.

- Overall keep everything simple when caring for your stoma.
- After selecting the appliance that you like, stay with it.
- Order your products in a timely manner. Do not over order but also do not leave it to the last minute.
- Have adequate number of stoma supplies on hand – one month backup is a good idea.
- Cut your base plate or pouch to the size of your stoma.
- Wash your skin with warm water and dry your skin well before applying your pouch or base plate.
- Empty your pouch when its 1/3 or 1/2 full.
- If you have a problem or question contact your STN before the problem becomes a big issue.

## COLOSTOMY

- Cut a one-piece pouch and/or base plate just a little bigger than the stoma (1-2 mm).

- Measure your stoma regularly. After surgery do it weekly for six weeks, then monthly for three months, then every three to six months to check for change.
- Eat a well-balanced diet, some fibre, vegetables, fruit, protein and the odd drink. Drink pear juice if constipated.
- Put small rolled up toilet tissue (size of a marble) into pouch to allow stools to drop more easily down to bottom.
- Warm up your base plate or pouch before fitting especially in the colder winter months e.g., put it inside your shirt against your warm body or use a hairdryer on a warm setting for 30 seconds.
- If stools are dry or pancaking put olive oil/lubricant deodorant on the inside of the pouch. This will help stools slide down.
- Drink 6-8 large glasses of water daily, plus tea and coffee if you desire.
- Use warm water only to clean skin around the stoma (we call that the peristomal skin).
- If the pouch filter gets wet, change the pouch.
- Change the pouch when its 1/3 or 1/2 full.
- Do not lift heavy objects – a hernia may develop.
- Contact a STN if you have leakage, skin problems, pouch fitting issues, pain or bleeding from your stoma.

## ILEOSTOMY

- Measure your stoma every week for the first six to eight weeks so you can cut your base plate or one-piece pouch to the right size (a hole 1-2 mm bigger than your stoma is ideal).
- Wash your skin with warm water only.
- Dry your skin with a soft low lint towel, Chux or dry with a hair dryer on a warm-cool setting.
- Warm up your base plate or pouch before fitting especially in the colder winter months e.g., put it inside your shirt against your warm body.
- Change your base plate or pouch in the morning before eating. This will reduce your output volume making for a better change.
- Keep up your fluids. 6-8 glasses of water daily plus other fluids e.g., tea, coffee and juices.
- Chew your food well and eat small meals to being with. This assists with

better digestion and reduces risks of blockages.

- Do not eat hard vegetables e.g., carrots, celery, corn, or tough meat, pineapple, mango and coconut. These foods can cause a blockage. Reintroduce foods slowly and maintain a balanced diet of carbohydrates, vegetables, fruit and protein.
- Seek help from your STN if you are experiencing leakage, skin problems, pouch fitting issues, pain or bleeding from your stoma.

## UROSTOMY

- Check your stoma size regularly - monthly for the first three months then six monthly to check for changes.
- Cut base plate or one piece pouch as close as possible to your stoma size (1 mm).
- Using a seal can help wear time and reduce urine leakage problems.
- Wash your peristomal skin with warm water only.
- Dry the peristomal skin well with a soft lint cloth, Chux or hair dryer on a cool-warm setting.
- Use rolled up gauze on top of the stoma to collect urine while drying your skin.
- Warm up your base plate or pouch before application.
- Change your pouch early in the morning before you start drinking fluids.
- If you use a night bag, connect the tubing to the bottom bed sheet, PJs or person.
- Drink 6-8 large glasses of water per day (unless your doctor says otherwise).
- Change your pouch daily or base plate every 3-4 days, or if leakage occurs.
- Wash your hands thoroughly before stoma care to prevent bacteria entering your stoma and developing an infection. A urinary tract infection will see your urine cloudy, smelly and you will have a reduction in your urine output. Seek a review with the GP if issues.
- Seek help from a STN if you have skin problems, pouch issues or bleeding from your stoma.
- Have a yearly review with a STN.

Source: <https://omnigonconnect.com.au/advice/tips-tricks-colostomy-ileostomy-urostomy/>

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# Diversion Proctitis

By Monica Stankiewicz, Stomal Therapy Nurse

Diversion proctitis is also known as diversion colitis as it can affect a part of the rectum or colon after stoma formation. Symptoms include abdominal or rectal pain, bleeding, excessive mucus or ongoing sensation of needing to pass a bowel motion or can even loosen motions from the stoma.

It is reported that the cause of diversion proctitis is due to a lack of short chain fatty acids (a biproduct of fermented dietary fibre) which are absent when the bowel is starved due to the diversion in the faecal pathway. This changes the way certain cells (enterocytes) absorb and metabolise. This leads to poor functioning, smaller, abnormal cells in the bowel /rectum mucosa (the cells that line our body cavities, such as mouth, intestines, rectum etc). This is known as ‘mucosal atrophy’. The risk of infection is due to increased bacterial load due to changes in the normal cells function and a decrease in normal healthy bowel bacteria.

### WHO IS AFFECTED?

Although suspected to be uncommon (as true incidence of the disease is unknown), it can occur in any patient with an ileostomy or colostomy, occurring in the remaining bowel or rectal stump.

Diversion proctitis is reported mostly in those who have inflammatory bowel conditions such as Crohn’s disease or ulcerative colitis but does not exclude other disease processes such as bowel cancer or diverticular disease.

### PROTECTION OF SKIN INTEGRITY

Incontinent mucus from the rectum is not uncommon. It is very important to protect the surrounding rectal skin due to increased mucus or bloody discharge from the rectum. Barrier wipes, barrier creams or barrier sprays can be effective in preventing skin loss.

Avoid soaps to cleanse the area as this may increase rectal skin pH and encourage skin breakdown. Warm water to wash the area is enough.

A panty liner or incontinence pad is often used to prevent under-pant soiling.

Copious amounts of rectal stump mucus is a concern and should be assessed by a medical specialist (general practitioner / colorectal surgeon / gastroenterologist). It may warrant further investigation.

### TREATMENT

It is very important to engage a gastroenterologist to assist with navigating a diagnosis, investigations and providing information on the best treatment for you, whether its medical or surgical.

There is some research conducted about the effectiveness of short chain fatty acid enemas to improve diversion proctitis or diversion colitis, however outcomes from the studies are varied. Medication management tends to be mainstay treatment ranging from oral anti-inflammatory/ immunomodulating medication to biologic treatment. Referral to a colorectal surgeon may be necessary if surgical intervention is required.

*Monica is a Wound Management, Stomal Therapy and Dermatology Nurse Practitioner\* for Community and Oral Health, Metro North, Queensland Health and can see ostomates with any skin or general concerns, through a referral from a GP.* ●



## what’s on?

### Discover new services and events at your local association

#### Mackay (QLD) Ostomy Support Group AWARENESS DAY

Following a very successful gathering in 2019, the Mackay (QLD) Ostomy Support Group will be holding its biennial Awareness Day on Friday 1 October 2021.

Entertainer Luke Escombe will again be in attendance along with a Motivational Speaker, Gastroenterologist, Stomal Therapy Nurse, Product Suppliers and other guest speakers.

For Queensland Ostomates, further details regarding this FREE event will be on a flyer with your order.

For further information phone Sandy on 0418 150 507.

#### Celebrate World Ostomy Day

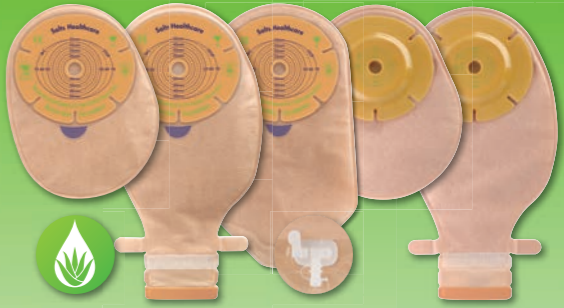
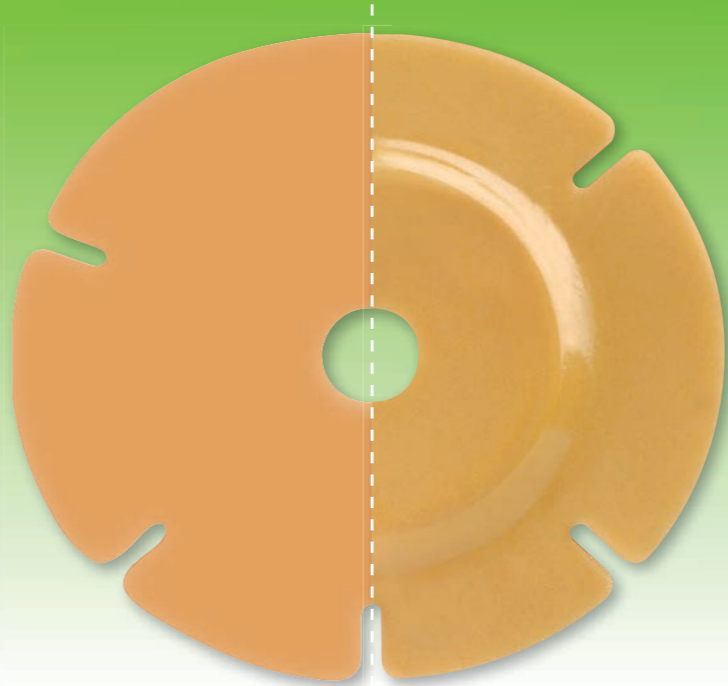
To all members, their families and carers of Ostomy Associations Australia wide.

Saturday 2 October has been internationally declared as World Ostomy Day.

We wish to raise and promote awareness for people with stomas and will be holding a free zoom event that will involve information and fun events on the day. We hope to enlist support from Stoma Nurses, Ostomy Supply Companies and Guest Speakers.

Save the date and keep an eye on your Associations’ websites for more information at it evolves with information, timings, the program and where to RSVP if you wish to register.

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# Zac's fight for his best life

By Ginny Deane

Zac was diagnosed with Crohn's disease when he was five years old. By the time he had been diagnosed he was severely unwell. After failed attempts to control the disease by using medications such as sulfasalazine, azathioprine and a liquid diet it was decided the best course of action for Zac was to have an ileostomy.

Zac's Crohn's was affecting most of his digestive tract but was particularly bad in his large bowel and rectum. By the time Zac was due to have the operation he was six-years-old and it had been seven months since his diagnosis.

Prior to the operation Zac would spend most of the day sitting on the toilet passing blood and pus. He was in agony. He had sores around his mouth and was emaciated.

We told Zac that the operation would address the symptoms he was living with and enable him to start leading a normal life again. The hope was that by diverting the flow of faeces at the ilium that the rest of the large bowel could heal and then maybe in the future the ileostomy could be reversed.

Unfortunately, this wasn't the case and following the ileostomy the large bowel continued to be affected by the Crohn's. Zac was put on numerous courses of steroids but whenever they were decreased, he would be in agony again, with no energy and unable to get on with life.

The consultant looking after Zac decided to create a colostomy instead, so Zac had surgery to close the ileostomy and form a colostomy. By this time the Doctors were considering that Zac's stoma may be permanent so they wanted to see if moving the stoma further along the bowel would worsen the Crohn's in the colon. They were hopeful that as the bowel had been able to rest the flow of faeces wouldn't flare the disease up again and Zac could live with a colostomy which they deemed more manageable as the flow of faeces wouldn't be constant.

Unfortunately, Zac never thrived with a colostomy, and he continued to have diversion colitis in his rectum. This was treated in numerous ways such as

mixing probiotics up and inserting a catheter into Zac's rectum to deliver them to the affected area and inserting metronidazole suppositories. This took its toll on Zac, it was painful, and he dreaded us doing it. Therefore, a decision was made to reform the ileostomy and start infliximab infusions to treat the disease.

The infliximab wasn't effective for Zac and he had further investigations into his rectum as that hadn't settled down with the reformation of his ileostomy. They found out that there was a mass in his rectum that was the damaged bowel blocking his rectum so the pus and mucus couldn't escape. The Doctors decided that anal dilations under anaesthetic would stretch the rectum and enable the fluid to escape, reducing the risk of infection and stopping the discomfort.

My concern was for Zac's quality of life now, not whether he may or may not be able to have a family of his own in the future

Zac's general condition deteriorated at this time, and it was decided that he would have a full colectomy. The colectomy was a success, but Zac's rectal stump was left behind.

Zac's wound didn't heal and he had a large swelling to his lower abdomen, after investigation it turned out that Zac had a collection of fluid in there that would need draining as the anus was blocked. A catheter was inserted into his abdomen that drained the fluid. We used to have to wash this out and insert enemas down the tube. Zac found this intolerable. By this time, he had been taking oramorph (morphine) for months to deal with the rectal pain and was on gabapentin. However, the pain was so

severe he could barely sit down. His life was consumed by his pain. At this time Zac was in and out of hospital frequently and the pain became so much he was also given a fentanyl patch and a tens machine to assist with pain relief.

Zac had numerous investigations to see if his rectum could be removed as it was that area that was causing all his pain. He had no quality of life, had been out of school more than he had attended and was weak and couldn't eat. He was admitted into hospital for a few weeks whilst investigations were carried out.

The surgeon that had always previously operated on Zac refused to remove his rectum on the grounds that the operation was too risky. He was concerned that as his rectum was in such a state that there would be too much irreparable nerve damage and that Zac may become incontinent and impotent. Zac had to spend much of his life wearing a nappy anyway to soak up the small amounts of purulent discharge that escaped from his rectum (we called it bum juice). My concern was for Zac's quality of life now, not whether he may or may not be able to have a family of his own in the future. Zac's health was getting so poor he was frequently in and out of hospital for treatment for the many infections and reinsertions of the drain. Zac even got pneumonia and his general health deteriorated.

During the long stay in hospital Zac was sent to a different children's hospital at the other end of the country to see if he would meet the criteria for a stem cell transplant. It was while he was in there that his bowel became obstructed as it had adhered to the inflamed mass that was his rectum. He had numerous scans and saw a surgeon who advised that he felt that removing Zac's rectal stump was achievable with minimal damage. He carried out this operation and four weeks later, Zac was discharged pain free.

His Crohn's is now managed with fortnightly humira injections and I'm pleased to say he is healthy, happy, and living his best life. ●

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## OPPORTUNITY TO JOIN OUR TEAM

### Executive Officer

We are currently seeking a part time Executive Officer provide administrative support to the ACSA Committee.

Reporting to the President, you will provide administrative support to the ACSA Committee to ensure the smooth and efficient operation of our services and managing relationships with our key stakeholders.

This role can be located anywhere in Australia. Some travel will be required, when safe to do so, to attend meetings and events in person.

The salary and hours are negotiable depending on final workload for the position, but it is estimated to be approximately 10 hours per week (flexible as to when worked).

#### YOUR KEY RESPONSIBILITIES WILL INCLUDE BUT WON'T BE LIMITED TO:

1. supporting the ACSA President as required
2. Member support services
3. ACSA meeting coordinator including venue organisation and meeting minute taking and preparation
4. data collection and statistical reporting
5. Executive Officer column for Australian Stoma Journal (3 times a year)
6. management of [australianstoma.com.au](http://australianstoma.com.au) website

7. management of [feedback@australianstoma.com.au](mailto:feedback@australianstoma.com.au) email
8. member of SAMS Committee
9. liaison for Australia Post Contract and Stoma Appliance Schedule (DHS & DoH)

#### YOU WILL HAVE:

1. a thorough understanding of the Stoma Appliance Scheme
2. strong IT skills (WordPress)
3. strong organisational skills
4. excellent written and verbal communication skills
5. able to work with stakeholders with a calm and professional approach
6. willingness to take on routine tasks as is often required in a small team
7. commitment to supporting ostomates and improving their wellbeing.

#### DESIRABLE:

1. experience in a stoma association at a senior level
2. positive 'can-do' attitude and initiative who works collaboratively with people.

For more information, please contact ACSA President, Allen Nash at [acsapres@australianstoma.com.au](mailto:acsapres@australianstoma.com.au)



## When was the last time you saw your Stomal Therapy Nurse?

Do you...

- experience frequent skin irritation (pain, burning, bleeding or itching)?
- get frustrated with your current ostomy solution?
- experience leakage around your stoma?

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1800 884 759

[nursingsupportAU@Coloplast.com](mailto:nursingsupportAU@Coloplast.com)

[coloplast.com.au/ostomy-nursingsupport](http://coloplast.com.au/ostomy-nursingsupport)



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# YOU Inc continues to support members wellbeing

By Bonnie Crowe

Young Ostomates United Inc (YOU) met on Saturday 15 May to listen to a fantastic presentation by dietitian Melanie McGrice.

YOU engaged Melanie to come and speak to the group about the relationship between diet, stomas and the impact one can have on the other.

Some common points were covered, including how to avoid blockages and what foods are easiest to digest.

Some key take-away points for ostomates –

- For **high output stomas** it is very important to stay hydrated. Increased salts and electrolytes can help and have some fluids half an hour on either side of a meal to help with digestion and absorption of nutrients. Dark urine can be a good indicator that more fluids are needed.
- **Avoid blockages** by chewing food well, and take particular care with food like celery, nuts, popcorn etc. These can potentially be tolerated later, but it's better to avoid these in the first six weeks of stoma surgery.

- Replacement shakes can help if you cannot tolerate food. Shakes such as Optifast are easy to buy or make your own shakes that are easily digestible and nutritious.

- Foods that are high in nutrition and easy to absorb include avocados and nut pastes. Cow's milk has the most nutrients if it can be tolerated, and honey can be used instead of sugar.

- If you are having trouble digesting tablets, see if the medication either comes in a liquid form or can be crushed.

- For those with a **slow-transient bowel**, it is helpful to increase foods that are easily digestible and to use probiotic supplements and insoluble fibres.

- Those with **urinary stomas** need to pay particular attention to their fluid intake.

It is important and advisable for anyone with IBD to have a care team plan with a GP, gastroenterologist, surgeon (if

required) and stomal therapy nurse (if required).

The session was recorded and further information can be provided to anyone interested to hear more about this important topic by getting in touch with Helen at YOU, or by joining the Facebook group.

YOU Annual General Meeting (AGM) will be held on 21 August, and the group are in the process of arranging a guest presentation to explore and discuss the management of hernias.

*If you would like further information on YOU or would like to become a member, please contact Helen Ebzery (Secretary) at [youincsecretary@gmail.com](mailto:youincsecretary@gmail.com) or [helshae@hotmail.com](mailto:helshae@hotmail.com).*

*Facebook - [www.facebook.com/groups/youinc](https://www.facebook.com/groups/youinc) (please note this is a closed Facebook page to protect the privacy of our members. Send a membership request and we will get back to you soon).* •

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## Covid-19 notice

To protect staff, ostomates and the wider community many associations have stopped all in person services. Please make sure to check with your association to find out how they are operating.

## AUSTRALIAN CAPITAL TERRITORY

### ACT & DISTRICTS STOMA ASSOCIATION

**W:** actstoma.net.au  
**E:** stoma@actstoma.net.au  
**T:** (02) 5124 4888  
**A:** Floor 2, 1 Moore Street Canberra ACT 2600  
**Open:** First and second week of each month on Monday, Tuesday, Wednesday 10:00am to 1:00pm

## NEW SOUTH WALES

### NSW STOMA LIMITED

**W:** nswstoma.org.au  
**E:** info@nswstoma.org.au  
**T:** 1300 678 669 or (02) 9565 4315  
**A:** Unit 5, 7-29 Bridge Road Stanmore NSW 2018  
**Open:** Monday to Thursday 8:00am to 4:00pm, Friday 8:00am to 2:00pm

### OSTOMY NSW LTD

**W:** ostomynsw.org.au  
**E:** orders@ostomynsw.org.au  
**T:** (02) 9542 1300  
**F:** (02) 9542 1400  
**A:** Ground Floor, 20-22 Yalgar Rd Kirrawee NSW 2232  
**Open:** Monday to Thursday 9:00am to 2:00pm

## NORTHERN TERRITORY

### CANCER COUNCIL NORTHERN TERRITORY

**W:** nt.cancer.org.au  
**E:** ostomy@cancernrt.org.au  
**P:** (08) 8944 1800  
**F:** (08) 8927 4990  
**A:** Unit 2, 25 Vanderlin Drive Casuarina NT 0811  
**Open:** Monday to Thursday 8:30am to 2:00pm

## QUEENSLAND

### GOLD COAST OSTOMY ASSOCIATION

**W:** goldcoastostomy.com.au  
**E:** gcoa@bigpond.com  
**T:** (07) 5594 7633  
**F:** (07) 5571 7481  
**A:** 8 Dunkirk Close Arundel QLD 4214  
**Open:** Tuesday and Thursday 9:00am to 3:00pm

### NORTH QUEENSLAND OSTOMY ASSOCIATION

**E:** admin@nqostomy.org.au  
**T:** (07) 4775 2303  
**F:** (07) 4725 9418  
**A:** 13 Castlemaine Street Kirwan QLD 4812  
**Open:** Monday and Thursday 8:00am to 4:00pm, Wednesday 8:00am to 12:00 noon

### QUEENSLAND OSTOMY ASSOCIATION

**W:** qldostomy.org.au  
**E:** admin@qldostomy.org.au  
**T:** (07) 3848 7178  
**F:** (07) 3848 0561  
**A:** 22 Beaudesert Road Moorooka QLD 4105  
**Open:** Tuesday and Thursday 9:00am to 3:30pm

### QUEENSLAND STOMA ASSOCIATION

**W:** qldstoma.asn.au  
**E:** admin@qldstoma.asn.au  
**T:** (07) 3359 7570  
**F:** (07) 3350 1882  
**A:** Unit 1, 10 Valente Close Chermside QLD 4032  
**Open:** Monday to Thursday 8:30am to 2:30pm, last Saturday of each month 8:30am to 12:30pm

### TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

**E:** bob.schull@bigpond.com  
**T:** (07) 4636 9701  
**F:** (07) 4636 9702  
**A:** Education Centre, Blue Care Garden Settlement, 256 Stenner Street Toowoomba QLD 4350  
**Open:** Tuesday 9:00am to 3:30pm

### WIDE BAY OSTOMATES ASSOCIATION

**W:** wboa.org.au  
**E:** wbestomy@bigpond.com  
**T:** (07) 4152 4715  
**F:** (07) 4153 5460  
**A:** 88a Crofton Street Bundaberg West QLD 4670  
**Open:** Tuesday, Wednesday, Thursday 8:30am to 3:00pm

## SOUTH AUSTRALIA

### ILEOSTOMY ASSOCIATION OF SOUTH AUSTRALIA

**W:** ileosa.org.au  
**E:** orders@ileosa.org.au  
**T:** (08) 8234 2678  
**F:** (08) 8234 2985  
**A:** 73 Roebuck Street Mile End SA 5031  
**Open:** Monday, Tuesday, Wednesday and Friday 10:00am to 2:00pm

### OSTOMY ASSOCIATION OF SOUTH AUSTRALIA

**W:** colostomysa.org.au  
**E:** orders@colostomysa.org.au  
**T:** (08) 8235 2727  
**F:** (08) 8355 1073  
**A:** 1 Keele Place Kidman Park SA 5025  
**Open:** Monday to Thursday 10:30am to 2:30pm

## TASMANIA

### OSTOMY TASMANIA

**W:** ostomytas.com.au  
**E:** admin@ostomytas.com.au  
**T:** (03) 6228 0799  
**F:** (03) 6228 0744  
**A:** Amenities Building, St. Johns Park, St. Johns Avenue, New Town TAS 7008  
**P:** PO Box 280 Moonah Tasmania 7009  
**Open:** Monday 9:00am to 3:00pm Tuesday to Friday 9:00am to 1:00pm by appointment

## VICTORIA

### BENDIGO AND DISTRICT OSTOMY ASSOCIATION INC

**T:** (03) 5441 7520  
**F:** (03) 5442 9660  
**A:** 43-45 Kinross Street Bendigo VIC 3550  
**P:** The Secretary, PO Box 404 Golden Square VIC 3555  
**Open:** Tuesday, Wednesday and Thursday 10:00am to 2:00pm. Second Tuesday of each month from 9:00am to 3:00pm

### COLOSTOMY ASSOCIATION OF VICTORIA

**W:** colovic.org.au  
**E:** info@colovic.org.au  
**P:** (03) 9650 1666  
**F:** (03) 9650 4123  
**A:** Suite 221 – Level 2, Block Arcade, 98 Elizabeth Street Melbourne VIC 3000  
**Open:** Weekdays 9:00am to 2:00pm

## GEELONG OSTOMY

**W:** geelongostomy.com.au  
**E:** goinc@geelongostomy.com.au  
**T:** (03) 5243 3664  
**F:** (03) 5201 0844  
**A:** 6 Lewalan Street Grovedale VIC 3216  
**Open:** Monday, Wednesday, Friday 9:30am to 2:30pm

### OSTOMY ASSOCIATION OF MELBOURNE

**W:** oam.org.au  
**E:** enquiries@oam.org.au  
**T:** (03) 9888 8523  
**F:** (03) 9888 8094  
**A:** Unit 14, 25-37 Huntingdale Rd Burwood VIC 3125  
**Open:** Tuesday to Friday 9:00am to 4:00pm

### PENINSULA OSTOMY ASSOCIATION

**W:** penost.com.au  
**E:** poainc1@bigpond.com  
**T:** (03) 9783 6473  
**F:** (03) 9781 4866  
**A:** 12 Allenby Street Frankston VIC 3199  
**Open:** Monday, Thursday 10:00am to 3:00pm

### VICTORIAN CHILDREN'S OSTOMY ASSOCIATION

**W:** rch.org.au/edc  
**E:** edc@rch.org.au  
**T:** (03) 9345 5325  
**F:** (03) 9345 9499  
**A:** Equipment Distribution Centre, Royal Children's Hospital, Basement 2 (green lifts), 50 Flemington Road Parkville VIC 3052

### WARRNAMBOOL & DISTRICT OSTOMY ASSOCIATION

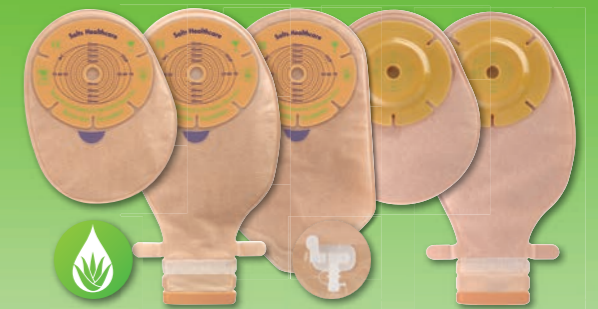
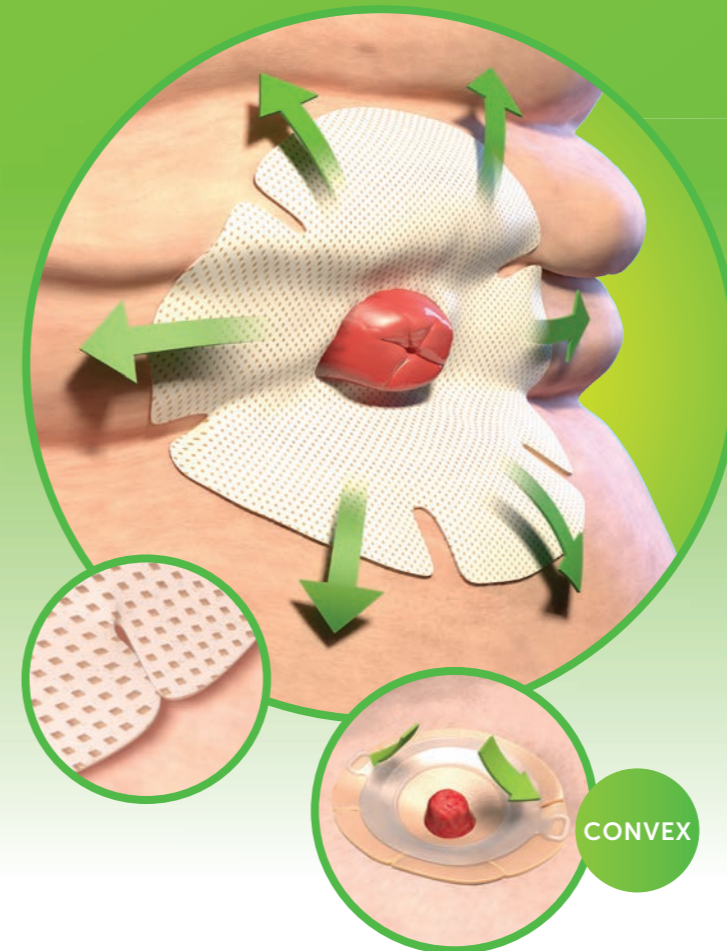
**E:** warrnamboolostomy@swl.net.au  
**T:** (03) 5563 1446  
**F:** (03) 5563 4353  
**A:** 279 Koroit Street Warrnambool VIC 3280  
**Open:** Friday 12:00 noon to 4:00pm

## WESTERN AUSTRALIA

### WESTERN AUSTRALIAN OSTOMY ASSOCIATION

**W:** waostomy.org.au  
**E:** info@waostomy.org.au  
**T:** (08) 9272 1833  
**F:** (08) 9271 4605  
**A:** 15 Guildford Road Mount Lawley WA 6050  
**Open:** Monday to Friday 9:00am to 4:00pm, Tuesday 6:30am to 4:00pm. Fourth Saturday of each month 9:00am to 1:00pm

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In 2005 I had my bladder and bowel removed due to a very rare mucus cancer of the abdomen called pseudomyxoma peritonei. I also lost my gall bladder, spleen and my appendix. Followed by a hysterectomy. Then a heated chemotherapy cleansing of the abdomen.

For about five years I was in and out of hospital every three months with bowel blockages which I was told was caused by scar tissue and would get better with time.

The bowel blockages did get better with time and stopped after five years and I had a few years with no problems.

By 2016 I thought I had beaten cancer and moved from Scotland to Adelaide. I have a son and daughter

and four grandchildren who live here so I wanted to be near them.

Two years ago a lump started growing on my colostomy and I thought I was getting a parastomal hernia. Unfortunately, it turned out to be the return of my cancer. The large lump now protruding through my clothes was the mucus cancer in my bowel.

The specialist consultant at the Royal Adelaide Hospital (RAH) said my abdomen was full of mucus. He said he could operate on my bowel but he could do nothing about the mucus now filling my abdomen and he would put me on palliative care I was devastated.

I agreed to the operation to remove the mucus pressing on my bowel but I knew this was only buying me time as

the mucus in my abdomen was now pressing on my stomach and causing me a lot of discomfort.

I am a member of an online support group of people who have the same cancer as me. One of the members advised me to contact a specialist in Sydney. The power of social media was going to save my life. Without it I would never have known about this amazing doctor who literally performs miracles.

I sent the specialist my CT scan. He said he could operate on me to remove the mucus. So, 18 months ago I flew to Sydney and had a 12-hour surgery. I had complications after it and was in hospital for three months. I lost a quarter of my body weight. I received the good news that I was cancer free. He said he had removed all the mucus from my abdomen.

I returned home to Adelaide and at a follow up CT scan I was devastated to be told that there was still some cancer in my bowel. So back I went to Sydney for more surgery.

Now it's six months later.

And I am happy to report that despite everything and all my weight loss. I am cancer free... again.

I decided long ago that I would not let the fact I wore two bags interfere with my life. Also, I try and talk about it to try and break down the stigma and the embarrassment some people feel about it.

I recently started working at the Ileostomy Association of South Australia as a volunteer. My duties include serving at the counter and packing boxes of stoma products for posting to our 2,500 members. I feel with all the help and advice I have received regarding my two stomas over the years it is great to be able to give something back.

I like to keep fit by hill walking and cycling and I really believe that being fit helps to kick cancer in the butt. I walk/run 5km every Saturday at Parkrun.

Living with a stoma... or two, can be challenging but I wear my bags with pride. ●

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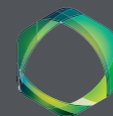
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NZ **0800 440 027** [www.omnigon.com.au](http://www.omnigon.com.au)

# National Directory of Ostomy Support Groups

## Covid-19 notice

Many support groups have paused due to COVID-19. Please contact the organiser before planning a trip to the meeting venue.

## AUSTRALIAN CAPITAL TERRITORY

### ACT STOMA SUPPORT GROUP

10am to 12noon, second Tuesday of each month (excluding January) at Level 2, 1 Moore Street Canberra (old stoma association rooms). RSVP required – Clare 0400921901 or geoff 0416206871 or aucldo@coloplast.com

## NEW SOUTH WALES

### ALBURY/WODONGA BORDER DISTRICT

10am on the second Tuesday of the month (except January).  
Venue: Hilltop Accommodation Centre, 600 Keene Street, East Albury NSW  
Contact: Alex Watson 0428 578 385

### BANKSTOWN AREA

A stoma support group hosted by Bankstown Hospital STNs for you and your family – everyone welcome.  
10am to 12noon on 3 March, 5 May, 7 July, 1 September, 3 November.  
Revesby Workers Club, 2B Brett St, Revesby (close to public transport and lots of free parking).  
Contact: Bankstown Hospital STN or Clare Jacobs on 0400 921 901 or aucldo@coloplast.com.  
Please RSVP for catering purposes.

### BATHURST

First Tuesday of March, June, September & December at Daffodil Cottage  
Contact: Louise Linke (02) 6330 5676

### BEAT BLADDER CANCER

7pm to 8:30pm, last Tuesday of the month from at Macquarie University Hospital, 3 Technology Place, Macquarie University.  
Contact: Adam Lynch, 0421 626 016

### BOWRAL STOMA SUPPORT GROUP

1pm to 2:30pm, second Friday in March, June, September, and December.  
Bowral Bowling Club, 40 Shepherd St, Bowral.  
Contact Lu Wang & Erin Wagner Stomal Therapists,  
Liverpool Hospital (02) 87384308 or Clare Jacobs 0400 921 901 / aucldo@coloplast.com.  
Everyone is welcome.  
Please RSVP 1 week prior.

### BROKEN HILL

Meet every third month or as required.  
Venue: Broken Hill Hospital Conference Room.  
Contact: Tarnadra (08) 8080 1333

### CENTRAL COAST

1:30pm to 3:30pm on third Wednesday in Feb, May, Aug and Nov at a different venue each meeting.  
For further information, phone the Stomal Therapy Service on (02) 4320 3323

### COFFS HARBOUR

2pm to 3:30pm  
Venue: Sawtell RSL Club, First Avenue, Sawtell.  
Ostomates & friends welcome.  
Contact Mandy Hawkins STN on (02) 6656 7804

### EUROBODALLA REGION

11am on first Sunday of Feb, Apr, Jun, Aug, Oct, Dec.  
Venue: Laughter Room, Moruya Hospital.  
Phone: Betty (02) 4476 2746

### FAR NORTH COAST

11:30am to 2pm. First Saturday of March, July, December.  
Meet at Lismore Workers Club 225, 231 Keen St. Lismore.  
Contact: Marie: (02) 6686 7248

### GOULBURN COMMUNITY STOMA SERVICE

9am to 3pm. Dates to be confirmed.  
Address: Goulburn Workers Club, 1 McKell Place, Goulburn, (02) 4821 3355  
The STN is Kelly Taylor RN STN 0402 250 475 e. kelly@communitystomaservice.com  
Kelly will provide individual consultations by appointment.

### GRAFTON & DISTRICT

9am to 11:30am, first Thursday of each month  
Contact: Anne: (02) 6641 8200

### GRIFFITH & DISTRICT

Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)  
Enquiries: Barry (02) 6963 5267 or 0429 635 267  
Email: ann.bar@bigpond.com  
Karan: 0434 785 309

### HASTINGS MACLEAY

10am to 12noon, third Wednesday in Feb, Apr, Jun, Aug, Oct, Dec.  
The Old Hospital  
Inquiries: Neil 0427 856 630 or Glennie 0410 637 060

### ILLAWARRA OSTOMY INFORMATION GROUP

10am to 12noon on 10 Feb, 14 April, 9 June, 11 August, 13 Oct, 15 Dec (Christmas luncheon. Venue to be advised).  
Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree.  
Contact Helen Richards CNC STN Wollongong Private Hospital phone: 042861109 or Julia Kittscha CNC STN Wollongong Hospital mob: 0414421021 office: 042551594 julia.kittscha@health.nsw.gov.au

### LIVERPOOL AREA SUPPORT GROUP

Meet from 1pm to 3pm. Dates to be determined.  
Cabra Vale Diggers Club, 1 Bartley St Canley Vale 2166.  
Contact: Erin or Lu on (02) 8738 4308

### MANNING/GREAT LAKES

10am to 12noon, first Wednesday in Feb, Apr, Jun, Aug, Oct, Dec.  
Venue: Skills for Life Building, 5-9 Elizabeth Ave.  
Taree NSW (wheelchair accessible)  
Web: www.mglostomy.co.cc  
Contact: Karla MacTaggart on (02) 6592 9469

### NEWCASTLE DISTRICT

1:30pm on the last Saturday in Feb, May, Aug (AGM), Nov.  
Venue: Hamilton Wesley Fellowship Hall,

150 Beaumont St. Hamilton.  
Enquiries: Geoff (02) 4981 1799 or Lynda 0425 209 030 or Maree (02) 4971 4351

### ORANGE & DISTRICT

From 12noon, Mar, June, Sept, Dec.  
Venue: 15 Oliver St, Orange, NSW  
Contacts: Louise: (02) 6330 5676 and Joanne: (02) 6362 6184

### SHOALHAVEN SUPPORT GROUP

From 2pm on 24 Feb, 25 Aug, 24 Nov at Nowra Showground Pavilion and 30 June and 18 Dec at Ulladulla Civic Centre.  
Contact Brenda Christiansen STN CNC. Ph. 02 44246300 or email brenda.christiansen@health.nsw.gov.au

### ST GEORGE AREA

10am to 12noon, third Tuesday of each month (except December / January).  
Ramsgate RSL Club, Ramsgate Road and Chuter Avenue, Sans Souci NSW 2219. (Close to public transport and free parking).  
Contact: Your STN or Clare Jacobs 0400 921 901 or aucldo@coloplast.com.  
Please RSVP for catering purposes.

### SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets: 1:30pm to 3:30pm on Thursday's 17 June, 30 September and 16 December in the Campbelltown Catholic Club, 20/22 Camden Rd, Campbelltown NSW 2560. For further information, contact: Erin or Lu on (02) 8738 4308, or Bernadette 0412 222 566

### SYDNEY - PENRITH AREA

Nepean Educational Support Group meets 2pm-3:30pm on 26 Feb, 23 April, 25 June, 3 Sept, 26 Nov. 63 Derby St, Penrith (University of Sydney Medical School) Family and friends are most welcome.  
Contact Naomi Houston on 4734 1245  
Access: The building is opposite Nepean Hospital's Emergency Department. Enter via the side path to the Clinical School's Outpatient waiting room. Please wait until 2:00 pm when you will be directed to the meeting room.  
Car Parking: Either on the street or in the multi-story car park on Somerset Street, Kingswood (free for pensioners for the first 3 hours)

### SYDNEY - NORTHERN AREA

10am – 11:30am, first Wednesday of the month in the Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Rd. Wahroonga.  
Contact: San Cancer Support Centre (02) 9487 9061

### SOUTH WEST SYDNEY STOMA SUPPORT GROUP

Meet from 1pm to 3pm.  
Dates to be confirmed.  
Camden Hospital, Heritage Auditorium, 61 Menangle Road Camden.  
Contact: Erin or Lu on (02) 8738 4308

### TWEED-BYRON

12noon to 2pm, third Tuesday of March, June, Sept. 2nd Tuesday in Dec.  
Venue: South Tweed Sports Club, 4 Minjungbal Dr., Tweed Heads South  
Contact: Lisa Clare STN (07) 5506 7540.

### WAGGA & DISTRICT

10am to 11am on first Wednesday of each month.  
Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga  
Enquiries: David (02) 6971 3346 or 0428 116 084 Baz (02) 6922 4132

## NORTHERN TERRITORY

### DARWIN

5:30pm to 6:30pm, first Tuesday of every month.  
Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810  
Contact: Marie Purdey: (08) 8944 1800

## QUEENSLAND

### BEENLEIGH

9:30am to 10:30am, first Monday of Feb, April, June, Aug Oct, Dec (Christmas Function)  
Logan Hospital, Room 1E. Cnr Loganlea and Armstrong Road, Meadowbrook 4131  
Ph: Leeanne Johnson STN (07) 3299 9107

### BOWEN

10am to 12noon, first Monday of every month at the Bowen PCYC

### INSIDEOUT TOOWOOMBA

These stoma mates would love to hear from you: ring for a chat or send an email.  
Margaret Brabrook (07) 4635 1697, emby1936@gmail.com;  
Leanne Wilshire (07) 4630 0629, leanne.wilshire@bigpond.com;  
Laurel Czynski, 0413 805 809

### ST ANDREWS HOSPITAL TOOWOOMBA OSTOMY SUPPORT GROUP

Meet the first Wednesday of every month between 12-1pm in Conference Room 2 at St Andrews Hospital, Toowoomba. 280 North Street, Toowoomba, QLD, 4350.  
Enquiries: Emily Day, (07) 46463029 and email: daye@sath.org.au

### MACKAY

2pm on the fourth Friday of Jan, Mar, May, Jul, Sep, Nov.  
Venue: St. Ambrose Anglican Church Hall, Glenpark Street, North Mackay.  
Contact: Graham Stabler for further information on 0428 776 258 or email: grahamstabler@bigpond.com

### SOUTH BURNETT

10am, second Tuesday of each month.  
Venue: Nanango Community Health Centre, Brisbane St. Nanango. QLD  
Contact: Anne Davoren  
Phone: (07) 4171 6750

### SUNSHINE COAST

Sunshine Coast Stoma Support Group meets at Maroochy RSL Events Centre, Memorial Avenue (off First Avenue), Maroochydore, second Monday of every month, commencing 10am.  
Enquiries: Laurie Grimwade: (07) 5445 9008 sid.and.laurie@gmail.com  
Janelle Robinson: 0409 762 457 candjrobinson@bigpond.com  
Kathy Himstedt: (07) 5445 9270 greg.kath1@bigpond.com

### WIDE BAY (Bundy Osto Mates)

10am to 12noon on the third Friday of each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West.  
Please contact Wide Bay Ostomates (07) 4152 4715

## SOUTH AUSTRALIA

### CENTRAL

2pm, third Tuesday of Jan, March, May, July, Sept, Nov.  
Ileostomy Assoc Centre, 73 Roebuck St, Mile End.  
Information: (08) 8234 2678 or speak with Val Macey (08) 8381 1646

### FLEURIEU

10am to 12noon, first Monday of March, June, September, December  
Flinders Rural Health, Bay road, Victor Harbour  
Contact: Lyn Sandford STN on 0421 000 960 or llynsandford09@gmail.com

### PORT AUGUSTA AND BEYOND

1:30pm on fourth Tuesday of each month in the Library/Bookshop behind St Augustine's Anglican Church, Church St. Port Augusta.  
Please contact Anne Wensley for more information on 0429 422 942

### PORT PIRIE

1pm to 2:30pm, third Tuesday of each month at GP Plus Medical Centre, 50 Gertrude Street, Port Pirie.  
Contact STN Jenni Edwards (08) 8638 4536

### SOUTHERN

2pm, first Wednesday of Feb, April, June, Aug, Oct, Dec.  
Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs.  
Information: Lyn Sandford STN 0421 000 960 or Sharmaine Peterson STN 0438 853 082

### YORKE PENINSULA

1:30pm, third Wednesday of Feb, April, June, Aug, Oct, Dec at Senior Citizens Hall, Verran Terrace, Moonta (next to Bowling Club). Contact Helen Collover on 0419 839 869

## TASMANIA

### ‘SEMI COLONS’

2pm to 4pm, third Friday of each month.  
Southern Cancer Support Centre, 15 Princes Street, Sandy Bay  
Contact Marg, Cancer Council Tasmania (03) 6169 1900

### TASMANIA SUPPORT GROUP MEETINGS

10am to 12noon, March, June, September & November

NORTH - Cancer Support Centre, 69 Howick Street, Launceston

NORTH-WEST - Ulverstone Senior Citizens Club, 16 King Edwards Street, Ulverstone  
SOUTH - Southern Cancer Support Centre, 15 Princes Street Sandy Bay  
Contact Adrian Kok on 0498 196 059 for dates

## VICTORIA

### BAIRNSDALE & DISTRICT

Available for people to talk to and for home visits in the local area.  
Contacts: Janine: 0418 854 562  
Derelle: 0448 458 997  
Email: bdosg@hotmail.com

### BALLARAT & DISTRICT OSTOMY SUPPORT GROUP

2pm, second Wednesday of each month  
Venue: Barkly Restaurant, cnr Barkly St and Main Road.  
Contact: Graeme on 0400 979 742 or David Nestor on (03) 5339 4054  
Emails: david.nestor2@bigpond.com or graob44@gmail.com

### BENALLA / WANGARATTA

2pm on the third Monday of each second month.  
Venues: Wangaratta: North-East Health, 4-12 Clarke St., Wangaratta, April, Aug., Dec. Benalla Community Health, 45 Coster St., Benalla, Feb, June, Oct.  
Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943.  
Email: mgpwang@gmail.com

### COLOSTOMY ASSOCIATION OF VICTORIA STOMAL SUPPORT GROUP

CAV offers support to all clients.  
We offer 30 minute consultations with a qualified STN, by appointment, two or three days per week.

### MILDURA

Meet: Every second month Venue: Mildura Base Hospital Conference room 1  
Contact: Vicky (03) 5022 3333 or Norma 0409 252 545

### SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2pm.  
Please contact Helen Lugethro on 0499 624 999 for more information.

### SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre  
Enquiries: Norma Murphy 0409 252 545

### WARRNAMBOOL & DISTRICT

10:30am, second Friday Feb, Apr, Jun, Aug, Oct, Dec.  
Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool  
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093  
Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

## WESTERN AUSTRALIA

### ALBANY

1:30pm to 3:00pm, first Friday of March, June, September and December.  
Albany Hospice, 30 Warden Ave, Spencer Park  
Contact Gerry 0498 666 525

### MANDURAH

5:30pm to 7pm, first Wednesday of each month.  
Training Room 3, Peel Health Campus 110 Lake Road Mandurah  
Contact: Lorrie Gray on 9272 1833 or info@waostomy.org.au

### PERTH

12noon to 1pm (New Members) and 1pm to 3pm (General support), fourth Saturday of each month.  
WA Ostomy, 15 Guildford Road, Mount Lawley.  
Contact: Lorrie Gray on 9272 1833 or info@waostomy.org.au

### NORTHERN SUBURBS SUPPORT GROUP

3pm to 5pm, second Saturday of each month. Various locations.  
Contact: d.carrybrown@me.com or call 9272 1833

### BOWEL GROUP FOR KIDS INC

Tel: 0458 596 185  
Email: enquiries@bgk.org.au  
Web: www.bgk.org.au

### YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623  
Email: helshae@hotmail.com  
Web: www.youinc.org.au  
Facebook: Young Ostomates United

### PARENTERAL NUTRITION DOWN UNDER

Tel: 0417 996 641  
Email: contactpndu@gmail.com  
Web: www.pndu.org

## Stoma Appliance Scheme Product Suppliers



### AinsCorp

PO Box 572, Niddrie, Victoria 3042  
Toll Free Number: 1300 784 737  
Email: service@ainscorp.com.au  
Website: www.ainscorp.com.au



### Dansac

PO Box 375, Box Hill, Victoria 3128  
Phone: 1800 880 851  
Email: priority@dansac.com.au  
Website: www.dansac.com.au



### Coloplast

PO Box 240 Mt Waverley Vic 3149  
Freecall: 1800 653 317  
Email: au.care@coloplast.com  
Website: www.coloplast.com.au



### ConvaTec

PO Box 63, Mulgrave, Victoria 3170  
Freecall: 1800 335 276  
Email: connection.au@convatec.com  
Website: www.convatec.com.au



### Sutherland Medical

Unit 2, 195 Chesterville Road Moorabbin Vic 3189  
Phone: 1300 664 027  
Email orders@sutherlandmedical.com.au  
Website: www.sutherlandmedical.com.au



### Future Environmental Services

PO Box 319, Blairgowrie, Victoria 3942  
Phone: +61 3 5985 2828  
Email: health@futenv.com.au  
Website: www.futenv.com.au



### Hollister

PO Box 375, Box Hill, Victoria 3128  
Freecall: 1800 880 851  
Email: priority@hollister.com.au  
Website: www.hollister.com/anz/



### Nice Pak Products

Free call: 1800 506 750  
Email: healthcare@nicepak.com.au  
Website: www.nicepak.com.au



### Omnigon Pty Ltd

PO Box 5013, Burnley, Victoria 3121  
Freecall: 1800 819 274  
Email: info@omnigon.com.au  
Website: www.omnigon.com.au



### 3M Australia

Locked Bag 19, North Ryde NSW 1670  
Phone: 136 136  
Website: www.3m.com.au



### Smith + Nephew

85 Waterloo Road, North Ryde NSW 2113  
Phone: 13 13 60  
Email: contactus@smith-nephew.com  
Website: www.smith-nephew.com/anz/



### Medline Australia

2 Fairview Place Marsden Park NSW 2765  
Phone: 1800 110 511  
Email: au.customers@medline.com  
Website: www.medline.com.au

# Did you enjoy this edition of the Journal?



Everyone's story can offer something to someone. Sharing the parts of our journeys that we've struggled through can be hard but can also help people on a similar path know they are not alone.

## We want your stories

Ostomy Australia is your publication. We are looking for your stories, your experiences, your letters, your photographs. Ostomates continually tell us how much pleasure—and how much useful information—they get from the journal.

## Send your stories to us

All stories, letters and articles are appreciated and valued.

### Please send them to the editor:

Editor: Ostomy Australia

Email: [journal@australianstoma.com.au](mailto:journal@australianstoma.com.au)

Post: PO BOX 267 Gosnells WA 6990

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