

Ostomy Australia

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**The power of
thinking differently
P14**

ALSO
IN THIS
ISSUE

Educate against stigma **P3**

Robots in surgery **P13**

Warming winter soups **P18**

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In this issue

P3 Stoma stigma

P7 Readers' letters

P13 Readers' stories

P23 Ask Wendy

P27 World news

P30 Support groups

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From the Executive Committee

By Ian Samuel OAM
ACSA President



Sophisticated program for orders

Your ACSA executive and its IT committee have had a busy and fruitful few months.

Earlier this year we appointed an IT committee to oversee the work of ACSA in the development of our SAMS program.

The program is used by all but one of our associations to conduct the ordering by you, their members.

The program is sophisticated and the IT committee, chaired by Mary Egan from New South Wales Stoma Ltd, is working with our IT employees, Kevin and Bryan, to ensure that your orders are processed and despatched in a timely manner.

A major initiative in the development of SAMS is a portal which will assist members to make their orders in an easier fashion.

It remembers what you have ordered in the past and can allow you to order based on your previous history.

This will take some time and a lot of money to roll out to all associations.

You will be told by our association when it is available for you.

I must repeat my plea to you to order wisely, ensuring that you have sufficient supply but not too much.

Surveys on distribution

Speaking of despatching products, the Department of Health and Aged Care, which has oversight of the Stoma Appliance Scheme, has been conducting surveys among ostomates and associations to gather thoughts on the most efficient means of distribution of products.

The ACSA executive has been involved with this process.

We should know the outcome of the process later this year.

Security on the radar

With people travelling a lot more the question of airport security for ostomates is at the front of our minds.

With the initiative of our vice-president, Lorrie Gray, we have had discussions with

airport security around Australia to ensure that ostomates are treated properly and not embarrassed.

Your association either has, or will be getting, special lanyards which will alert airport security that the wearer has a hidden disability.

You need to tell staff that you have a stoma and should be searched discretely.

Toy is not just child's play

As part of increasing stoma awareness, we have seen that Lego has a new figurine called Sara who has a stoma.

This is a fantastic initiative on the part of Lego and will go a long way to dispelling the myths around stoma bags.

I have written to Lego Australia to thank them and to explore the idea of them writing an article for *Ostomy Australia* and perhaps advertising in the journal.



Conference on guidelines

ACSA is supporting an ostomate representative to attend a conference in Glasgow to review the International Stoma Guidelines.

How you can help us

If you would like to assist the work of ACSA or your own association, please contact me to discuss what you might be able to do. Contact me by email: acsapres@australianstoma.com.au or 0416 044 881.

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Ostomy Australia was established in 1992 through the inaugural sponsorship of ConvaTec Australia and is published three times per year. It is available free to every member of an Australian Ostomy association.

Education stops stigma

By Eric Martin

ONE of the procedures that many people, including doctors, shy away from is the thought of completely losing the ability to go to the bathroom normally.

The thought of having to use a bag, strapped to their abdomen, to collect their waste can jolt potential patients into shock or dismay.

The creation of a surgically formed fistula, be it a colostomy, an ileostomy or urostomy, brings a range of issues to the surface, not just for the practical operation and maintenance of the stoma and appropriate bag but also psychologically.

And in a huge State like WA, managing those impacts can be especially challenging.

Stomal therapy nurse (STN) Tania Norman from the WA Ostomy Association is one of 26 specialist nurses who assist about 4000 ostomates across WA about the obstacles many people still face trying to arrange appropriate care for a procedure that was first performed in 1776.

“Stoma surgery is a life-changing event, and even though patients can live an otherwise normal life thanks to modern advances in care, they still need to make significant adjustments to their lives,” Ms Norman said.

“A stoma nurse is pivotal in the preparation prior to surgery: people need to be shown what the bags are like, what their stoma could potentially look like, what they could expect after the operation, and most importantly, how they can manage it after returning home.

“The nurses in the hospital will follow patients up post-surgery to check that everything is healing and then choose the right bag for them to wear.

“If you don’t have the right fitting bag, then leakage can occur, and you can imagine the effect that has.

“Some people won’t leave their house because they’re worried it could happen.

“Not only is that horrendous for their quality of life, but it also impacts their skin, which breaks down very quickly under those conditions.

“Trying to get anything to stick on it is almost impossible, which starts a vicious cycle if there is not intervention.

“Patients’ mental health can really suffer, and the post-traumatic stress is often particularly pronounced for younger people.”

So, situating the stoma appropriately for the ostomate’s needs is important – this involves putting it in a position where that person can see it away from any creases or folds in the abdomen, or scar tissue that might interfere with the bags sticking properly.



Dedicated care: Stomal therapy nurse (STN) Tania Norman.

Ms Norman pointed out that lifestyle factors were the other important consideration when working out the best location for a stoma, including recreational activities such as sport and more private pastimes such as sex.

“There are many things that STNs take into consideration when placing the mark for a stoma on their patient and, basically, we say that you should be able to do anything with it,” she said.

“You can take your bag off, you can shower with your bag off, swim with the bag on, you can jump out of planes – you can do all those things if the underlying reason why you’ve had a stoma isn’t impacting the rest of your life.

“But those who have emergency surgery and the surgeon’s not familiar with those factors, it frequently becomes problematic for the ostomate.”

Ms Norman said for people in regional centres, it was often an emergency procedure, with little or no warning for the patient, a fact further complicated by the lack of any STNs employed in WA north of Geraldton.

“These are often among the most impacting procedures for ostomates,” she said.

“Yet we have over 1000 members who do not have direct access to the support of an STN.

“To address this issue, I run a stomal therapy clinic at the association and travel across the State running stoma clinics and providing education sessions to health professionals.”

During her travels, she regularly encounters what would normally be considered outlandish breaches of patient care in a metropolitan setting.

“For example, there is an awful story from the Pilbara of a lady who had to go in for emergency surgery who woke up with a bag, no stoma nurse onsite to prepare her as to what to expect afterwards and, because it was the weekend, she was discharged with three hospital bags to wash out and a phone number of the stoma nurse at Royal Perth Hospital, which she couldn’t do until the following Tuesday,” Ms Norman said.

“She taught herself how to change her bags by watching YouTube, which while great, is also absolutely horrendous in terms of outpatient care.

“I met her again some years after and luckily, she was able to have her stoma reversed, but she was still suffering post-traumatic stress from her ordeal.

“Kalgoorlie’s another [WA] centre where it’s been historically challenging for ostomates.

“Last year, there were six new stoma procedures performed, with no stoma nurse to support them. Kalgoorlie is a major regional hub – we’ve got nearly 45 ostomates in total living in that region.”

Ms Norman has been travelling to Kalgoorlie annually for eight years to run the stomal therapy clinic and was thrilled that there were now two nurses at the local hospital that had completed the course – and were planning on staying in the region.

“If there is someone that has to have that surgery, then that care can be provided as part of the outpatients services,” she said.

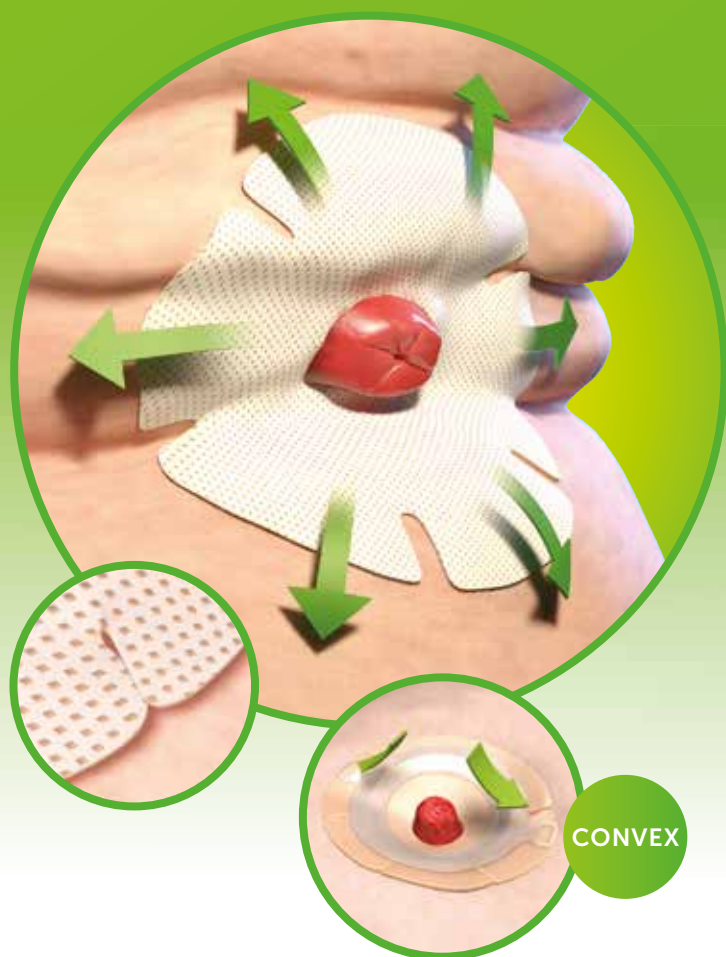
“But otherwise, if you are in a smaller regional community, the expectation is that ostomates fly to Perth and ideally stay for a good six months while they are going through the introduction to care, training, check-ups, and refits, as well as undergoing monitoring for complications, which are most likely to occur two to three months after surgery.

“But as you can imagine, most ostomates don’t stay that long.

“You are taking them away from their family and everyone else in their support network.”

□ Continued on page 5

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Embracing stoma helps overcome stigma

□ From page 3

Ms Norman explained that even though some hospitals, such as Royal Perth Hospital, could provide telehealth services for ostomates living in areas north of Perth, it was not on par with the hands-on care that ostomates could get with regular follow-up in the city.

“We have over 2500 different products to choose from, and we are incredibly fortunate in Australia that they are government funded,” she said.

“But if you are not given the correct product in that first instance, then you’re already behind the eight ball, and as most people require a stoma over a relatively long period of time, the requirements for the bag can also change.

“That’s why we recommend regular reviews at two weeks post-surgery, six to eight weeks, 12 weeks and then at six months until the end of the first year.

“Following that, we recommend a review every one or two years, because if you put on or lose weight, your stoma changes shape and will need refitting.

“Similarly, if you develop a hernia, which unfortunately is a common complication, then the stoma changes again.

“There are things that can happen that people, and many doctors, are not fully aware of.”

Ms Norman explained that providing stoma services in the bush was also potentially more challenging given the tough rural mentality that exists in the regions.

“The rural mentality is that ‘Well, we don’t have access to these facilities – this is what we’ve got, and this is what we put up with.’

“They are much less likely to go to a

doctor or to approach a nurse, or to reach out. When I started doing these rural trips, I met a gentleman in Carnarvon, who’d had his urostomy for six years and every night since had wet the bed.

“He hadn’t thought to reach out to anybody.

“When I reviewed him and put him on a different bag, he had his first dry night in six years – and has been dry ever since.”

The other issue Ms Norman highlighted was that many GPs were unfamiliar with stomas and were hesitant to advise as they don’t know what to do with it.

“It is still a taboo subject,” she said.

“I have worked in breast cancer nursing, and everyone will talk about breast cancer, but even though we tell our stoma patients that there is no reason why they cannot live a normal life, people will still dramatically change their lives because they don’t want others to know that they have a stoma.

“And, unfortunately, that stigma has partially transferred to the medical profession in terms of service provision.

“If patients are going back to their surgeon for review and they happen to mention that they have a problem with their stoma, they will often be told to contact the STN.”

The WA Ostomy Association is negotiating to offer specific training for GPs on stoma care and has made inroads on addressing the initial stigma by making presentations to medical students studying at Curtin University and the University of Western Australia.

“We’re hosting third-year medical students here at the association and are able to discuss stoma care right at the start of their education,” Ms Norman said.

“It can be very hit and miss during the doctors’ hospital training, whether they actually see a stoma formed or deal with an ostomate.

“We would like to see it incorporated into the actual program and then be offered as continuing professional development as well.

“It’s important to realise there are several reasons why a patient might need a stoma, such as cancer, inflammatory bowel disease and Crohn’s.

“We have had people who’ve been sick for years with Crohn’s disease and have put up with it because to them, they would rather die than have a stoma.

“But once the procedure is done – because they have no choice – they say they wish they’d had it done years ago, because suddenly they feel well again.

“Embracing your stoma does help people to deal with it psychologically and we now have ostomates, including weightlifters and even women in bikinis, willing to take their bag off and talk positively about it to help raise general awareness.

“But then there are also those people where their best friend of 50 years doesn’t even know they have had a stoma for the past 20.

“No one talks about it, even though nationally there’s 46,000 people with stomas.

“There are more than a million ostomates in America, it is not something that just happens sporadically.

“The lack of knowledge is quite apparent and that must change.”

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Your say

Letters to the editor

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Free to swim

IN response to Tom's wish for tips on swimming (*Ostomy Australia*, April), I would like to pass on my solution.

My stoma nurse in Albany has helped me with this exact problem 12 months or so ago.

There is a product available which is a tubular, elasticated support bandage.

It is similar to a compression style bandage and is lightweight, discreet, extremely form fitting, very supportive (great for bodysurfing or ocean swimming) and dries very quickly.

I have the option to wear boardies with or without a rashie depending on the weather.

I am more than comfortable in just boardies in either the leisure centre pool swimming laps or bodyboarding with the kids in the surf; I was previously reluctant to do either of these.

Another bonus to this product that I wear 24/7 is that it allows me to wear fashionable jocks, not those terrible black high ride boxer undies that I endured for the first 12 months of my appliance.

I wish I had known a whole lot earlier about this product.

It can be bought online or from larger chemist shops in 10m rolls, cut at home to size and lasts forever.

Maybe ask your stoma nurse for a sample if they have it, that is where I first came across it. Enjoy your new freedom in the water, Tom.

Geoff Aubrey, email.

Swimming adventures

I HAVE had a stoma for nearly 13 years and regularly swim – Mediterranean Sea, Florence Waterfall and Buley Rockpool in the Northern Territory, friends' pools or just regularly in the local ocean pool

or any small surf. I tried with boardshorts originally but they would drag down and I was not confident that the bag or shorts would stay in place.

Since 2018 I have used racing bathers (budgies) with a snug-fitting rash shirt.

The rash shirt helps hold the bag when doing laps and while there is a slight bulge under the shirt, it works.

I use a one-piece bag with a seal and a flange around the outside of the bag.

I have found that this allows me to go in the water a number of times during the day.

I empty the bag just before going into the water and again after the swim. The bags hold up extremely well and there have not been any leak issues from my swimming.

It does not matter if I do the bag change before or after the swim, the only thing is keeping hydrated.

So if I'm going out for an early swim I will change when I get back and if it's a late swim owing to tides or other things I will bag change before I go.

Hope this helps, good luck with the swimming and other adventures.

Warren Bell, email.

Ease the wipe costs

I HAVE read with interest a correspondent's comments and your editor's note on the topic of the supply of cleanser wipes (*Ostomy Australia*, April).

Some months ago now, I purchased a bulk supply box of water wipes, aloe vera, from a supermarket.

It was my contribution to easing the financial burden on the Stoma Appliance Scheme. The wipes have been excellent and super cheap.

We are extremely fortunate in this country to be looked after so well. It is incumbent on all of us to assist Medicare to save money.

Wet wipes from supermarkets are cheap and work well, so let us all do our bit to ease the costs on the SAS.

Eric W. Estlin, VIC.

Life has changed

I HAVE had a stoma since 2016; I have had a rollercoaster of emotions since then.

I am a positive, logical and very emotional person and I would like to say I am not the same as I was.

I just read the letter 'Need to vent' from Tara (*Ostomy Australia*, April).

I applaud you for venting.

I too have discovered that life is not the same. I have many times where I get angry, upset and full-on sulk about things I can't do anymore, about how my life is changed. I read your letter and said ... Amen! Too true!

I have tried to go swimming, ended up more paddling.

I have travelled and done the whole triple check on packing supplies.

Got tired of checking my diet – live and learn now.

I am super grateful for my supportive family whom without I would be doing a lot more sulking.

I try every day to find the person I was before.

I cling to things I can control and let go of stuff that is out of my hands.

I revel in my grandkids, my craft and take it day by day.

Christine, QLD.

Problem solved

A FEW years ago when I started using a two-piece system for my ileostomy, I was having trouble attaching the bag to the base as I had to press down too hard on the soft and pliant flesh of my abdomen.

I mentioned this on the Australian and New Zealand Ostomy Facebook support group and someone suggested using a base with a floating flange.

Never having heard of a floating flange, I rang around the stoma product supply companies and I was very surprised that some of them did not understand what I was talking about.

Then one company said "Ah, an accordion flange."

They sent me samples and my problem was solved – it was so easy to use and such a relief.

A floating flange is the specially designed base plate of a two-piece stoma pouch system.

It is especially helpful for arthritic fingers like mine as there is room to place the fingers under the baseplate to help minimise pressure on the abdomen when attaching a pouch.

The specially designed pouch has a tab near the top which is used for lifting and reattaching it to the baseplate.

I think the word accordion better describes the shape and function of this baseplate, especially as one company uses floating flange to describe all their baseplates, which is confusing.

There are many ads in our magazine for the latest and most comfortable baseplates but I have never seen one for a floating or accordion flange.

I think quite a few of us elderly stoma mates might have arthritic fingers so it would be helpful to see some ads for according flanges in the next edition of our magazine.

Margaret Brabrook, email.

More letters on page 9

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Continued from page 7

All done with mirrors

I HAVE been an ostomate since May last year, and I turn 80 this year.

The good people at the Wide Bay Ostomate Association introduced me to your very informative and professionally detailed magazine *Ostomy Australia* which I always look forward to receiving.

We have two very dedicated stoma nurses (Heidi and Nicole) at our Bundaberg Base Hospital and I and others are very grateful to have them both to care for and educate us new ostomates,

But there comes a time when one must carry out the twice-weekly pouch change oneself, which I have been doing now for some time.

It is my decision not to involve my lovely wife Theresa in the process of my pouch changing when I am capable of doing 99 per cent of the job myself.

This brings me to the one per cent bit I struggle with when I am fitting my pouch.

My stoma has now prolapsed to a length of 70mm and the difficulty I have is the stoma is so long, when I am fitting the barrier seal and the pouch opening around the bottom of the stoma I can't visually see how to fit these correctly as the prolapsed stoma is hanging down and covers the bottom area from my eyesight and I run out of hands.

With Theresa and I being travellers for many years across oceans and four-wheel-drive land adventures, we have always had to get ourselves out of trouble and use whatever we could use to rectify our problem of the day.

I have discovered a light which does the trick for the individual person to change their stoma themselves; it has three-way individual lights.

I place the zero magnified side of my travelling mirror on the inside of the light and turn just one bat wing light on at the back as shown in the photo.

The light shows on to my stoma area and reflects into the mirror lighting the whole area of my stoma area.

The visual problem is fixed and I don't need to ask for anyone's help.

At first I had the doubled magnified side of the mirror turned to the front and I couldn't believe it when I saw the Growler (my stoma's name) had doubled in size and for once in my adventurous life I thought I was in trouble – big time.

It didn't take me long to sort out the problem and with relief I had a smile on my face a mile wide.

Thanks to the good people of *Ostomy Australia* for giving us an avenue for us Aussie ostomates to share our stories and happenings.

Moss Hunt, QLD.

Change affects lives

AFTER reading Russell Cross's letter in the April edition, I agree.

I have had a colostomy for 66 years and I have had in excess of 45 operations, so it's a difficult stoma to manage.

I have used the same two-piece appliance for approximately 45 of those years, until recently when I was notified the appliance I have been using would no longer be available.

It immediately concerned me so I contacted the company representative, to be told unfortunately it is correct.

They sent me samples of the new system and I must I was shocked at how much trouble I had using them as I had gone from a two-piece drainable pouch with a clip that worked second to none, to a fold up hook-and-loop closure and I have found that they are not very user-friendly, particularly when trying to drain one.

I'll put it this way, I think they're unhygienic and very difficult to deal with and I have had at least three seam failures and you can imagine how that ended.

Now for the life of me I can't understand why they have done this and I can not get a satisfactory answer from them.

I have written to their Australian, American and British head offices and they have just danced around the issue and not answered my questions.

I would imagine this has affected a lot of lives and I'm not sure a lot of thought was put into that fact, in particular concerning long-term users.

I would hope that they may reconsider their position or certainly change the new ones because I can't use them the way they are.

Unfortunately they are affecting people's lives.

Shane Wilkinson, NSW.

Clip is unusable

I HAVE been an ostomate since 1974 and have progressed from the "old rubber bag" to today's appliances and I am very grateful not to be back in the 70s.

However, I must agree with Russell Cross of Tasmania (*OA*, April) as I use the two piece 'clip method' and sincerely hope that these are not going to disappear altogether.

The new clip is unusable for me as, being very short, I tuck the end of the pouch under.

The new clip is curved which means when tucked under it faces outwards – impossible! It's also not easy to open and close.

Fortunately, for the moment, I have enough of the old straight clips to last another 12 months.

I don't know what I'll do after that – to the manufacturer, please bring back the straight clip.

I don't like the hook and loop fastener method, I find it very hard to clean after emptying as you can't get a flat edge.

Also, the clip is useful to scrape the contents to the end of the bag. As I'm in my eighties now I really don't wish to change to a new method so I beg the companies to please keep a good thing going.

Margaret, email.

Another one for clamp

RE: Russell Cross's story (*OA*, April), you've said actually how I feel about the new appliances.

The only difference to Russell's comment is I've been using the clamp system since 1983 and I'm 83 years of age.

We had no warning – this is what you get, like it or not, and yes I would've like to stay with what we had until the end.

Paul George Peles, email.

Bag disposal advice?

I AM new to the stoma world.

I would appreciate any advice on the disposal of a used bag when at someone's home for a meal, especially if one doesn't know the hostess well.

What do others do in this situation to avoid embarrassment?

Any ideas or tips would be appreciated please.

Jeanette, QLD.

Supplies delayed

THANK you for your magazine; I have been an ostomate for 11 years (I really grappled with that title for a long time).

Recently, because of unrest in the Middle East, and attacks on shipping in the Suez Canal, and wharf strikes in Melbourne ports, our supplies were delayed.

It seems to me, with the world in a state of unrest, supplies could be sorely interrupted at anytime.

My question is have we ever sought out companies to manufacture here?

Maybe too we need to be more discerning in what is really needed in supplies – not endless options.

Inez Woods, email

More letters on page 11

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Continued from page 9

Travel is a mixed bag

TWO years ago, I had rectal surgery and now have a colostomy bag.

For my first overseas trip since my surgery, I was feeling a bit anxious over what horror stories I have heard and travelling with the bag for the first time.

I read about the Sunflower lanyard and procured one.

On arrival at the airport and trying to check in, we had some assistance as a dear friend who works for the airline had put comments next to my booking about my recent surgery; the two ground staff assistants were very helpful.

We headed off to security and after putting my bag on the conveyer belt to be X-rayed, I was then asked to enter the X-ray machine.

Two security guards looked baffled and asked me to show them what was under my t-shirt; to my amazement he asked me to take my ostomy bag off.

I then explained what it was (he thought it was a money belt).

At this time my bag and passport were at the end of the X-ray machine; luckily I was travelling with a friend and he picked them up.

I was asked to wait for a supervisor and after a wait I was then asked for my passport and they filled in a consent form.

I then stood up and was asked to rub my hands over the bag, then was asked to rub my hands over this little device, which was taken away for analysis for explosives.

After coming back negative I was told I could go, so I went on my merry way.

Coming back from New Zealand I had a better experience as I went through the X-ray machine.

I was asked to look at the screen and asked about two yellow squares showing up.

I replied that one was the colostomy bag, which he asked to feel and to which I obliged, and the other one was the metal on my braces.

This was a much more pleasant experience.

Peter Addison, NSW.

No privacy at airport

ON Christmas day last year I went through the scanner at Melbourne Airport knowing I was going to have my ostomy bag questioned as they always do now with their use of the X-ray scan.

A woman stopped me and asked me what it was my stomach that had come up on the scanner; I told her I have an ostomy.

She asked if I wanted to show it to her where I was, or go to a private room.

There was of course a crowd of passengers waiting behind me to go through the security who could hear the conversation.

I replied I would rather go to a private room (did she really expect me to pull down my pants in the queue and show everyone my bag?).

She then yelled out to a staff member about 10 metres away at another scanner: “We have an ostomy here, can you come over?”

Privacy suddenly had no place for me and I had to wait for a second officer to come over.

I was escorted to a shabby room and the door closed with the two officious women standing by me.

I had to sign a form saying I consented to the inspection (I did not consider it true consent), and then the first officer told me to show her my bag.

I did so by pulling down the front of my trousers.

My husband, who was told nothing, had waited outside.

He was appalled at the way I was treated. He had heard the officer shout out about my ostomy and told me to complain.

I felt humiliated by the process but I didn't make a complaint because it was Christmas day.

Last year, I travelled to London, Norway and Abu Dhabi and not once was I treated like this. It seems to be a Melbourne airport “thing”.

Paula Loughnane, email.

More airport stories

JUST when I thought it was safe to pass through the Tullamarine airport security scan booth, everything went pear shaped (pouch shaped) two weeks ago.

I really believed that we had made good progress through the Sunflower lanyard Hidden Disability program and my recent flights out of Tullamarine airport reflected there was no need to show my pouch at the security area, a simple hand test for possible drugs and I was on my way.

Everything changed on my trip in April – I went through my usual drill, stepped into the security scan booth, explained to the security officer I had a medical device and placed my hand over the area that would appear on the security screen.

The security person called for a female officer to attend.

I was not prepared when I was told to lift my clothing to expose the pouch.

Standing there in full view of the crowds of onlookers waiting to go through the security scanning booths,

I asked the officer why I needed to do this as usually a hand scan will suffice.

The officer said her supervisor had told

her to do it and she asked if I wanted to go to a private room.

I shook my head, lifted my shirt to expose the top of the pouch and the officer, horrified, fled to the drug testing device, checked my hand and let me go.

I asked the supervisor why, after 11 trips in the past 12 months, this was the first time I was asked to expose my pouch.

She replied: “Because you might have a gun, knife or other weapon in there and some security scan officers are too lazy to check.”

It was like a flashback to the first humiliating experience at Tullamarine airport security scanning I had in 2022.

I have corresponded over the past years with the Department of Home Affairs who make the rules and regulations for airport security; my complaint was taken very seriously, yet here I was back to square one.

I decided that those with a hidden medical disability deserved to be treated with far greater respect, including those with a urostomy, diabetes and other medical conditions.

I wrote a complaint submission to the Australian Human Rights Commission asking for representation to address the situation that exists at Tullamarine airport for those with a hidden medical disability, outlining the inconsistency of treatment we endure at the airport security screening process, the humiliation we feel and the need for informed training, respect and understanding.

One week later I received the amazing news that the Australian Human Rights Commission had confirmed acceptance of my complaint and I would hear from the person allocated to investigate and represent the case in due course.

Understanding this procedure will take time, I would be grateful for any personal stories from fellow ostomate travellers to add to my submission.

Look forward to sharing how this process unfolds.

Viv Parry, VIC.

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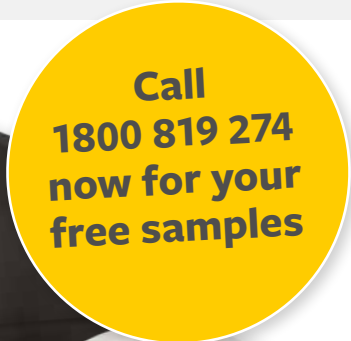


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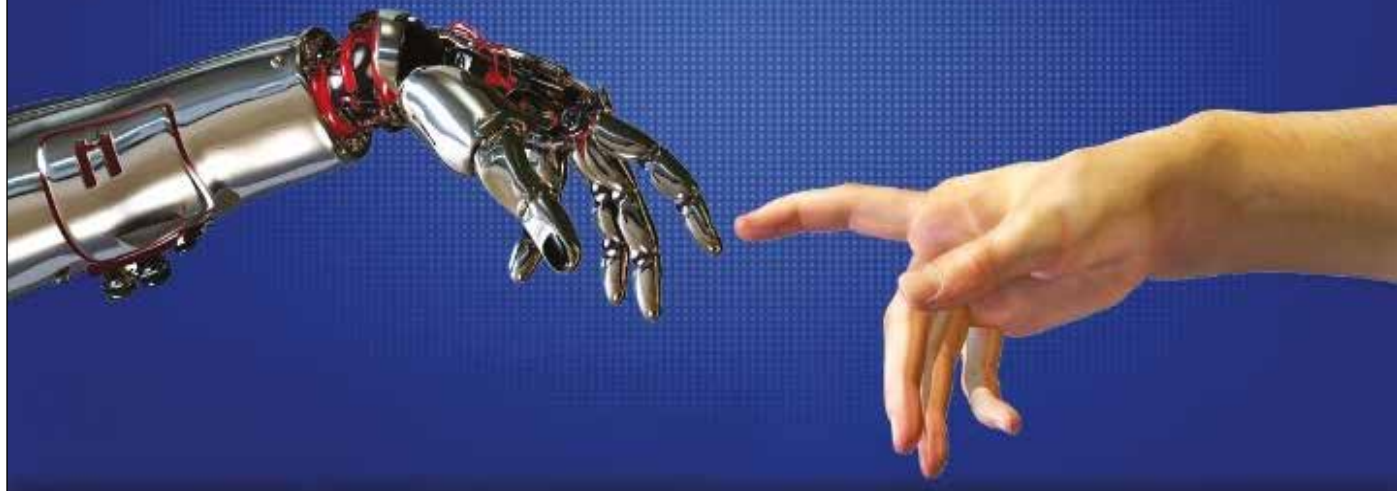
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One in 50,000



Technology: A robotic cystectomy was part of Stephen Reed's life-changing surgery which made him one of Australia's nearly 50,000 ostomates.

Robotic surgery leads to exclusive club

By **Stephen Reed**

IT was life-changing.

I had just come out of hospital after having a robotic cystectomy (a bladder surgery method using tools attached to a robotic system), a mode dissection, prostate removal and ileal conduit.

In my layman's terms, it was a six-and-a-half-hour surgery to remove my bladder, parts of my pelvic nodes and my prostate, and to set up for an external bag.

I am now at home and I feel well but in discomfort.

I had stayed one night in the intensive care unit and five nights in the ward.

They said my recovery was textbook; I put it down to the quality of the surgeon and the hospital team.

For me my life changed two weeks after my 70th birthday last year in October.

I had some blood in my urine, a lot on the first urination and reducing over the next two.

This was totally unexpected as my doctor kept telling me I was the healthiest person my age.

It was only eight days before we started a 35-day holiday to Honolulu which included cruising back to Sydney.

Going against my male pride, I went the next day to my doctor and had pathology tests done.

Later in the week, my doctor said the tests didn't show anything but she still referred me to a urologist surgeon – I made the appointment for immediate-

ly after my holiday. Returning really refreshed from our holiday I went to my urologist appointment.

He made me feel really at ease by saying my results were 'unremarkable'.

I had never been called unremarkable before but I happily accepted it.

However, he wanted to check my prostate. I went to lay on the bed and found out what the test really involved.

Whilst I felt a little embarrassed he booked me in for a cystoscopy.

Within the fortnight I was in surgery for the first time in my life.

After a short 30-minute sleep, my immediate thought on waking was: "Ouch!"

The surgeon had found a non-muscular carcinoma.

I had cancer.

What a range of emotions went over me and my wife.

Stage two was to go for intravesical immunotherapy, commonly called a BCG (from *Bacillus Calmette-Guerin*, the name of a vaccine which stimulates the immune system).

The treatment started in early January and went for six weeks.

Being so healthy early last year, we had booked not only our October trip to Honolulu but also a cruise for February, April and late May.

Yes, we love cruising and we didn't downsize to free up money to sit at home.

Now I had to cancel all of the cruise as I would be undertaking treatment and follow-up.

At the end of the BCGs I went back for an additional cystoscopy; I really believed it would come back clear as I had done everything right.

However, two more non-muscular carcinomas were found.

The doctor advised me the only option from here was to remove the bladder, parts of my pelvic lymph nodes and my prostate – and it was to be done within the fortnight.

He quickly pointed out the operation would be life-changing, not life-threatening.

The operation was booked for the morning I was meant to flying into Rome for a three-day stay before cruising the Mediterranean.

I had the operation and it was successful.

I was cared for in the hospital and I now sit at home – well, for a few hours as I need to walk for five minutes, six times a day.

My life has changed but at the point I would say for the better.

I should be cancer-free as the cancer was only in the wall of my bladder.

Family and friends have been so loving and kind, especially my wife who has been with me at every appointment, scan, blood test and for my time in hospital.

I don't like the bag but the thought of doing nothing is scarier.

I know I will be here for the long haul.

Plus, I have joined a new club which has about 50,000 Australian followers – sounds a bit exclusive to me.

Stressed or blessed? The

By **Ray Veal**

Retired member of the Australian Association of Family Therapists

TWO years ago I did not know what an ostomate was – now I know because I am one.

As someone who has had the life-changing and life-saving surgery that led to having a stoma and a colostomy, I would have preferred my journey to have been like that in the old Irish saying: “As you slide down the bannister of life may the splinters never point in the wrong direction.”

There were certainly many splinters pointing the wrong direction when I began my journey to becoming an ostomate.

It all began when I followed nature’s call to the toilet and discovered I was having a massive diverticular haemorrhage.

I drove myself to the local Base Hospital emergency department where I was rushed into the skilled care of a great medical team.

By now I was unconscious and I am told that I had to be revived a couple of times and given copious amounts of blood.

Eventually the bleed source was found and stopped and I was able to go to a ward, where I remained for three weeks.

I thought I had dodged a bullet and would soon fully recover but my recovery was slow and my body was not responding to care and rest.

Then one night I doubled up in pain that resembled that of appendicitis, a diagnosis supported by the ambos who came and took me back to hospital.

But we were all wrong.

The previous medical team had stopped the bleed, but my blood supply was not reaching another part of my large bowel and necrosis was slowly killing that part – I now had a perforated bowel.

I had emergency surgery and my secret life as an ostomate had just begun.

Stress and the ostomate

Actually, the life of an ostomate is not so secretive because much is known and written about the physiological and psychological impacts of stoma surgery and the mental health of patients following surgery.

Aside from the physical implications, having a stoma can also have a significant effect on mental health and can affect an ostomate’s sexual life, the ability to return to employment, general anxiety, depression, body image and low self-esteem.

Mentally ostomates may be wired differently but some things are common to all, such as thinking of the stoma as a

stigma, and feeling stressed or anxious, especially in social situations where a bag malfunction would be very distressing.

Adjusting to the new ostomate lifestyle is at times not so easy at home or in a public place.

I have dramatically reduced my social activities and grieve the times I spent pre-stoma mixing socially with my friends and church family.

There are always the what-if questions to answer: What if my colostomy bag fills quickly or starts to leak or becomes detached? What if people notice the bulge in my clothing?

Stomas have a reputation for being rude in the ways they interrupt conversations.

They can blow bubbles, burp persis-

“Unless we acknowledge that we have a problem there will be no solution to that problem

tently, introduce phonetic punctuation to any conversation.

Ostomates can develop a parastomal hernia, which I have, as well as a prolapse – which I also have.

Any one of these issues can create stress and anxiety for an ostomate, and these reasons and more, having a stoma can bring either stress or blessing.

Stress seems to be a sign of our modern times; as dwellers in the 21st-century industrialised and technologically advanced nations we are rich, healthy, educated and cultured beyond the imagination of our grandparents – and yet chronic illness and mental health concerns are more evident than ever before.

I think it would be fair to say that living with a stoma adds another stressor

to life for ostomates.

So, let’s look at stress and anxiety as experienced by some ostomates and suggest ways to manage these two imposters.

How stress works

Often stressors can be part of a cluster of things causing stress, or the particular stressor might be managing one aspect of life with a stoma.

For ostomates one key stressor is the stoma itself and some aspects of managing it both at home and in the social arena.

Keeping the thoughts in our heads positive is so very important – if we don’t dispel negative thinking our brain will believe what we think, and our stress and anxiety level will increase.

Saying to yourself “I won’t be able to manage a stoma leak if it happens in a public place,” is the kind of negative thought that will be believed by our brain.

Not just in your head

Physiological responses play a part in the stress we experience.

As your body attempts to adapt to a stressor, biological and psychological events may occur.

If you are feeling uncertainty and lack of control over your stoma, your body will continue in a state of alert.

This is where the body releases hormones to help fight the fight and you will experience significant stress, and maybe physical exhaustion, as a result of living in a state of anxiety.

Your emotions also play a part in the stress response, as our thoughts precede our feelings.

If we think we can’t cope then we will feel out of control.

If we feel stressed, anxious or depressed about managing our stoma it may help to remember that many worries we have can sometimes come from unfounded pessimistic thoughts.

So, the message for ostomates who worry about a bag malfunction or any such related problem is change your thinking and reduce your stress and anxiety.

In response to the stressors in our life, we continually are making choices, choices that determine our behaviour.

This is more commonly known as our fight or flight responses.

The question is do we stand up and fight the stressors or do we escape or try to avoid them?

We do have choices – to be stressed or to be blessed.

But to make the best choices we must acknowledge our negative self-talk.

We must avoid saying things like, “I can’t do this,” or “If I do go out what if the bag malfunctions?”

answer is all in your head

The secret is to capture and change our negative self-talk and so change our behaviour.

Train your brain

Some neuroscientists now contend that contrary to what we used to believe, the brain does not peak in growth at a young age and then gradually decrease in functional ability as we grow old.

Modern fields of research suggest the brain may have life-long plasticity that enables it to change at any age, generating new neural pathways and transmitting messages; this could help you to make different decisions, like the decision to change negative pathways into positive ones.

The brain is the most amazing organ in your body, ready and waiting to help you have a great positive and healthy life as an ostomate.

This is a powerfully positive message to all of us – it is possible to teach an old dog new tricks.

Medical research now suggests we may be able to turn our lives around by changing our thought patterns. There are many research articles on how to do this, but I will simplify the way with just two basic but powerful steps.

Step one is acknowledgement.

Unless we acknowledge that we have a problem there will be no solution to that problem.

The first step is critical: we must admit that we are stuck in a negative mindset where of the thousands of thoughts we have every day, a staggering majority are likely to be negative.

Be aware that you do have a lot of mental control over your thoughts.

If you have significant other people in your life, it will be a very good move for you to share your story with them and use them as a kind of life coach.

Change your mind set

Remember, it is what we believe that determines how we behave.

The trick is, change your mind and change your brain – and your life.

If we believe that our stoma will malfunction, our behaviour will reflect this fear and stress will build up.

The truth is that bad things can and do happen but they happen far less often than we think.

We must acknowledge every negative and toxic thought that the inner critic plants in our mind and consciously change that thought to the truth.

One powerful way to do this is called reframing.

The best way to explain this art is by a specific example.

Recently I woke at 4.15am to realise that my colostomy bag had become detached and had created an awful mess.

The previous time this happened, I responded in all the wrong ways.

I looked at the negative parts of the problem, blaming myself for allowing this to happen and fearing that it would happen again soon.

This time I automatically responded by reframing the situation – by being thankful that this had not happened for more than six months; by not blaming myself for not putting the bag on correctly, and by being thankful that life-saving surgery meant that I was still alive and well, albeit inconvenienced.

Our brains can be rewired.

Our thoughts can be changed from negative to positive and we can silence that pesky inner critic who tells us we can't win.

Our brains can and do change and create new neural pathways.

The positive voice will tell us that for every stoma malfunction there are hundreds of times when there was not a malfunction.

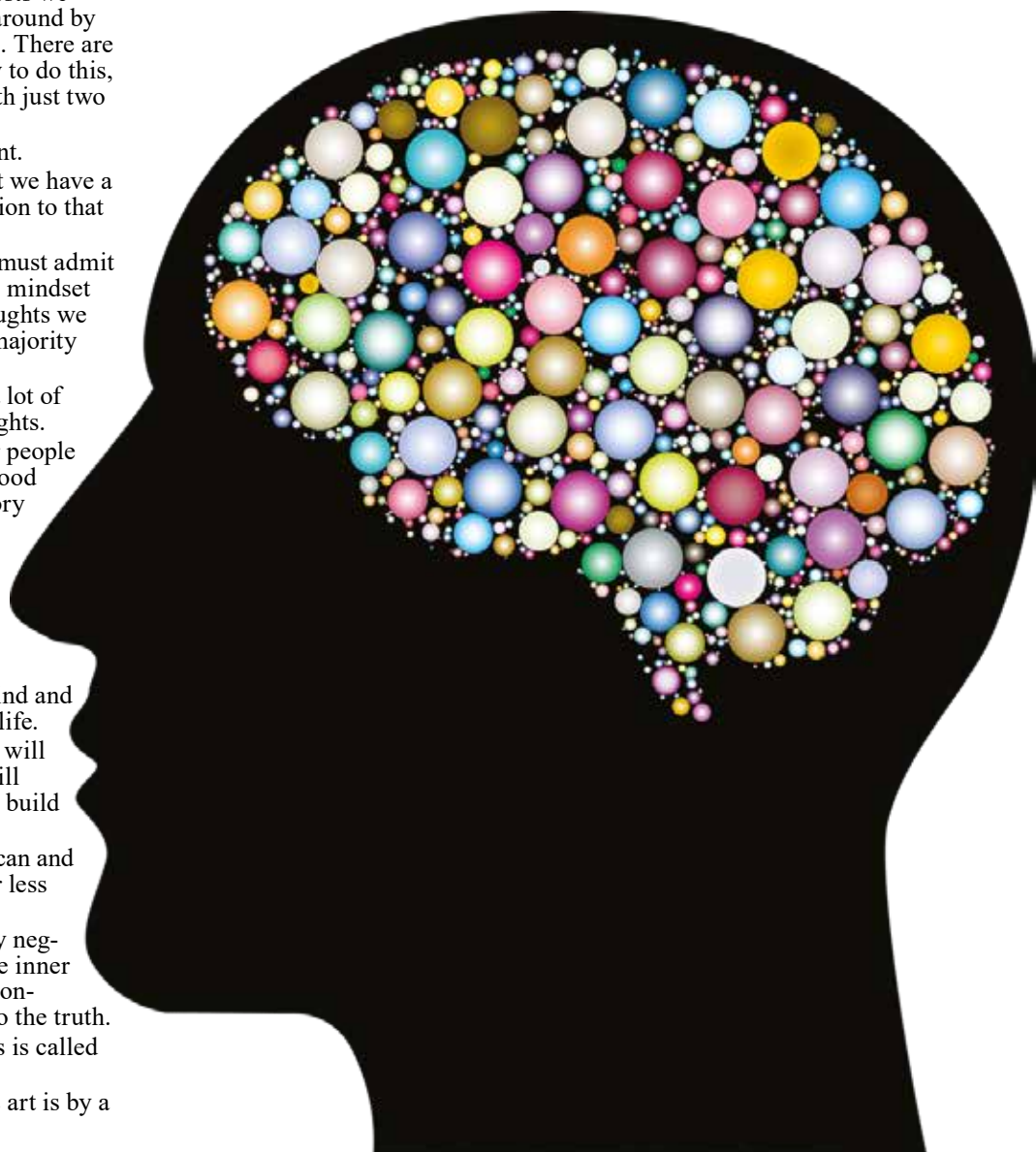
For ostomates this means that we literally capture any wrong thinking as it happens.

Your amazing brain has about 86 million neurons ready and willing to reduce your stress and anxiety and to greatly improve your wellbeing – if you choose to make the changes.

Having stoma surgery is life-changing and life-saving for ostomates, giving them a new lease on life.

This is the blessing that matters much more than the little inconveniences.

To be blessed or stressed? I guess it is up to you.



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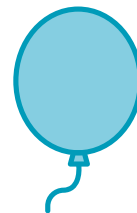
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Warm up with



Butternut pumpkin soup

Ingredients

100g butter
800ml vegetable stock
1 onion
2 garlic cloves
1 tsp cumin powder
1 butternut pumpkin
100g double cream
Salt and pepper
Chopped chives



Method

Peel and dice the onion, peel and crush the garlic, peel and remove the seeds of the pumpkin then chop into small cubes.
Heat the butter in a large saucepan and sweat the onion and garlic for 3-4 minutes, or until translucent.
Add the cumin and cook for an extra minute.
Add the butternut squash and cook for a further 5 minutes.
Cover with the vegetable stock, bring to the boil and then turn down to a simmer for 20 minutes, or until the pumpkin is tender.
Blend the soup in a food processor until smooth and pass through a fine sieve.
Taste to check the seasoning then add the cream for a nice texture.



delicious soup

Get the scoop on soup

FOR ostomates, finding suitable and nourishing foods is crucial for maintaining health and comfort.

Soup is easy to digest and gentle on the digestive system and can be easily customised to accommodate dietary restrictions or preferences.

Soups have high water content, helping ostomates maintain proper hydration.

This is crucial as ostomates can be prone to dehydration, especially those with ileostomies.

The liquid form of soup allows for easier absorption of nutrients, which can be beneficial for ostomates who may have reduced absorption capacity due to shortened bowel length.

The cooking process often breaks down fibres and softens ingredients, making them easier to digest for sensitive digestive systems.

Warm soups can help stimulate digestion and provide comfort, while cold soups can be refreshing and hydrating in warmer weather.

Butternut pumpkin is easily digested for most people and provides starchy carbohydrates that can reduce the chance of a stoma pouch overflowing.

Full of vitamins, fibre, magnesium and potassium, this recipe is a perfect autumn and winter warmer.

To top it all off and make it a main meal, toast some crusty bread such as a French baguette.

Like everything in life and especially ostomy life, it's important to remember that everybody is different; the soup recipes should be taken into account with your personal needs and dietary requirements.

Cheesy broccoli soup

Ingredients

1kg broccoli
50g butter
1 onion, chopped
1 large potato, peeled and quartered
1.5 litres vegetable stock
Salt and pepper
125ml single cream
1 tbsp lemon juice
1 tsp Worcestershire sauce
A few drops of Tabasco sauce
125g mature Cheddar, grated

Method

Remove tough stems and leaves from the broccoli
Cut off stalks, peel and cut them into 2.5cm pieces, break the broccoli florets into small pieces and set them aside
Melt butter in a large saucepan
Add onion and broccoli stalks and cook, covered, for 5 minutes over a moderate heat, stirring frequently
Add reserved broccoli florets, potato and stock to pan, bring mixture to boil
Cook, partially covered, for 5 minutes
Season to taste with salt and pepper and continue to cook over moderate heat for 20 minutes, or until vegetables are soft
Using a blender or food processor, puree mixture, then transfer to a clean saucepan
Add cream, lemon juice, Worcestershire sauce and Tabasco
Simmer for 3-5 minutes – do not allow to boil or the soup will curdle
Just before serving, stir in the grated cheese

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PARTICIPATION IN THIS STUDY INVOLVES

- Completion of an online questionnaire approximately 20-30 minutes duration
- If chosen you may also be asked to complete an optional online telehealth interview, approx. time commitment 60 minutes

To be eligible you must be over 18 years and have or have had a colostomy or ileostomy

For more information or to sign up for this research contact Associate Professor Teresa Mitchell-Paterson
tmitchell-paterson@torrens.edu.au



Potential benefits: Participating in this study brings the patient voice to the forefront of this important and sometimes challenging part of a stoma patient's life, and may stimulate further study in this nutritional field

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of Torrens University Australia, ethics reference 0189



Irritated skin an opportunistic fungus

Hello everyone. I hope that wherever in Australia you are that you are managing the cooler weather (or drier if you are in the north).

It's certainly been harder to get out of bed in the mornings here in Perth.

I have had one question – thank you “A” for such a good question!

“After recent surgery I was put on a prolonged course of antibiotics, a side effect of which was a bad case of candidiasis (thrush). As I am now an ostomate who has had a total pelvic exenteration, I didn't get the usual vaginal discharge, but I did find the skin around my urostomy stoma was very irritated, which is unusual for me - is this how thrush can manifest in an ostomate? What is the best way of dealing with this?”

Thrush is caused by a fungus called *Candida albicans*.

This fungus is a part of our normal everyday ‘flora’ that lives on our skin and is quite a common cause of a peristomal dermatitis.

It appears as a red (erythematous) rash and can sometimes also have little pustules or papules.

It often feels itchy and can be a bit

patchy (these are called satellite lesions).

The peristomal skin around any stoma provides a warm, moist environment making it the perfect setting for *Candida albicans* to flourish.

It is also a particularly opportunistic fungus; that means that when the setting is right, the fungus kind of takes over rather than just co-habiting nicely with all the other bacteria and fungi that lives on our skin and therefore becomes problematic.

My rule of thumb is that the skin around the stoma should look like the skin on the other side of your tummy (i.e. the skin that doesn't sit under your stoma's baseplate).

If the skin around your stoma looks different, then please contact, or see your stoma nurse if you have any concerns about the skin around your stoma.

To answer this issue's questions, we do tend to see peristomal thrush more in urostomates than other types of stomas.

This probably happens because the output from a urostomy (being urine) is more liquid than other types of stomas so things are a little bit more moist.

The infection can be triggered by antibiotics as antibiotics can kill the healthy

bacteria that live on the skin.

The loss of the healthy bacteria can disrupt the balance that exists with the normal skin flora.

Any topical medication that you are going to put under a baseplate should be in a lotion or powder form.

Creams and ointments can affect how the baseplate will stick to your abdomen and can contribute to leakage and lifting of the base.

You can buy antifungal lotions and powders over the counter at the chemist.

Personally, I prefer the lotion formulations as I find that these will rub in well and absorbs into the skin better than powders do but both formulations will work.

If your local pharmacy doesn't have an anti-fungal lotion or powder in stock, please ask them to order one in for you rather than settle for a cream or ointment.

Do you have question for Wendy about stoma health or anything to do with ostomies? Send an email to journal@australianstoma.com.au

Dietary choices critical for stoma needs

By Teresa Paterson-Mitchell
Associate Professor, Torrens University

LIVING with a stoma presents its own unique challenges, particularly when it comes to diet and nutrition.

While dietary choices are critical for managing a stoma, there is currently no standardised guidance for post-surgical stoma patients in Australia and New Zealand.

This gap in knowledge means that many patients leave the hospital without the necessary dietary advice to support their recovery and long-term health.

Challenges of post-operative stoma

One of the most common complications after stoma surgery is postoperative ileus (POI), a condition where bowel movements are delayed, and gastrointestinal motility is reduced.

POI is also called an a dynamic or paralytic ileus, meaning the intestines do not move food along the intestinal tract as they should after surgery.

This can slow down the transit of bowel matter and make it hard to produce output and cause difficulty eating and drinking normally.

This can cause significant discomfort, including abdominal pain, nausea, and stoma discomfort. POI affects approx-

imately 30 per cent of patients and can last from days to weeks, making recovery more difficult and distressing.

Following the POI's temporary paralysis, the bowel may become overactive leading to high output from the stoma.

The reality of dietary changes

While we have some understanding of the dietary habits of rural stoma patients in Australia, there is limited knowledge about the dietary choices of the broader Australian stoma patient population.

Without proper dietary guidance, many patients struggle with nutritional deficiencies and other health issues.

A survey in New Zealand revealed that many stoma patients had poor dietary habits, with only 20 per cent meeting the recommended fruit and vegetable intake.

Furthermore, 40 per cent of patients who experienced nausea reported that their dietary choices to address this issue had worsened since their stoma surgery.

The need for Australian stoma voices

As a bowel care nutritionist with 15 years of experience, and experience with my father's stoma, I have witnessed stoma patients' difficulties in finding reliable dietary information.

A lack of understanding of the impacts of particular diets can lead to increased

stoma output, blockages, or discomfort, significantly affecting the quality of life.

Recent research indicates that 30 per cent of stoma patients are discharged without any dietary advice, and 90 per cent of these patients wish they had received more guidance.

Share your experience

To address this critical issue, research is currently being conducted with stoma patients across Australia.

More information on this research and how to take part in the survey can be found on the opposite page.

By participating in the survey, stoma patients can share their experiences and insights on how diet affects stoma output and quality of life.

The aim of the study is to understand the challenges stoma patients face and highlight the importance of timely dietary guidance and its effect on stoma output and quality of life.

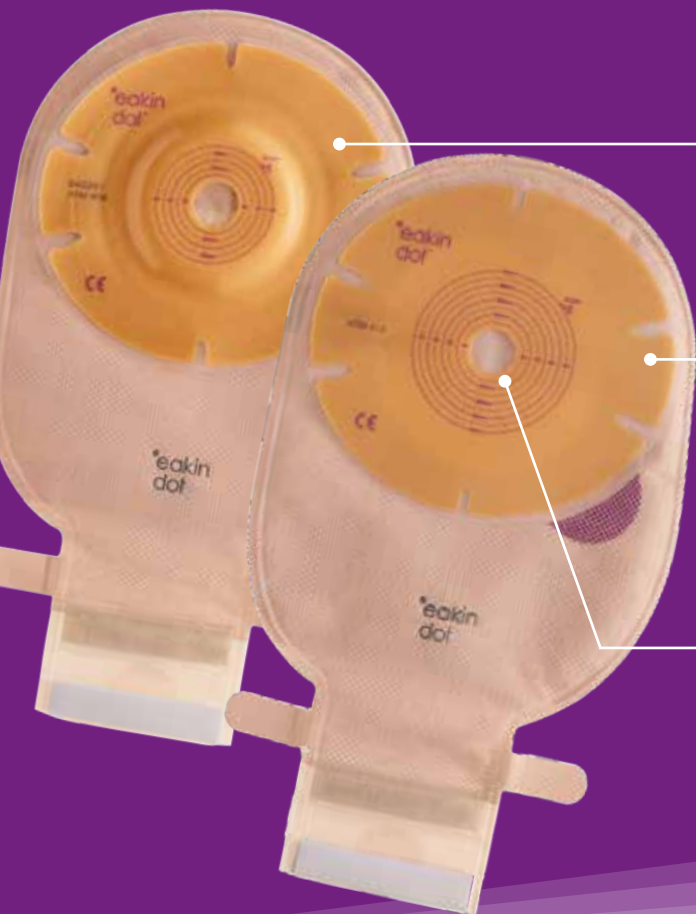
Managing life with a stoma involves many challenges, but with research, we can bring attention to the dietary issues stoma patients face.

By sharing experiences, a voice will be given to Australian stoma patients and contribute to improving dietary guidelines and support.

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1. eakin dot® user evaluations. Data on File, 2019

2. T.G. Eakin Laboratory Testing Summary report. skinsmart hydrocolloid 2020 (Data on file)

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1. Salvadalena et al. “Lessons Learned About Peristomal Skin Complications Secondary Analysis of the ADVOCATE Trial”. J Wound Ostomy Continence Nurs 2020;47(4):357-63. ©2023 Convatec Inc. All trademarks are the property of their respective owners. AP-64644-AUS-ENG-v2 O640 September 2023

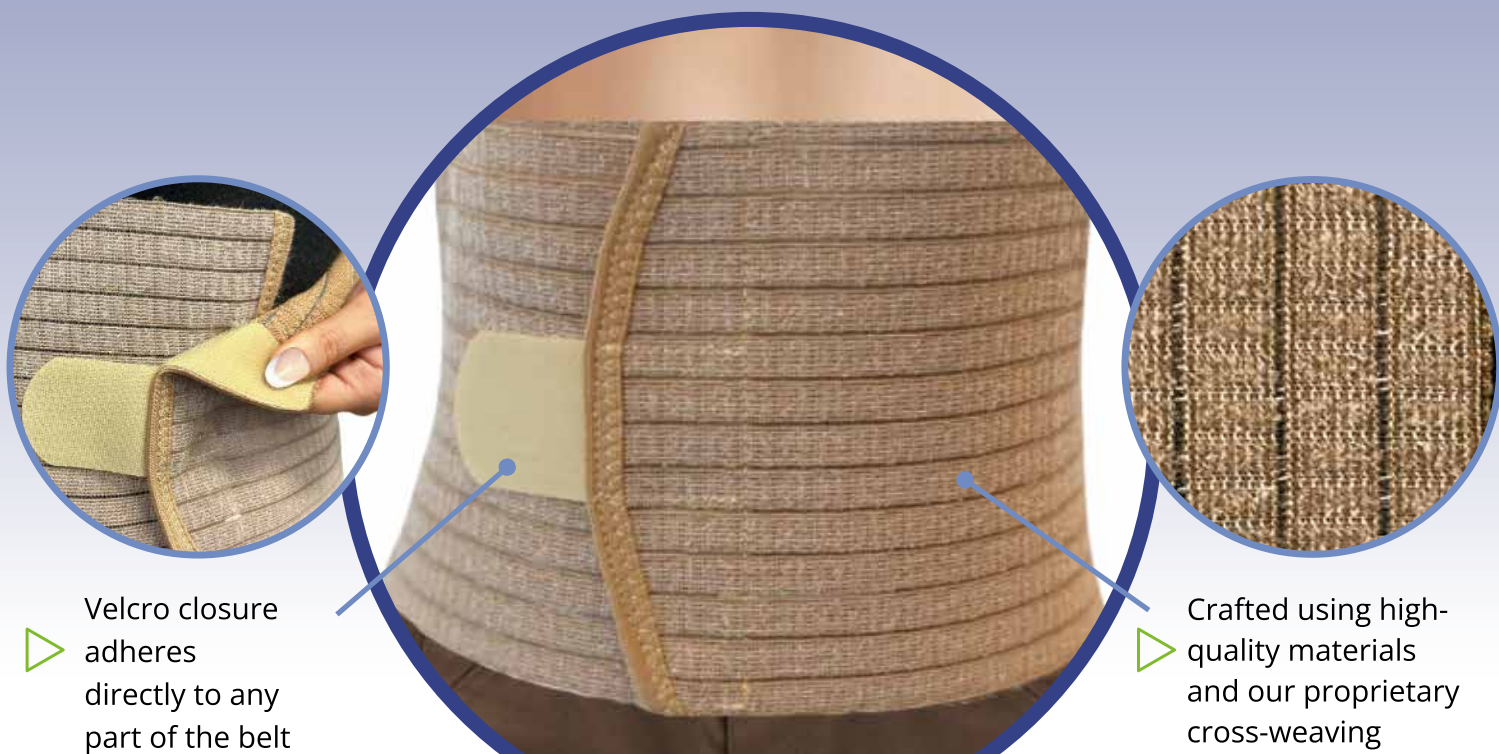


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SBNLXL23	LGE/XLGE	23cm	80-155cm

4 belts per year available from your Association

News of the World

A dedicated win



USA: A professional golfer who tasted success in his senior major debut has dedicated the win to his brother, who is battling cancer.

Englishman Richard Bland won the Senior PGA Championship in May with an eight-under 63 at Harbor Shores in Michigan (USA).

What made his success all the more emotional for Bland was not the \$630,000 pay day but being able to dedicate it to his older brother Heath.

“He got diagnosed about a year ago now with bowel cancer,” Bland said.

“He had chemotherapy and radiology and what have you and he had to have surgery, so he’s had his bowel and I think his prostate and bladder removed.

“So now he’s got two colostomy bags.

“I’m just so pleased that I could do this for him – this doesn’t feel like it’s my tournament, it’s his.”

(www.irishtimes.co)

Chairman of the bag



USA: A new memoir by *Magnum PI* star Tom Selleck has detailed how fellow celebrity Frank Sinatra was “bad-tempered and navigating a

colostomy bag” while appearing on the hit TV show.

Sinatra underwent surgery in 1986 for diverticulitis, a serious inflammation of the colon, which later progressed and left him with a colostomy.

Magnum PI was his final acting appearance, in 1987.

After being diagnosed with bladder cancer, Sinatra died of a heart attack in 1998.

In his memoir *You Never Know*, released in May, Selleck wrote that

despite his bad temper, Sinatra was keen to appear on the show.

“I called Frank and said we would have to write a part especially for him,” Selleck said.

“He said he didn’t care what the role was, as long as he got to beat somebody up.”

A biography of Sinatra released in 2015 claimed he could not have fathered Ronan Farrow, the son of Mia Farrow who was born while the actress was in a relationship with director Woody Allen, as Farrow claimed, because Sinatra was at the time “at home in Palm Springs with a colostomy bag and his ever-watchful wife.”

(www.usatoday.com)

Reality of IBD



ENGLAND: A reality TV contestant wants to ‘break the taboo around poo’ with a new campaign to highlight bowel disease

that she said left her terrified she’d soil herself.

The Traitors’ star Mollie Pearce, 22, has had ulcerative colitis since she was 11 and is keen to help others suffering from symptoms she says many are embarrassed to talk about.

As part of this she is fronting a new campaign called Where’s Crohn’s & Colitis which invites people to participate in an online game to learn more about the ‘invisible condition’ of IBD.

Pearce said she used to have panic attacks about being able to find a toilet.

The anxiety carried through to many aspects of her life and it wasn’t until she got a stoma at the age of 18 that she said she finally managed to overcome it.

“It took me a while to get used to the bag obviously but I knew I wasn’t going to have an accident and the anxiety doesn’t affect me any more,” she said.

“People who are suffering with IBD symptoms sometimes aren’t going to the doctor’s because they feel embarrassed.

“I want to try change that and make sure no one is feeling embarrassed when it comes to their UC.”

(www.dailymail.co.uk)

High rates of disease



NEW ZEALAND: A PhD candidate has completed research which suggest New Zealand has one of the highest rates of inflammatory bowel disease in the world.

The main types – Crohn’s disease

and ulcerative colitis – cause ongoing inflammation in the digestive system that can lead to complications such as scarring, ulcers, and cancer.

Angela Forbes, a national authority on IBD epidemiology, calculates that in Canterbury alone, there are now more than 4000 patients with inflammatory bowel disease, a three-fold rise in the past 20 years.

Aotearoa already has one of the highest rates of IBD in the world, with 1 in 161 diagnosed with the lifelong progressive condition – a prevalence comparable to type 1 diabetes.

Rates are growing rapidly, estimated at 5.6 per cent annually.

Rates started climbing rapidly in the Western world in the 1950s and numbers are still rising; what is driving the increase is a scientific puzzle.

Specialists and researchers say there’s too little research to identify causes yet but point to interactions between the gut microbiome, environmental exposures such as antibiotics, and diet, particularly the rise of ultra-processed foods.

A 2017 report commissioned by Crohn’s & Colitis New Zealand estimated that the cost to healthcare and lost productivity was \$245 million annually.

(www.stuff.co.nz)

Inaugural clinic



KENYA: Stoma World Kenya (SWK) has celebrated a significant milestone with the launch of its inaugural clinic at Guru Nanak Hospital.

It is the first clinic of its kind in Kenya to provide specialised care for patients with stomas.

At the inauguration ceremony, speakers highlighted the significance of the clinic’s establishment in enhancing access to quality healthcare services for stoma patients across Kenya.

The launch also served as a platform to raise awareness about stomas and the challenges faced by individuals living with the condition.

By bringing together healthcare professionals, policymakers, and advocates, SWK aims to foster a supportive environment for stoma patients and their families, promoting education, empowerment, and inclusivity.

The event was attended by dignitaries including the Director General of Health from the Ministry of Health, the Manager of the National Health Insurance Fund (NIHF) and representatives from the Kenya Medical Supplies Authority (KEMSA).

(www.ostomyeurope.org)



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I was told early on to
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passionate about in
life, no matter what
challenges you have
”

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in your own skin

Darren, Ulcerative Colitis Champion

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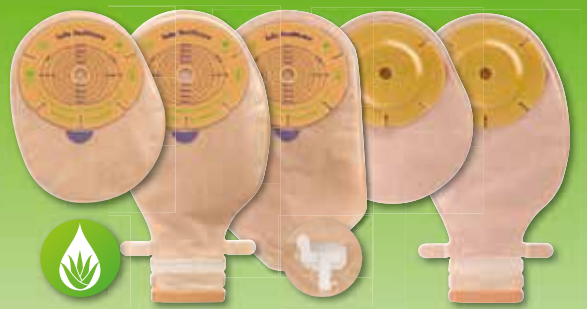
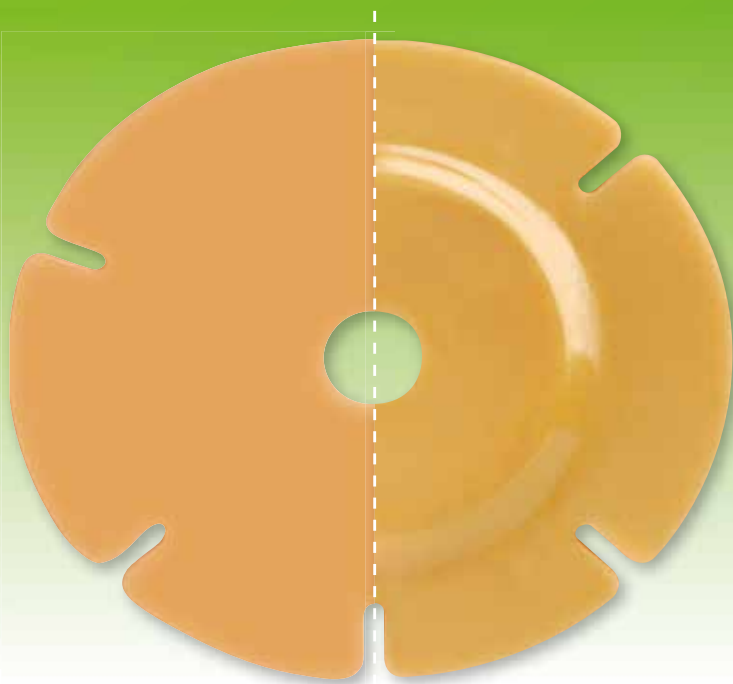
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National Directory of Ostomy Support Groups

AUSTRALIA

Beat Bladder Cancer: The Australian national support group (online via Zoom) for bladder cancer patients/carers from all across Australia. All welcome. Last Tuesday of every month 7.30-9pm AEST. Register at: www.beatbladdercanceraustralia.org.au

ACT

Canberra: ACT support group, 10am to noon, second Tuesday bi-monthly. Location: 2nd Floor, City Health Building, 1 Moore St, Canberra. Contact Geoff Rhodes on 0416 206 871 or email grhodes@home.com.au

NEW SOUTH WALES

Albury/Wodonga: 10am on the second Tuesday of the month (except January). Studio Room, SSA Club Albury, 570-582 Olive St., Albury. Contact Alex Watson 0428 578 385.

Bankstown: 10am-noon on the first Wednesday every third month, next meeting November 1. Revesby Workers Club, 2B Brett St, Revesby (close to public transport and free parking). Please RSVP for catering purposes to your Bankstown Hospital STN or Mariam Elfoul on 0400 921 901, email: aumael@coloplast.com

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

Bowral: Bowral Bowling Club, 40 Shepherd St, Bowral. Contact: Lu Wang and Erin Wagner (stomal therapists), Liverpool Hospital (02) 87384308 or Mariam Elfoul on 0400 921 901, aumael@coloplast.com. Please RSVP one week prior.

Central Coast: 1.30-3.30pm on third Wednesday in February, May, August and November. Different venues each meeting. Contact the stomal therapy service on (02) 4320 3323.

Coffs Harbour: 2-3.30pm. Every second month at RSL Club, First Avenue, Sawtell. Contact Mandy Hawkins, stomal therapy nurse, on (02) 6656 7804.

Dubbo: Stoma Support Group meets on the last Friday of the month, 2-3pm. Dubbo Health Service Ian Locke, building Room 8. Contact 0408 769 873 or email: Thulisile.Moyo@health.nsw.gov.au

Eurobodalla Region: 11am on first Sunday of February, April, June, August, October, December. Laughter Room, Moruya Hospital. Contact Betty (02) 4476 2746.

Goulburn: 10am to noon. Goulburn Workers Club, 1 McKell Place. Contact

Clare Jacobs 0400 921 901 or aucldo@coloplast.com

Grafton/Clarence Valley: Meets on the second Tuesday bi-monthly. Aruma Community Health, 175 Queen St, Grafton. Register with Jane Kulas (02) 6640 2222 or 0459 943 062.

Griffith district: Contact Barry (02) 6963 5267 or 0429 635 267 or email ann.bar@bigpond.com or Karan 0434 785 309.

Hastings Macleay: 10am-noon, third Wednesday in February, April, June, August, October and December. The Old Hospital. Contact Neil 0427 856 630 or Glennie 0410 637 060

Illawarra: Ostomy information group. August 9, Oct 11, Dec 13. 10am-12pm. Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree. Contact: Helen Richards CNC STN Wollongong Private Hospital 4286 1109 or richardsh@ramsayhealth.com.au; or Julia Kittscha CNC STN Wollongong Hospital 0414 421 021 or 4255 1594 or julia.kittscha@health.nsw.gov.au

Liverpool area: 1-3pm. 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: 10.30am, first Wednesday of every second month. Taree Group Three Leagues downstairs meeting room, 43 Cowper St. Contact Karla MacTaggart on (02) 6592 6169, email karla.mactaggart@health.nsw.gov.au

Nepean: The Nepean Education Stoma Support Group meets at 2-3.30pm on September 8 and December 8. Medical School, outpatients department, 62 Derby Street, Kingswood. The building is opposite Nepean Hospital's Emergency Department. Contact Naomi Houston on 4734 1245 or NBMLHD-Stoma@health.nsw.gov.au

Newcastle district: 1.30pm. Last Saturday in February, May, August and November. Hamilton Wesley Fellowship Hall, 150 Beaumont St. Contact Geoff (02) 4981 1799, Lynda 0425 209 030, Maree (02) 4971 4351.

Orange and district: noon, March, June, September and December. Venue: 15 Olver St, Orange. Contact Louise (02) 6330 5676 or Joanne (02) 6362 6184.

Shoalhaven: August 30 Ulladulla Community Health Centre (cnr South St and Princes Hwy), November 29 Nowra Community Health Centre (12 Berry St). Time: 2pm. Register with STN CNC Brenda Christiansen (02) 4424 6300 or brenda.christiansen@health.nsw.gov.au

St George: 11am-1pm, third Tuesday quarterly. Ramsgate RSL Club, Ramsgate Road and Chuter Avenue, Sans Souci. Close to public transport and free parking. Please RSVP for catering purposes to your STN or Mariam Elfoul on 0400 921 901, email: aumael@coloplast.com

Sydney: Continent Urinary Diversion Support Group meets on the last Saturday afternoon of the month in February, June and October in Sydney CBD. We all have had internal urinary pouches formed using bowel and usually using an Indiana Pouch. We meet at the Bowlers' Club in Sydney or at 99 On York. Contact Sandra Burgess (02) 9913 3287

Sydney – Liverpool/Campbelltown: 1-3pm Thursdays. Heritage Auditorium at Camden Hospital, Menangle Road. Contact: Diane or Lu (stoma therapy nurses) on (02) 8738 4308

Sydney – Penrith: 2-3.30pm, 29 April, 24 June, 26 August and 4 November. 63 Derby St, Penrith (University of Sydney Medical School). Contact Naomi Houston on (02) 4734 1245. The building is opposite Nepean Hospital's Emergency Department. Enter via the side path to the outpatient waiting room.

Sydney – Northern: 10-11.30am, 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 and Liverpool: 1.30-3.30pm, Oct 19 and Dec 7. Campbelltown Catholic Club, 20/22 Camden Rd. Contact Erin 0419 224 662 or Lu 0417 026 109 for catering purposes please.

Tweed-Byron: noon to 2pm, second Tuesday of March, June, September, December. South Tweed Sports Club, 4 Minjungbal Dr., Tweed Heads South. Contact Lisa Clare stoma therapy nurse (07) 5506 7540 or Kate Rycroft 0432 251 703.

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

QUEENSLAND

Logan: Aug 5, 10-11.30am; Oct 14, 10-11.30am Jingerrri Meeting Room, Logan Hospital. Bldg 3, Level 5. Dec 16, 10-noon Christmas party. Mibbun Meeting Room. Building 3, Level 1. Logan Hospital, Meadowbrook, cnr Loganlea and Armstrong Roads. Contact: Leeanne Johnson CNC Stomal Therapy (07) 3299 9107.

Bowen: 10am on the first Wednesday of every month. Bowen Hospital. Contact natasha.leaver@health.qld.gov.au

Brisbane: The Brisbane Ostomate Support Group meets from 10am-12pm on the fourth Thursday of each month at the Chermerside Bowls Club, 468 Rode Road, Chermerside. Contact ilonalanyi@hotmail.com or QSA (07) 3359 7570.

Logan: May 30 at 9.30-11am, July 10 at 4.30-6pm, September 5 at 9.30-11am, November 13 at 5-6.30pm, December 15 at 2.30-5pm. All meetings are held at the Logan Hospital in the auditorium. Contact Leeanne Johnson on (07) 3299 9107 or leeanne.johnson@health.qld.gov.au

Mackay: 2pm, fourth Friday of January, March, May, July, September and November. St. Ambrose Anglican Church Hall, Glenpark Street, North Mackay. Contact Graham Stabler on 0428 776 258 or email grahamstabler@bigpond.com

St Andrews Stoma Support Group: 280 North Street, Toowoomba. Meets on the first Wednesday of every month (except December and January) 12-1pm in the conference room. Lunch provided, education talks and friendly conversation by stoma therapy nurse and ostomates. Contact Emily Day: daye@sath.org.au or 4646 3029.

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

Sunshine Coast: 10am on the second Monday of every month in the Keith Payne Room, Maroochy RSL Veteran Hub, Memorial Avenue, Maroochydhore. Contact Laurie Grimwade 0419717889, email sid.and.laurie@gmail.com; Janelle Robinson 0409762457, email candjrobinson@bigpond.com; or Kathy Himstedt (07) 54459270, email greg.cath@bigpond.com

Toowoomba: Insideout. Contact Margaret Brabrook (07) 4635 1697, emby1936@gmail.com; Leanne Wilshire (07) 4630 0629, leanne.wilshire@bigpond.com; emby1936@gmail.com; Laurel Czyski, 0413 805 809.

Wide Bay: Bundy Osto Mates. Starting again in September 2024. New time and date to be advised. Contact Wide Bay Ostomates (07) 4152 4715.

SOUTH AUSTRALIA

Adelaide Hills: 10am-noon on the second Wednesday of January, March, May, July, September and November at Nairne Soldiers Hall, Main Road, Nairne. Contact Alicia 0403 663 837 or Betty 0428 373 770.

Barossa: Either 12-2pm or 7-9pm on the third Monday of February, April, June, August, October and December at Vine Inn, Hoopman Room 14-22 Murray Street, Nuriootpa. Contact Barb 0417 068 177.

Central: 1-3pm on the third Tuesday of January, March, May, July, September, and November. Hilton RSL, 147 Sir Donald Bradman Drive. Contact John 0414 233 295.

Clare: 2-4pm on the third Monday of Jan, Mar, May, July, Sept, Nov. Clare Uniting Church Hall, 18 Victoria Rod, Clare. Contact Nadja 0434 497 011.

Eyre Peninsula: 11am-12.30pm third Friday of February, May, August and November. Port Lincoln RSL, 14 Hallett Place Contact Helen 0429 882 833.

Fleurieu: 11am-12.15pm on first Monday of March, June, September and December at Grosvenor Hotel Victor Harbor. Contact Phillip 0408 831 774.

Kangaroo Island: 10am-12pm on the second Tuesday of February, April, June, August, October and December. Kangaroo Island Business Hub, Commercial St, Kingscote. Contact Cindy 0418 837 378.

Murraylands: 10am-12pm first Monday of February, April, June, August, October and December. Murray Bridge RSL, 2 Ross Rd. Contact Sandrina 0428 104 439 or Steven 0427 978 699.

Northern: Elizabeth Playford Lions Club, Hilcott Street, Elizabeth North. Fourth

Tuesday of the month 2-4pm. Febuary, April, June, August and October Contact Mel 0401 447 740 or Jo-Ann 0421 118 962.

Port Augusta: Port Augusta RSL, 17 Fulham Road. Meetings 1-2.30pm on the fourth Tuesday of January, March, May, July, September and November. Contact Terry Smith 0488 069 943.

Port Pirie: 1-2.30pm on third Tuesday of each month at Pt Pirie Lions Club Hall, cnr Federation Rd and Hallam St, Port Pirie. Contact Jenni Edwards 08 8638 4536 or 0481 484 347.

Riverland: 10am-12pm, first Thursday of January, March, May, July, September and November. Renmark RSL, 91 Fifteenth St. Contact Neville 0419 835 589.

Southern: 2pm on first Wednesday of February, April, June, August and October at Elizabeth House, 112 Elizabeth Road, Christie Downs. Contact Shar-maine 0438 853 082.

South East: 10.30-12.30 on a Thursday every six weeks, Mount Gambier hospital Conference Room 2, Wehl Street Mount Gambier. Contact Leeanne Paterson 0418 733 111 or Barbara 0415 477 978.

Yorke Peninsula: 2.30pm on third Wednesday of February, April, June, August, October at the Joyce Olsen Room, Wontama Homes, East Terrace, Kadina. Contact Helen Colliver on 0419 839 869.

TASMANIA

All Cancer Support Group: Meets the fourth Tuesday of every month, 2-4pm at 15 Princes Street, Sandy Bay. Contact Support Services 6169 1900 to register interest or Cancer Council Helpline 13 11 20.

Tasmania support groups: Meet March, June and September. Contact Adrian Kock 0498 196 059 for dates. South: District Nurses' Centre 10am-noon, 2 Birdwood Ave, Moonah. North: Legacy House, 10am-noon, 59 York Street, Launceston. North West: Apex House 10am-noon, 3 Gollan Street, Ulverstone.

VICTORIA

Bairnsdale and 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 Bag Buddies: 2pm, second Wednesday each month at BRICCC (Ballarat Base Hospital), use the Sturt St. Entrance. Contact Graeme on 0400 979 742 or grarob44@gmail.com or David on 0400 393 897 or david.nestor2@bigpond.com

Benalla/Wangaratta: Monday, August 19, at Masonic Hall, Appin Street, Wangaratta from 2pm (Jessica Ferguson Sutherland Medical); Monday, October 14, at Benalla Bowls Club, 24 Arundel St, Benalla at 2pm (Anj Costall Salts); Monday December 9 at Masonic Hall, Appin Street, Wangaratta at 2pm (Christmas meeting).

Bendigo and district: Stoma support group offering support to ostomates and/or their partners. Meets last Monday of each month. Contact Pam on 0419 585 951 or email p.sorrell@bigpond.com

Colostomy Association of Victoria: Stoma support group. Offers support to all clients. We offer 30-minute consultations with a qualified stoma therapy nurse, by appointment, three days a week. AGM last Wednesday of November at 12pm. Phone 9650 1666 or email info@colovic.org.au

Latrobe Valley: Coffee Bags support group meets in Moe on the first Wednesday of each month for a cuppa, chat and information sharing in a relaxed and social setting. Ostomates are encouraged to attend, bringing their support person with them. Contact Sue Graham 0415 751145.

Mildura: Meet every second month at the Gateway Tavern, on the corner of 15th Street and San Mateo Avenue, Mildura. Contact Norma 0409 252 545, stoma nurse Vicky 0437 099 129 or Dianne 0419 516 455.

South Gippsland: Meet on the first Tuesday of each month at 2pm. Contact Helen Lugettho on 0499 624 999.

Sunraysia/Riverland: Venue: Sunraysia Cancer Centre. Enquiries: Norma Murphy 0409 252 545.

Warrnambool and district: Meets on the second Friday of each month from Feb to November at 10.30am. Venue: Cafe Lava, Lava St, Warrnambool, for coffee and a meet and greet. Contact Anne on 0417 319 146.

YOU (Young Ostomates United): search for us on Facebook. Website: www.you.org.au. Secretary Helen Ebzery helshae@hotmail.com. Postal address: YOU Inc., PO Box51, Drouin, Victoria, 3818.

WESTERN AUSTRALIA

Albany: 1.30pm first Friday of each quarter. Free Reformed Church Meeting Room North Road, Albany. Contact: Gerry 0498 666 525.

Bunbury: Third Friday of the month. Bunbury Geographe Seniors Community Centre. Contact Maria 0408 165 959.

Esperance: Last Tuesday of every month at 10am. Aurelia's Ice Creamery and Cafe (if closed go to Breakaway Cafe). Contact Len (08) 9075 9099.

Geraldton: Fourth Tuesday of the month, 1-3pm. Regional library (occasionally at CWA). Contact Rhonda 0418 231 007.

Kalgoorlie and Kunurra: Contact WA Ostomy Association on (08) 9272 1833 or info@waostomy.org.au

Mandurah: 5-6.30pm first Wednesday of every month. Greenfields Family and Community Centre, 2 Waldron Boulevard, Greenfields (cnr Murdoch Drive).

Narrogin: First Wednesday quarterly. 12-1.30pm, Senior Citizen's Centre. Contact Lorraine 0429 812 552.

Northam: Second Saturday of every month. 10am-noon, venue TBA. Contact WA Ostomy Association (08) 9272 1833.

Perth: New members' support group: noon-1.30pm, fourth Saturday of every month at WA Ostomy Association, 15 Guildford Road, Mount Lawley.

Perth Young Ostomates: Request to join on Facebook at www.facebook.com/groups/365461825146299.

West Ossie Gutsy Kids: Babies to 15-year-olds with stomas and their parents. Request to join via Facebook www.facebook.com/groups/381866953308120.

National Directory of Ostomy Associations



AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSOCIATION

W: actstoma.net.au
E: stoma@actstoma.net.au
T: (02) 5124 4888
A: Second floor, City Health
Building, 1 Moore Street,
Canberra ACT 2601
Open: Phone service Monday-
Thursday 10am-1pm

NEW SOUTH WALES

NSW STOMA LIMITED

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

OSTOMY NSW LTD

W: ostomyNSW.org.au
E: orders@ostomyNSW.org.
au
T: (02) 9542 1300
F: (02) 9542 1400
A: Unit 3, 228-232 Taren
Point Road, Caringbah, 2229.
Open: Monday-Thursday 9am
to 2pm

NORTHERN TERRITORY

CANCER COUNCIL NORTHERN TERRITORY

W: nt.cancer.org.au
E: ostomy@cancernt.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 2pm

QUEENSLAND

GOLD COAST OSTOMY ASSOCIATION

W: goldcoastostomy.com.au
E: assoc@gcostomy.com.au
T: (07) 5594 7633
F: (07) 5571 7481
A: 8 Dunkirk Close,
Arundel QLD 4214
Open: Tuesday and Thursday
9am to 2.30 pm

NORTH QUEENSLAND OSTOMY ASSOCIATION

W: nqostomy.org.au
E: admin@nqostomy.org.au
T: (07) 4775 2303
F: (07) 4725 9418
A: 13 Castlemaine Street,
Kirwan, QLD 4817
Open: Monday and Thursday
9am to 4pm, Wednesday 9am
to 12.30pm.

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: Mondays 9am to 2pm,
Tues and Thurs 9am to 3pm

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

TOOWOOMBA & SOUTH WEST OSTOMY ASSOCIATION

E: admin@tswoa.asn.au
M: jason 0438 554 064
T: (07) 4636 9701
A: Education Centre, 256
Stenner Street, Middle
Ridge QLD 4350
Open: Tuesday 9am-3.30pm

WIDE BAY OSTOMATES ASSOCIATION

W: wboa.org.au
E: wboostomy@bigpond.com
T: (07) 4152 4715
F: (07) 4153 5460
A: 88a Crofton Street
Bundaberg West QLD
Open: Tuesday, Wednesday,
Thursday 8.30am to 3pm

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
10am-2pm. Closed
Thursdays.

OSTOMY ASSOCIATION OF SOUTH AUSTRALIA

W: ostomysa.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
10am 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 9am to 3pm,
Tuesday to Friday 9am-1pm

VICTORIA

BENDIGO AND DISTRICT OSTOMY ASSOCIATION

W: bendigo-ostomy.org.au
E: benost@bigpond.com
T: (03) 5441 7520
F: (03) 5442 9660
A: 43-45 Kinross Street
Bendigo VIC 3550
P: PO Box 404 Golden
Square VIC 3555
Open: Tuesday, Wednesday,
Thursday 10am to 1pm.
Closed first week of each
month.

COLOSTOMY ASSOCIATION OF VICTORIA

W: colovic.org.au
E: info@colovic.org.au
P: (03) 9650 1666
A: suite 221 level 2, Block
Arcade, 98 Elizabeth
Street, Melbourne
VIC 3000

Open: weekdays 9am to
2pm, STN by appointment
Monday, Wednesday and
Friday

GEELONG OSTOMY

W: geelongostomy.com.au
E: goinc@geelongostomy.
com.au
T: (03) 5243 3664
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 Road
Burwood VIC 3125
Open: phone service
Monday to Friday 9am to
3pm. Collections available
Tuesday to Friday 10am to
3.30pm

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@
swh.net.au
T: (03) 5563 1446
F: (03) 5563 4353
A: 279 Koroit Street
Warrnambool VIC 3280
Open: Friday 12pm to 4pm

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: Mon and Tues 9am-
4pm, Wed 9-1pm, Thur 9am-
4pm, Fri 9am-1pm. Fourth
Saturday each month 9am
to 1pm.