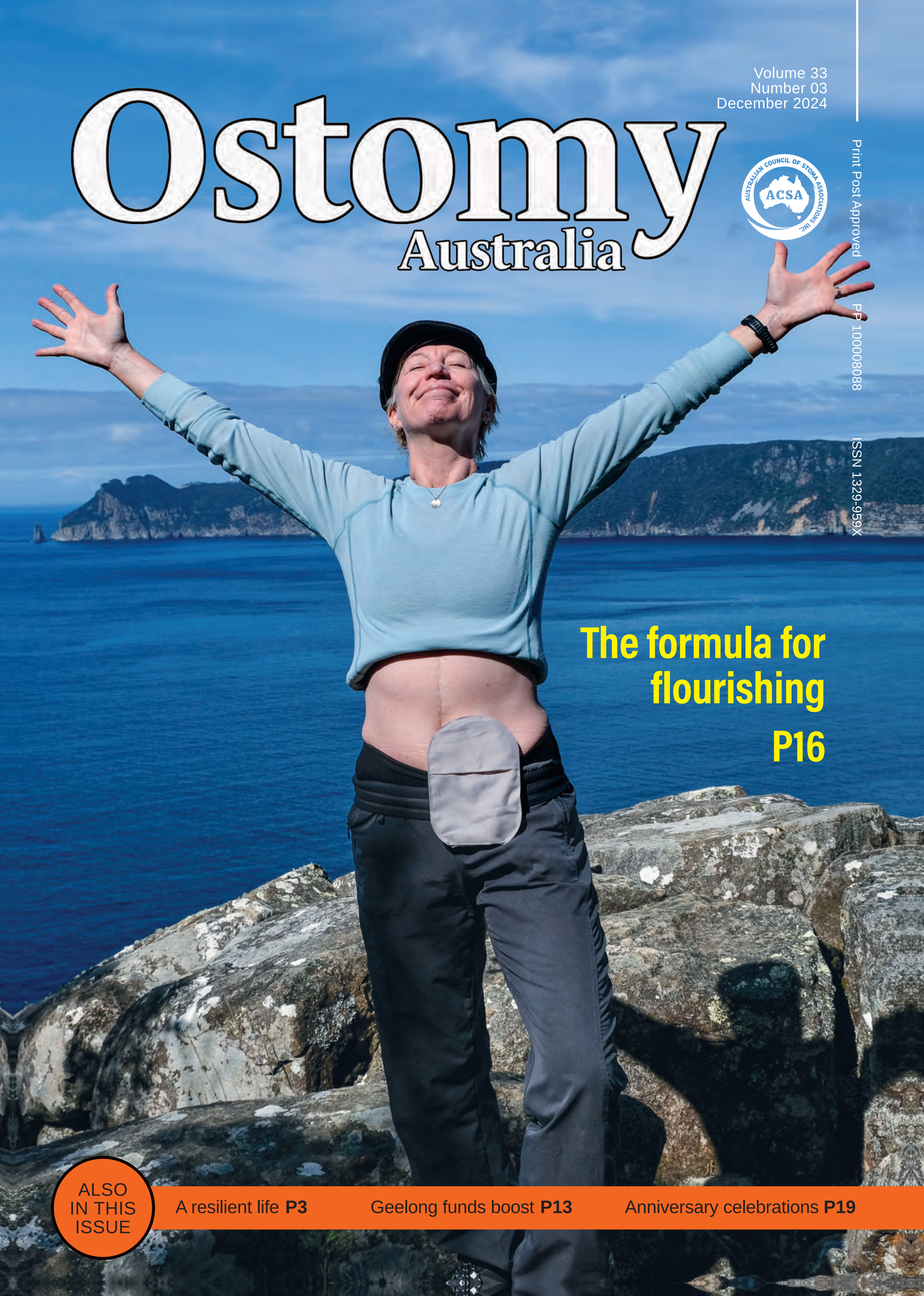

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ACSA

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The formula for flourishing

P16

ALSO IN THIS ISSUE

Connecting the Ostomy Community
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Executive matters

by **Ian Samuel OAM**
ACSA President

A busy time behind the scenes

THIS year has been a busy one for the Australian Council of Stoma Associations (ACSA).

The executive committee has been working with the Department of Health and Aged Care and Services Australia to review the distribution methods as well as the supply of materials to ostomates.

I am delighted to report that the ACSA executive has worked most cooperatively with both the Department and Services Australia.

We hope to have a report by the start of 2025.

Our vice-president, Lorrie Gray, has been working with the Department of Home Affairs to assist people with a stoma when travelling.

This is a tedious task, but she is making headway. If you have a problem with airport security please write to Hermione Agee, our administrative officer (hermione@oam.org.au) outlining your issue, I am sure that she will be able to resolve it.

As usual, our honorary secretary David Swift has been dealing with Australia Post to achieve the best possible rates and to fix up any issues that might arise between Australia Post and associations.

Adam Keam is our incredible treasurer.

He is the chief operating officer in the Pacific for one of the world's largest banks as well as being on the board of Bowel Cancer Australia and Ostomy NSW Ltd.

For ACSA, Adam keeps us up to date with financial matters.

ACSA now has three employees: Hermione Agee is our go-to person on almost anything to do with stomas – for me, she is my right hand and left hand and everything in-between.

Looking after our IT, we have Kevin Barry and Bryan Storey; between them we have round-the-clock service for our SAMS program.

Kevin and Bryan work with an IT committee, headed by Mary Egan who is manager of NSW Stoma.

Finally, we are lucky to have our wonderful editor of *Ostomy Australia*, Amanda Haines.

This has always been a difficult position to fill however Amanda has taken to it with gusto.

This is just a snapshot of the work of the ACSA team.

It has been a busy year led by me as president, but without the assistance of Team ACSA we would be lost.

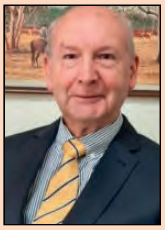
Wishing you, our readers, a happy and holy Christmas and a happy Channukah.

If you are driving away for holidays, please be careful on the roads.

▸ *Ian Samuel*
acsapres@australianstoma.com.au

Ian Samuel
President

Lorrie Grey
Vice-president



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Hermione Agee
Administration

Your executive council advocates for you

OSTOMY Australia is the official publication of the Australian Council of Stoma Associations (ACSA).

ACSA represents, at a national level, the interests of 21 regional stoma associations and, through them, approximately 50,000 people living with an ostomy and located throughout Australia.

ACSA provides liaison with the Australian Government in relation to access by ostomates to products funded through the Stoma Appliance Scheme, co-ordinates ostomy-related support services throughout Australia, and provides advocacy for Australian ostomates.

Our primary objective is to assist the wellbeing of all people following ostomy surgery to ensure that they can maintain a normal quality of life where possible.

Governance of ACSA is through a voluntary executive committee elected by ACSA members; representatives of each member association form the ACSA Council.

A journey of resilience

by **Kylie Collas**

AT the vibrant age of 103, Mark Pammer (born Miroslav Pammr) is a living testament to resilience, strength and an unwavering positive attitude towards life.

What adds an additional layer of uniqueness to Mark's story is his life with a stoma bag and how he has become an inspiration to show his family, friends, his community and his carers that life with a stoma bag does not hold you back.

Born in 1921 in the small town of Ricany, in what is now the Czech Republic, Mark left after the second World War to escape the Russian Communist regime.

It was while working in Bulgaria, on a stop-over in Yugoslavia en route back to Prague, that Mark made the spontaneous decision not to return to the USSR-controlled Czechoslovakia.

"All the passengers got off the plane to get on another to Prague, and Dad decided not to get onto the next plane although he had a ticket to go the whole way back to Prague," Jane said.

"He distinctly remembers saying to himself 'It's now or never,' and so it was now.

"He left behind family (father, siblings, aunts he was very close to) and friends."

Growing up, he had experienced both the highs and lows of life, witnessing at close hand a tumultuous Europe, technological advancements such as the birth of the internet, and other major events that would shape the modern world.

However, it was in his later years, around 1980, that Mark faced one of his biggest challenges: the early stages of bowel cancer that led to a stoma.

Mark embraced this new reality with an unwavering optimism that has set him apart, and it is now thought that Mark might be the oldest living person in Australia with a stoma bag.

Despite the physical changes, Mark continues to live his life to the fullest.

He remains actively engaged in various community activities, spending time with his loved ones, friends and his dedicated carers, and pursuing his passions such as learning languages and getting out and about in his community.

Mark's story serves as a reminder that age is just a number and that our potential for growth and contribution knows no bounds.

Despite the challenges he has faced with his age (hearing loss, macular degeneration and arthritis) and mobility, Mark continues to defy expectations and through his journey, he has adapted to life with a stoma.

Resilient: Mark has always been an inspiration to his family and friends.

On the town: A trip to the local hardware store was a regular occasion for Mark, as was a visit to the local coffee shop (right).

He does not hold back from life with a stoma bag, in fact, he is more active than ever.

When Mark isn't sleeping or resting at home, he is living his life to the fullest with his stoma bag.

Mondays he is busy organising his paperwork and undertaking his personal care activities at home.

He attends a lifestyle community group exercise class on Tuesdays, then has a chinwag over coffee and biscuits afterwards, while on Wednesdays he is at the pool, doing some laps and having a session with his exercise physiologist in the water. On Thursdays and Fridays, you'll find Mark roaming the streets of Melbourne looking at neighbours' gardens and beehives, or on a trip to the local nursery, cafe or hardware store.

On Saturdays Mark travels to Warrandyte to see his daughter and Sundays he attends a church service or goes to the Czech Club for lunch.

In his spare time, Mark loves learning languages, in particular Chinese, but also a little Vietnamese and Sudanese from his diverse and committed support workers.

▶ Editor's note: Mark passed away shortly before this edition went to press and is fondly remembered by his family, friends and carers.

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Ask Wendy

By **Wendy Pearson**
Clinical nurse consultant

Pelvic muscles play a fundamental role

Hello everyone. I have been sent another (very good!) question that is more common than you think but something not often spoken about.

Thank you, "B", and know that you aren't alone in what you've experienced. They write:

I have had a colostomy for nearly two years now. I find having sex with my husband can sometimes be very painful. I feel it mostly in my abdomen. Could this be a pelvic floor issue and would exercises help? Could a physiotherapist help me or would I need to see a specialist in this area? Any advice gratefully received.

I don't know your history but I'm presuming that you had your stoma because you've had a pelvic cancer (either colorectal or gynaecological) as this is the most common reason why women can experience pain and discomfort during intercourse.

Dyspareunia (pain during sexual intercourse) can occur because of several reasons –

Nerves or tissue can be damaged because of the radiotherapy and/or surgery.

Depending on the type of surgery, sometimes the vagina needs to be narrowed or shortened.

Radiotherapy to the pelvic region can also cause shortening, drying and tightening of the vagina.

If you have had your rectum removed, the angle of the vagina can change, which can make some sexual positions more comfortable than others.

Chemotherapy can induce menopause, causing vaginal dryness and thinning of the vaginal walls. Help is available.

I'm not sure where in Australia you are but there are specialist women's health physiotherapists who specialise in this area and may discuss the possibility of vaginal dilatation, and many have special ultrasound machines that can be used to teach you how and which muscles you can exercise or identify if your pelvic floor muscles are too tight.

Your GP should be able to refer you.

They are available through the public as well as the private healthcare sector.

Meanwhile, here are a few general tips that may help improve things:

Using a water-based lubricant is important. You may have lost some of the ability to 'self-lubricate' and it's not unusual to have to apply this several times during sexual activity. Intimate massage with plenty of lubricant prior to intercourse may also help.

Pelvic floor muscle exercises (PFMEs) may help as these muscles play a fundamental role in sexual function and improvement in pelvic floor muscle strength has been shown to reduce pain during sex in women who have had pelvic radiation.

Core muscle training (such as Pilates or yoga) in conjunction with PFMEs has also been shown to improve sexual function and decrease pain.

Depending on the reason for your surgery, topical therapies may be beneficial in conjunction with some/all the above.

Discuss with your GP about vaginal moisturisers, creams or pessaries as these can help maintain or improve the suppleness and stretch. These can sometimes be oestrogen based (may not be suitable for some women) or there has been some promising literature regarding the use of vaginal hyaluronic acid gel preparations.

I hope that this helps point you in the right direction and you can enjoy intimacy again without the pain that you've been experiencing.

Thank you again for your questions and please feel free to send through whatever may be on your mind. Due to not knowing your specific medical history, all advice is general. Send your questions in by email to journal@australianstoma.com.au

I hope that you all have a very merry festive season and that 2025 is kind to you all.

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Your say

Letters to the editor

We welcome letters to the editor from all readers, on all subjects. Tell us what you think! Letters must be accompanied with your name and address – this is not for publication but is required. Opinions expressed do not necessarily reflect the views of the editorial staff or publishers of *Ostomy Australia.* Email correspondence to journal@australianstoma.com.au

What not to eat?

IN 2023 my life changed when I was admitted to hospital for emergency surgery for a perforated bowel and large abscess.

I was told that I would come out of surgery with a stoma and I replied that I would rather die.

I now have an ileostomy and I was in hospital for almost four weeks recovering and learning how to deal with my stoma and bags.

When I left hospital the only food that I was advised to avoid was corn.

There have been very few days in the past year that I have not experienced nausea and abdominal discomfort.

In May I had surgery to reverse the previous year's surgery but it was not successful and I awoke after seven hours in theatre with my stoma still there.

In July I raced to hospital in severe pain and vomiting and after a CT scan it showed that I had a bowel obstruction.

I was not aware that this could happen. I had eaten some salted mixed nuts unaware that they were a no-no.

Fortunately the obstruction was cleared without surgery.

I was admitted for two days and saw a dietitian who gave me a comprehensive list of foods to avoid.

Many of these I had been eating on a daily basis, thinking that I was eating a healthy diet of fresh fruit and vegetables. This would explain why I have had nausea and abdominal discomfort.

When I was leaving the hospital I met one of the STN nurses in the corridor and told her why I had been there; she said that one of the main causes of bowel obstruction that they see was from mushrooms.

I had been eating mushrooms and all of the other fresh vegetables on the list I was given, including raw carrots, celery, unpeeled apples, mangoes and the list goes on. Since I have removed these from my diet the nausea and abdominal pain have settled down.

I wonder if anyone else has had issues with certain foods?

Apparently it is only because I have an ileostomy; if it had been a colostomy the fresh food would not be an issue.

Lynette Robertson, VIC

Go ahead and vent

I HAVE had an ostomy since 2020.

Reading Christine from Queensland's letter (*Ostomy Australia*, April) has made me realise, wow, there's how I feel right there.

Thank you for taking the time to vent for yourself, it helps others.

I also feel that life is not the same in some ways.

But I do revel in our grandchildren, thank goodness for their ability to always make us laugh and enjoy every day.

I also agree that an ostomate's diet is live and learn, and I'm still stubborn and learning.

I do sulk at times but thankfully I also have an inner voice, that reminds me to shut up and get on with it.

Thank you again for venting.

Frakvin, via email

Bag disposal advice

IN reply to the letter published in August asking for bag disposal advice, the best method I have found is to use the bladders which come with 10-litre boxes of water.

Cut the end off where the tap is and hang on the line to dry completely.

Place the used stoma bag inside, roll and fold, then put into a small bin liner bag and tie tightly. I use these (and have done for seven years now) all the time.

When at home I place maybe four used bags in before disposing, the bin doesn't smell and no-one is the wiser.

Having used spring water for many years now does make it easier to accumulate these water bladders.

If you're not in the habit of buying water put the call out to friends/family.

Using them certainly takes away the embarrassment of smell.

Doris McEwin, SA

Don't be embarrassed

IN response to Jeanette's question (*OA*, August) about disposal of a bag at a host's place, I would like to offer this suggestion.

Ask the host politely if they have a small garbage bag that you can use to deposit your used bag so that you can pop it into their garbage bin.

I'm sure that they would be understanding if you explain your condition.

There is no need to be embarrassed.

As a fellow ostomate, I'm sure your hosts will understand.

Gary Dowling, email

More disposal advice

REGARDING the disposal of bags when at someone's home: have a large handbag with all supplies plus disposable gloves.

Ask to use bathroom and place supplies, spray, wipes, a clean bag on top of the toilet cistern.

Have a strong disposal bag to place used stuff; make sure all air is out of the disposal bag, screw up and close with a knot, place in handbag for disposal later – it should not smell.

With practice this can be done very quickly.

If you have travelled by your own car, another option is to change in the car.

I have often done this and put a towel on the window for privacy.

Another option is to ask the person who knows the host well to explain your circumstance.

Janet, SA

Clips on bags

I WOULD like to add my voice to those who have spoken in favour of plastic clips on bags instead of hook-and-loop roll-up closures.

I hope all the manufacturers are reading this.

My bag of choice is an oldie but a goodie: the bag end can be sealed with plastic clips (although it does come with a separate stick-on wire closure that I don't use).

In my opinion a clip makes a better seal (no leakage under pressure), is easier to empty and clean up at the end and is more discreet in a public toilet (no sound of ripping apart the closure).

I have a supply of old, straight clips that may no longer be available, I think.

The curved ones are not as good.

I also like that my product uses plastic that doesn't rustle noisily.

I am very grateful for this excellent subsidised product that has enabled me to live a full and active life – and I don't want to change it.

Megan, NSW

More letters on page 9

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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.

Continued from page 7

Bus trip lessons

MY husband and I booked on a six-day bus tour with our Probus group and I wondered how I would go with changing my bag as I never know when it needs changing, sometimes even three times a day.

My major concern was what if the bag leaked when I was in the motel's bed – what would I do?

Fortunately, I had no leakage over that time.

Next concern was what to do if I needed to change the bag during the day as we were travelling to tourist destinations each day.

Once again I was lucky as I needed to change at one of the tourist destinations and was able to dispose of the bag safely.

I had to change my bag in a National Park and to my horror there were no bins anywhere.

I had to embarrass myself and ask the bus driver to store it under the bus until we reached a bin.

The next stop was at a park where I was greatly relieved to dispose of the bag in the nearest bin

My next near miss was when I decided to change my bag in a hotel rest room – I retrieved all the supplies I needed and was about to take my bag off when I realised I did not have a spare.

I was shocked and very disappointed with myself as I usually carry items to change several bags with me.

What would I have done if I had taken the bag off before realising I did not have a spare?

When we were on a boat cruise people were talking about the old TV series *Gilligan's Island* and it made me wonder how would ostomates manage.

Fortunately we arrived home and learnt a few lessons for future travels.

Janice Glassington, NSW

Stringent measures

IN response to Viv Parry (*OA*, August) I will share my travel story.

I have been an ostomate for 20 years, I have travelled the world and visited many airports in my time without any mishaps.

I hadn't travelled for the past few years but did so earlier this year and to my surprise when going through the scanner at Sydney Airport was pulled up and asked about the area around my stomach.

I simply replied to the female officer that I had an ostomy.

She then called for two female officers to take me to a side room and asked me to sign a consent form, which I did (I don't think I had an option otherwise).

They did not ask me to show them my bag or anything, just to rub my hand under my clothing which I did and then one person took this away for testing and of course came back all clear and I was on my way.

I was a little disturbed by the incident because I had never done this before, but otherwise it was OK.

During that trip I went through and cleared a further six security scanners at various airports including Singapore and throughout Germany.

Not one of these pulled me up and I'm wondering why Australia is so stringent?

I was shocked to read about the treatment of some people being humiliated by the process and do feel there should be training of all security officers at airports on how to handle these situations much better.

I understand the security measures required to stop drugs entering other countries.

However I don't see that a particular Sunflower lanyard displaying a hidden disability would work as even some people with disabilities could be hiding anything in there too.

Belinda, NSW

More needs to be done

I THANK Viv Parry for the airport letter published in the August edition.

I too have an airport story that I would be happy for Viv to add to her submission to the Australian Human Rights Commission.

My story centres on Adelaide airport; in July I had flown with my husband to Adelaide and my incident occurred prior to my return flight back to Sydney.

I was stopped at security screening in Adelaide and asked to explain what had appeared on the screen.

That security officer was polite but I was beginning to get very anxious about what I may then need to do.

Another security officer involved in the search process was then asked to investigate more and I informed her that I was an ostomate and that my bag was what had appeared on the screen.

This officer then quietly said to the person operating the security screen that I was wearing an ostomy bag.

To my embarrassment I could see the person at the screen mouth the words "What's an ostomy bag?" to this officer attending to me.

To see the screen image on full view to other passengers too left me feeling humiliated.

I was very annoyed at this stage and said to the officer it's for my poo.

She still proceeded to hand scan my ostomy bag before allowing me to proceed.

Fortunately my husband was in the queue ahead of me and was able to take care of my luggage (personal items) on the conveyor. I do agree with the comment made in Viv's letter to the editor "For those with a hidden medical disability they deserve to be treated with far greater respect including those with a urostomy, diabetes and other medical conditions".

My experience highlights that there is a big dilemma with the treatment of ostomates at screening booths in airports.

There is a great need for security officers to have education and adequate training to help us pass through the security process in a dignified, respectful manner with our privacy protected.

I am pleased though that airports have addressed the need for our security and safety but there remains much work to be done to treat people with hidden medical disabilities politely, gently and ensuring their comfort.

It seems to me from my personal experience and reading of incidents for others that the screening/security process needs to change as at the moment some airports are using a "sledgehammer to smash a walnut" approach when dealing with people with hidden medical disabilities.

In discussing this with my husband, he raised another issue.

What if I was a solo traveller?

There seems to be no consideration for the safekeeping of personal items (including my phone and wallet) that have travelled to the end of the conveyor while I'm held for further security screening.

I am thankful for this forum to share my story and add to the evidence of change being required.

Jenny Bennett, NSW

Airport humiliation

I WOULD be happy to add to Viv Parry's Human Rights Commission submission – I too have had humiliating experiences at Melbourne Airport, exactly like Paula and Viv describe in the August *OA*.

The yelling out to another staff member to come over and accompany me to a private room, signing a book without knowing what for (they told me it was so they have a record of inspection).

My husband had to look out for my passport, tickets, phone and carry-on luggage, which I had to leave while I was 'inspected'.

The Sunflower lanyard has helped, but not always – it did work well in Sydney and Brisbane.

I emailed Melbourne Airport customer complaints and they sent an automated response that they would respond but I have never heard back.

In contrast, in San Francisco we were funnelled through an area with detection dogs.

I tried to tell the customs officer that I

Continued on page 11

Continued from page 9

have a urostomy bag and she said (with a happy smile): “Ma’am, we are only interested in weapons and explosives; if the dog says you are good to go, then you are good to go, have a nice day!”

What a difference!

The Melbourne Airport experience is a horrible way to start a journey, so undignified and humiliating.

I was recently travelling to Canberra with a colleague and she couldn’t believe that I was pulled aside and questioned in such a loud way.

Some work colleagues are not aware I have a stoma and I don’t appreciate them finding out at the airport; so much for privacy.

Thank you for your wonderful magazine, it is so supportive and informative.

Wendy Dawson, VIC.

No dramas this time

I RECENTLY travelled from Melbourne to Perth and was dreading the airport security procedures, having read other people’s stories.

However, I found the staff to be very discreet and respectful.

When they detected my bags and asked about them they spoke quietly, took me to a private room where they got me to pat my bags area and then they checked my hands to see if I was carrying explosives.

They didn’t want to see the bags and I was very appreciative of the way they handled it.

Coming back from Perth was even easier – I told the first security guy at the scanning booth that I had bags, he didn’t bat an eyelid but waved me over to a different device.

They scanned me and sent me on my way without any dramas.

Maybe the message has got through and the staff now know how to handle it.

Thank you for your newsletters and journals, I really appreciate them.

Jenny Fiddian, VIC

Airport discretion

I HAVE had an ileostomy for 45 years and travelled all over the world without incident until a couple of years ago when new airport scanning equipment was installed.

I had the embarrassing experience that Paula Loughnane (OA letters, August) had where a security person shouted to another “She’s got an ileostomy.”

This was at Sydney International airport.

I have also found Tullamarine to be particularly bad.

The experience does vary widely though, from the simple request to rub your hand over the area to have it tested for explosives to having to go to a private room to have it viewed.

Thank you to Viv Parry for making a complaint.

Simple awareness training for security staff would be a good start (many are sensitive and discreet).

It is quite possible that we’re travelling with someone who is not aware of our condition and attention should not be drawn to it.

I now always queue for security with apprehension.

I’m glad this didn’t happen earlier in my life as an ostomate.

Lynn Graham, email

Irrigation a clever idea

THIS morning I took time to read *Ostomy Australia*’s letters of travel dilemmas while having a ostomy bag.

I travel frequently to the EU and also have had to put up with Tullamarine.

I do like the bag for travelling because it’s a safeguard for accidents because of different foods to eat during the flight.

I found irrigation was my sporting and travelling saviour.

I would irrigate my system before a flight and just before that flight, I would insert a plug (much like a tampon but a special one for ostomates) and going through the security became normal once again.

You could wear the thinnest shirt and it could not be seen as it literally looked just like a round bandaid.

Before boarding or during the flight I would change again to the bag.

As I have read, it seems other countries are much more aware of what is out there.

Tullamarine to date is the only place where I have had issues.

Every airport has a medical centre, I do use these places to check, bags, plugs and so on. Singapore was great at their centre, the medical staff asked if they could watch me do the checking (a learning curve for them) and they asked so many questions.

Well done, Singapore.

Life is great, do not let that stoma slow or stop you from living, you have dodged that bullet so to speak, use the time you have left to get out there and live.

I hike, I travel the world, I also ride mountain bike races, and I am 74.

Do not let it hold you up, get out there.

Rod Morrison, email

Sensitivity required

I TOO have had very humiliating experiences at Melbourne Tullamarine Airport when passing through the X-ray machine.

It’s interesting because I have not had any issues at other airports.

Each time at Melbourne they have made me stand aside and wait until they find another security person to take me to a side room.

They do not say things in a private manner when arranging this which makes it very exposing whilst standing in front of other passengers who now know about my bag.

Despite my trying to explain each time this has happened that it is a stoma bag they have been rude and dismissive.

To make matters even worse, each time my carry on bag with my passport, phone and wallet has been left on the conveyor belt and they have refused to let me get it until after the inspection which can take a long time.

Each time when I have been taken into the side room, I have been told to expose my bag and while doing this I have found the security people to be so rude and dehumanising.

They have stood and stared very rudely at my exposed body and bag.

One security guard had unveiled disgust on their face.

I do understand that they do need to check for explosives but doing so with sensitivity and allowing some dignity would be appreciated.

I have come to pre-empt their antics and it does make me grin a bit now.

I try to jolly them along and tell them that of course it is explosive but with something that smells!

I really appreciate knowing that this issue is being addressed.

S Mcfadyen, email

Much appreciated

I HAVE just received the latest *Ostomy Australia* magazine and would like to say thank you to all involved with this excellent publication.

I have been a reader for over 20 years and eagerly peruse the arrival of the latest edition when it arrives.

Thanks to all involved for an excellent publication.

Brendon Smith, email

Write us a letter

journal@australianstoma.com.au

Funds boost for Geelong

All clear: Geelong Ostomy vice-president Elaine Scott, president Garry Wall, federal MP Libby Coker, and volunteer Faye Gordon with the defibrillator bought by the group with government funding.

VITAL equipment for safety and education has been bought by Geelong Ostomy after a successful application for federal funding.

Through the association's local member of parliament Libby Coker, the group applied for a Commonwealth Community Volunteer Grant and was awarded $3000.

The grant money was used to assist with the purchase of a defibrillator and light projector.

The defibrillator had been identified by Geelong Ostomy's all-volunteer team as an important piece of equipment to enhance the safety of volunteers and visiting members.

The light projector will support education and training activities for new volunteers and new ostomates.

Ms Coker recently inspected the operations at Geelong Ostomy and, following a tour of the premises, she met with volunteers as well as members calling in to collect their monthly stoma supplies.

The meetings provided an opportunity for a fruitful exchange of ideas on the funding and operation of the Stoma Appliance Scheme.

The challenges and opportunities for community-based organisations, and the profile of the stoma community supported by the Geelong association were also discussed.

Geelong Ostomy was delighted to have had an opportunity on behalf of its 900 members to raise awareness of the stoma community with its local representative in federal parliament.

The visit concluded with Ms Coker expressing admiration for the work undertaken by a dedicated group of volunteers.

She described volunteer work as the backbone of the community and congratulated Geelong Ostomy on its grant.

"Their dedication and tireless efforts make such a difference, and it is truly inspiring," she said.

The Volunteer Grants Program supports volunteers and encourages participation in volunteering.

To apply, organisations must be nominated by their federal MP.

Bowel cancer screen age bias addressed

MORE Australians are now eligible to receive bowel cancer screening tests in the mail with the lowering of the National Bowel Cancer Screening Program (NBCSP) age from 50 to 45.

Bowel Cancer Australia advocated for screening from age 45 given the rising rate of bowel cancer in people under 50.

An additional 1.6 million Australians aged 45-49 are now eligible to request their first bowel cancer screening test by opting in to get the test mailed to them, with their next screening test to automatically be mailed every two years after the last screening test has been completed.

Australians diagnosed through the National Bowel Cancer Screening are 59 per cent less likely to die from bowel cancer. The updated clinical practice guidelines also recommend people aged 40-44 (previously 45-49) are able to request screening via their healthcare professional prior to receiving their first NBCSP invitation.

A program has been launched by Bowel Cancer Australia which includes a range of GP educational activities to help overcome the perceived age bias by people under the age of 50 diagnosed with bowel cancer.

The series was developed in response to requests from early-onset bowel cancer advocates and recent Australian research which cited the mounting imperative for GPs to receive more information and clinical guidance on early-onset bowel cancer specific diagnosis. Limited clinical awareness of early-onset bowel cancer presents a challenge for young people seeking diagnosis and can have life-changing consequences.

Early-onset bowel cancer patients differ from late-onset bowel cancer patients in their diagnostic trajectories; time to diagnosis can be 60 per cent longer with a greater number of missed diagnostic opportunities, and younger people are more likely to be diagnosed in later stages of the disease.

Late-stage diagnosis increases the likelihood of aggressive treatment with physical and psychosocial outcomes that can be challenging for the under-50 patient population, especially regarding fertility and ostomy management.

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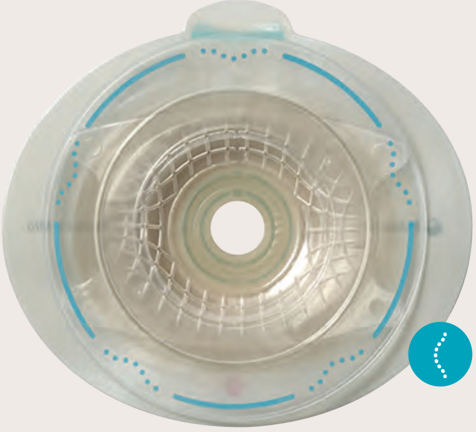

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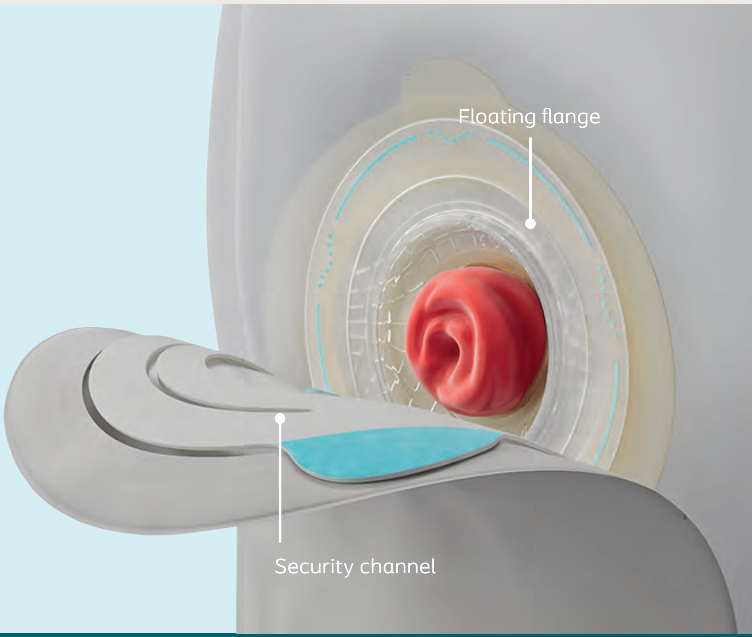

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Tiny figure does big job

Ostomy education, recognition, and awareness in colourful plastic toy

By **Amanda Haines**

WHAT'S all the fuss about?

Social media on the internet in the past few months has been filled with excited posts about a subject not normally the topic of conversation outside of specialised spheres – that of ostomy awareness.

And the viral ambassador of this phenomenon?

A five-centimetre-tall plastic doll.

Part of a playset made by Danish toy manufacturer Lego, the figure named Sara wears a bikini top and board shorts, showing off her ostomy pouch and operation scar.

That this is the first ostomate character to be produced by a major corporation is something the company says it takes pride in, as part of its overall policy of promoting inclusiveness through play.

"We work hard to ensure that everyone feels welcome and valued in the Lego universe," Lego Group creative director Fenella Charity said.

"We know that representation in toys and marketing has a profound and long-lasting impact on the children and fans we engage with, and we take our responsibility to fulfil the request from both children, parents and adult fans of more inclusive play experiences seriously."

Sara the ostomate joins other inclusive characters from the toy company, among them Hanna (a diabetic with a glucose monitor on her phone), Jordan (who has vitiligo), Paisley (a character with anxiety), and – representing the animal kingdom – Pickle, a dog with a wheelchair.

The variety of Lego figurines across the board and the often limited time period they are available for sale contributes to a collectibles culture which means adults are also big fans.

According to brickranker.com, a site for Lego collectors, one of the most valuable figures available on the open market, a Spiderman character with red legs, is worth $146,000.

While it may be easy to dismiss the manufacture of toy characters with both visible and invisible health conditions as a cynical marketing gimmick, Charity said Lego's underlying ethos of making learning fun was what drove the company to provide diverse representation.

"Our research shows that representation in toys is important to kids, and we know that our products enable learning through play, not only from the qualities that come from building with Lego bricks, but also from the kids talking about and asking their parents to understand more context for the representation we have created within our characters," she said. "Representation in our portfolio is a central part of our commitment to build a more kind, empathetic and understanding society now, and for future generations.

"Children want the characters they encounter to be more like the diverse personalities they meet in real life."

For children with a stoma, having a doll to play with that looks just like them, with an ostomy bag and abdomen scar, can not only affirm a positive body image but can also normalise for other children (and their parents) what can be an unusual physical condition.

In order to represent an ostomy, Lego researched the condition and consulted with ostomates.

"When we developed the character with an ostomy bag, we worked closely with our design governance team and a consultant with lived experience, an activist member of the ostomy bag community," Charity said.

"She is a spokesperson and representative for the community and was able to share the details of what it's like to live with the ostomy bag.

"In collaboration with our consultant, we designed the character aiming for accuracy in the details and the context.

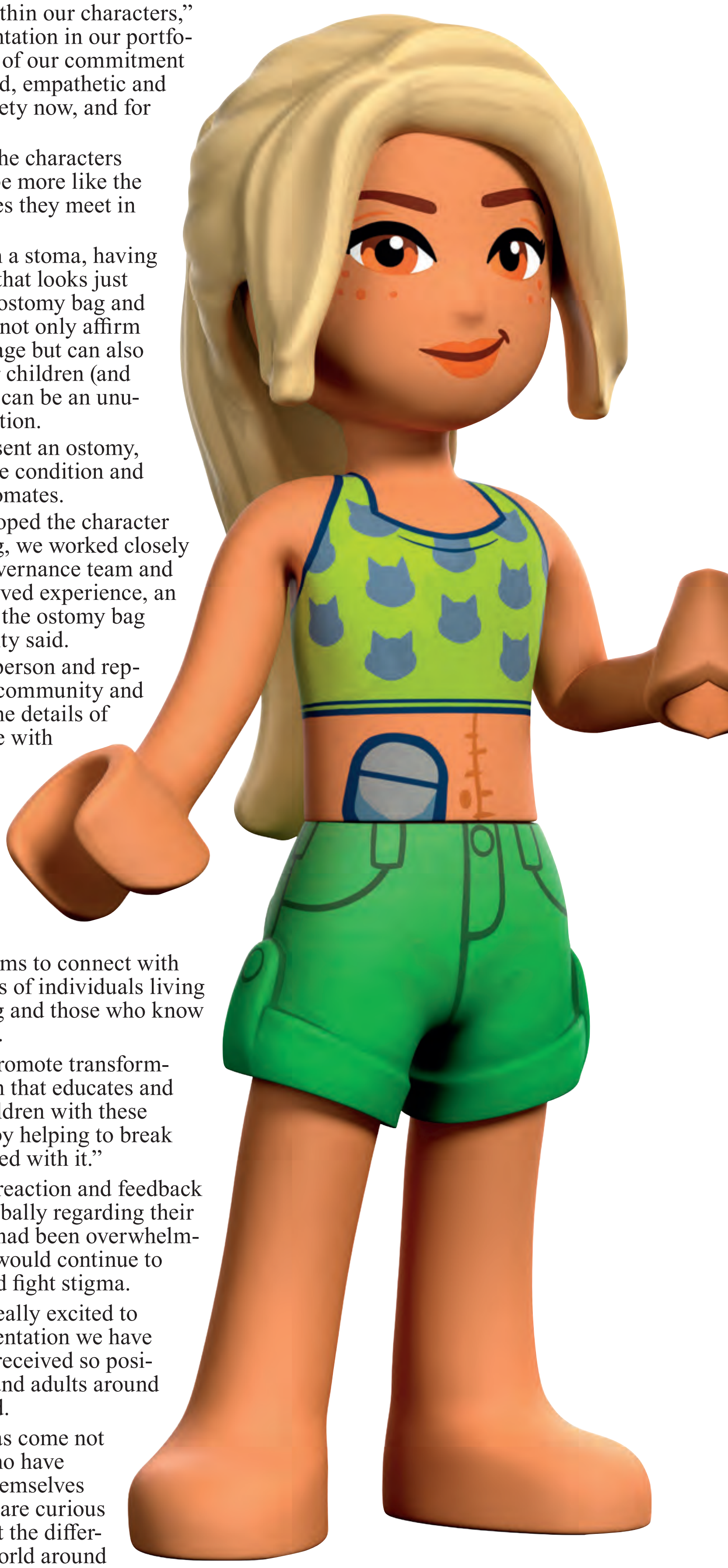
"This decision aims to connect with the real experiences of individuals living with an ostomy bag and those who know someone who does.

"Our goal is to promote transformative representation that educates and familiarises all children with these experiences, thereby helping to break the stigma associated with it."

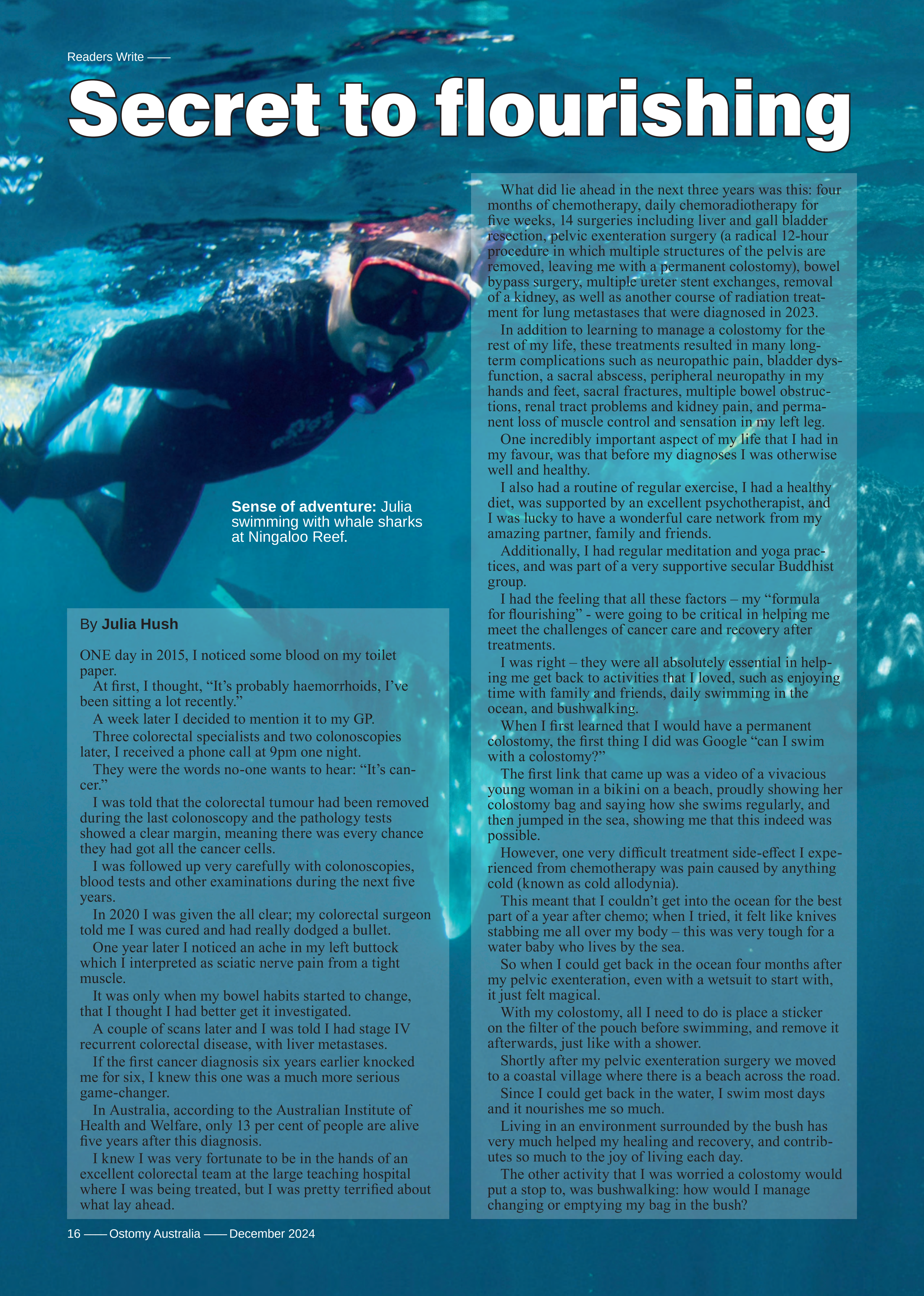
Charity said the reaction and feedback from Lego fans globally regarding their diversity products had been overwhelmingly positive and would continue to raise awareness and fight stigma.

"We have been really excited to see how the representation we have included has been received so positively by children and adults around the world," she said.

"This reaction has come not only from those who have lived experience themselves but also those who are curious to learn more about the different people in the world around them."



Secret to flourishing



Sense of adventure: Julia swimming with whale sharks at Ningaloo Reef.

By **Julia Hush**

ONE day in 2015, I noticed some blood on my toilet paper.

At first, I thought, “It’s probably haemorrhoids, I’ve been sitting a lot recently.”

A week later I decided to mention it to my GP.

Three colorectal specialists and two colonoscopies later, I received a phone call at 9pm one night.

They were the words no-one wants to hear: “It’s cancer.”

I was told that the colorectal tumour had been removed during the last colonoscopy and the pathology tests showed a clear margin, meaning there was every chance they had got all the cancer cells.

I was followed up very carefully with colonoscopies, blood tests and other examinations during the next five years.

In 2020 I was given the all clear; my colorectal surgeon told me I was cured and had really dodged a bullet.

One year later I noticed an ache in my left buttock which I interpreted as sciatic nerve pain from a tight muscle.

It was only when my bowel habits started to change, that I thought I had better get it investigated.

A couple of scans later and I was told I had stage IV recurrent colorectal disease, with liver metastases.

If the first cancer diagnosis six years earlier knocked me for six, I knew this one was a much more serious game-changer.

In Australia, according to the Australian Institute of Health and Welfare, only 13 per cent of people are alive five years after this diagnosis.

I knew I was very fortunate to be in the hands of an excellent colorectal team at the large teaching hospital where I was being treated, but I was pretty terrified about what lay ahead.

What did lie ahead in the next three years was this: four months of chemotherapy, daily chemoradiotherapy for five weeks, 14 surgeries including liver and gall bladder resection, pelvic exenteration surgery (a radical 12-hour procedure in which multiple structures of the pelvis are removed, leaving me with a permanent colostomy), bowel bypass surgery, multiple ureter stent exchanges, removal of a kidney, as well as another course of radiation treatment for lung metastases that were diagnosed in 2023.

In addition to learning to manage a colostomy for the rest of my life, these treatments resulted in many long-term complications such as neuropathic pain, bladder dysfunction, a sacral abscess, peripheral neuropathy in my hands and feet, sacral fractures, multiple bowel obstructions, renal tract problems and kidney pain, and permanent loss of muscle control and sensation in my left leg.

One incredibly important aspect of my life that I had in my favour, was that before my diagnoses I was otherwise well and healthy.

I also had a routine of regular exercise, I had a healthy diet, was supported by an excellent psychotherapist, and I was lucky to have a wonderful care network from my amazing partner, family and friends.

Additionally, I had regular meditation and yoga practices, and was part of a very supportive secular Buddhist group.

I had the feeling that all these factors – my “formula for flourishing” - were going to be critical in helping me meet the challenges of cancer care and recovery after treatments.

I was right – they were all absolutely essential in helping me get back to activities that I loved, such as enjoying time with family and friends, daily swimming in the ocean, and bushwalking.

When I first learned that I would have a permanent colostomy, the first thing I did was Google “can I swim with a colostomy?”

The first link that came up was a video of a vivacious young woman in a bikini on a beach, proudly showing her colostomy bag and saying how she swims regularly, and then jumped in the sea, showing me that this indeed was possible.

However, one very difficult treatment side-effect I experienced from chemotherapy was pain caused by anything cold (known as cold allodynia).

This meant that I couldn’t get into the ocean for the best part of a year after chemo; when I tried, it felt like knives stabbing me all over my body – this was very tough for a water baby who lives by the sea.

So when I could get back in the ocean four months after my pelvic exenteration, even with a wetsuit to start with, it just felt magical.

With my colostomy, all I need to do is place a sticker on the filter of the pouch before swimming, and remove it afterwards, just like with a shower.

Shortly after my pelvic exenteration surgery we moved to a coastal village where there is a beach across the road.

Since I could get back in the water, I swim most days and it nourishes me so much.

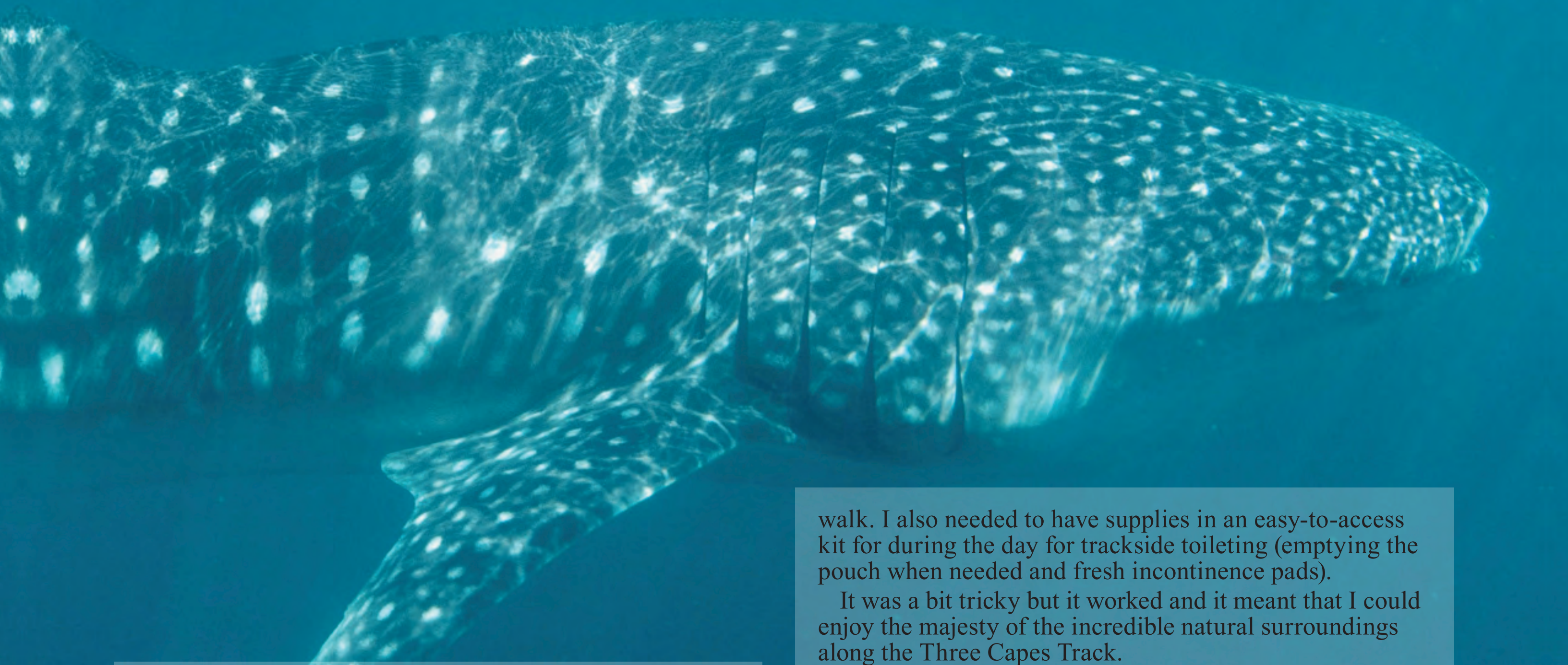
Living in an environment surrounded by the bush has very much helped my healing and recovery, and contributes so much to the joy of living each day.

The other activity that I was worried a colostomy would put a stop to, was bushwalking: how would I manage changing or emptying my bag in the bush?

is to just add water

Up and about: A year after a pelvic exenteration and colostomy, Julia Hush was camping in the Red Centre.

The next generation: In August, Julia celebrated the birth of her grandson Finn.



But I soon found that this was possible, even though it took a bit of trial and error to find what worked for me.

I started off gently, with small day walks and built it up from there.

At six months after my pelvic exenteration, I managed to climb up a 700m mountain (Didthul, or Pigeon House, on Yuin land), and then about eight months after that, completed a four-day, 45km hike, the Three Capes Track in Tasmania.

This long bushwalk took a lot of planning, not only food-wise to avoid bowel obstructions I had been getting then, but to prepare to manage my colostomy on a walk with a “leave no trace” National Park policy.

To do this, at the end of each day I changed my pouch for a new one, then rinsed out the old pouch as best I could into the pit toilet, then bagged and double-bagged the old pouch, along with used wipes.

These bags (also including my incontinence pads because of my bladder problems since surgery) then went into a dry bag to contain odour for the duration of the walk. I also needed to have supplies in an easy-to-access kit for during the day for trackside toileting (emptying the pouch when needed and fresh incontinence pads).

It was a bit tricky but it worked and it meant that I could enjoy the majesty of the incredible natural surroundings along the Three Capes Track.

Since then, I have been on a five-day camping trip in the Red Centre of Australia, travelled overseas to Japan, camped in the Pilbara desert hiking through the stunning Gorge country and number one on my bucket list, swum with whale sharks in Nyinggulu (Ningaloo) Reef.

All of these experiences have required planning, patience and acceptance when things don’t go well with my colostomy or I experience health problems during the trips.

I feel incredibly privileged to have had these experiences. Every morning I remind myself that I am grateful for my life exactly as it is.

When I got my diagnosis three years ago that I had stage IV recurrent colorectal cancer, the first thought I had was that I would never meet my grandchild, and that just shattered me more than anything else.

Because of the amazing care I have received from my healthcare team, and the hard work I have put into my health and wellbeing, not only am I still alive, but last month I celebrated the birth of my grandson, Finn.

And that is everything.

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Support and care for 25 years

by **Casey Luke**
Stomal therapy clinical nurse

THE Hastings Macleay Ostomy Support Group recently marked a remarkable milestone – its 25th anniversary – with a special celebration at the Port City Bowling Club.

The milestone event was made possible in part by the generous support of the club's travelling bowls group, which helped fund the day's festivities.

The support group, established in August 1999, originally held its meetings at Port Macquarie Community Health until the COVID-19 pandemic forced a pause.

However, it was the first local group to resume meetings, transitioning to outdoor gatherings after lockdowns were lifted, before eventually moving to their current venue at the bowling club.

The event was filled with nostalgia and appreciation as attendees looked back at the group's history of supporting ostomates and their carers.

The group has seen many members come and go over the years, and while some moved away or had their stomas reversed, the sense of community has remained strong.

One special guest at the event was Heather Hill, a renowned stomal therapy nurse from the South Coast of NSW, who made the long trip via train to be part of the day.

Heather, a regular attendee of past meetings, gave a heartfelt speech: "I have been involved with many support groups across Australia and internationally, but this is the best support group there is."

Another speaker, Maria Emerton Bell, has been with the group since its inception, and is the clinical nurse consultant for stomal therapy in Hastings Macleay.

In her speech, she acknowledged the contributions of previous presidents, committee members, local surgeons, and guest speakers who supported the group over the years.

She also recognised past and present stomal therapy nurses and representatives from stoma companies who provided ongoing education and resources.

Maria went on to highlight what makes the group truly unique.

"This group goes beyond the traditional definition of a support group," she said.

"I've seen emotional and financial support, assistance with transport, social connections, and so much more.

"Whether it's creating awareness displays at the local library, donating to stoma associations and nursing scholarships, or arranging shipments of excess products to countries like Papua New Guinea and Samoa, this group continuously finds ways to give back."

Celebration: Support group committee members (left to right) Janet Kesby, Maria Emerton-Bell, Lynne Henry, Glennie McCartney, Wren Mathews, Neil Lang and Quenton Henry.

The Hastings Macleay Ostomy Support Group is one of the longest-running support groups within the Mid North Coast Local Health District, and the longest-running ostomy support group in the Mid North Coast and Northern Rivers regions.

Maria concluded with an inspiring message to the group: "Congratulations to you all, you've given and gained support for many people, helping each other through the challenges of ostomy surgery and recovery.

"Enjoy today's celebration filled with food, friendship, and a sense of pride for all you've accomplished."

The event was a fitting tribute to a quarter-century of resilience, community, and care.

Specialists: Past and present stomal therapy nurses Kate Hallett, Casey Luke, Maria Emerton-Bell, Jeanie McCarroll, Nez Cook and Michael Rohr.

Sweet treat: Heather Hill and Jeanie McCarroll cut the cake at the support group's 25th anniversary celebration.

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Surgeons share knowledge

By **Dr Binura Lekamalage**
Surgical registrar

FIJI is a popular holiday destination for Australians with its world-class resorts, white sand beaches and unique cultural experience.

While only a short three-hour flight away, unbeknownst to most tourists, the healthcare in Fiji is vastly different to that in Australia.

The rates of diabetes, stroke and heart attacks are among the highest in the world.

Bowel cancer in Fiji is common; unlike Australia, there is no national bowel screening program.

As a result of this and the lack of access to health services, many patients with bowel cancer present to hospital with advanced disease.

Treatment options for bowel cancer are limited to surgery only.

There is no radiation treatment available in Fiji and very limited access to chemotherapy.

Hence, the majority of patients are treated with emergency surgery and stoma (end colostomy).

Sadly, the majority of Fijians with ostomies do not have a regular supply of ostomy bags.

Many get by using plastic bags and ziplock bags held in place with pieces of tape.

According to Dr Timoci Qereqeretabua, a Fijian surgeon, "Stoma bags, particularly reusable bags, are a golden resource to patients in Fiji."

Colonial War Memorial (CWM) Hospital in Suva is the largest of two hospitals on the main island of Fiji, and is the primary referral centre for all of Fiji and the neighbouring islands.

Resources at the hospital are extremely scarce, including a lack of simple wound dressings, stoma bags, sterile gowns, gastrointestinal staplers and vascular grafts.

The hospital relies heavily on equipment that is donated by overseas visiting teams.

Two Australian colorectal surgeons, Dr Asiri Arachchi and Dr Andrew Bui, led a volunteer team to help the hospital earlier this year.

In this, they were assisted by Dr Binura Lekamalage and Dr Henry Witcomb-Cahill, trainee surgeons in New Zealand.

The aim of the visit was to donate equipment, operate on patients with bowel cancer and provide education to locals on bowel cancer.

The team donated nine boxes of surgical equipment including stoma bags that will be an extremely valuable resource to the people of Fiji.

Drs Arachchi and Bui have also established a program to improve expertise at the hospital by bringing Fijian surgeons to Australia for further training.

The state of bowel cancer treatment is vastly different in Fiji and the team hopes to continue its support of Pacific nations.

Smooth operators: The surgeons in the operating theatre and (below) scrubbing up in preparation. **Bottom photo:** Much-needed surgical and ostomy supplies on the airport conveyor belt.

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News of the World

Cool fashion for all

ENGLAND: A woman who found she had no stylish options to choose from when forced to wear compression gloves for her rheumatoid arthritis has been inspired to create a line of fashion accessories.

Destiny Pinto, from West Sussex, creates glamorous items to complement hearing aids and stoma bags, as well as compression gloves.

"It's almost like everyone forgot about these devices in fashion," Destiny said.

Her designs have had millions of views on social media.

Among her interactions are Olympic gold medallist Simone Biles, singer Sza and model Tasha Ghouri, who wears a hearing aid.

Ms Pinto said: "I hear personal stories, like children who wear colostomy bags or hearing aids, and they've never felt confident before seeing my designs."

Ms Pinto's best friend Nikola underwent life-saving bowel surgery at the age of 21 and permanently wears a stoma bag, making finding fashionable yet functional clothing a challenge.

"Anything tight around the waist causes leaks or pancaking so I have to think about baggy clothing or waistlines that sit higher or lower to avoid putting pressure on my stoma," Nikola said.

"There are some covers available, but they often look like tablecloths or come in plain colours.

"I like to be out there and I want something that makes a statement - different materials, different designs.

"The stoma bag can look very clinical, which stands out.

"These covers let me match my outfit; they're not just practical, they're a way for me to feel like myself again, like an accessory that adds to my style rather than detracting from it."

Libby Herbert, chief executive of Colostomy UK, said: "If the industry doesn't embrace accessibility, it can lead to isolation and poor mental health.

"People may avoid returning to work or struggle to maintain relationships. But being able to express yourself - even with a stoma bag - through fashion can significantly impact someone's wellbeing."

- *Source: bbc.co.uk*

Ostomy on the street

UK: Long-running soap opera *Coronation Street* has aired a storyline based on a significant health issue that experts are urging viewers to see as a warning – as well as raising more awareness about ostomies.

Character Bethany Platt, portrayed by Lucy Fallon, faces life-altering consequences following her decision to have cosmetic surgery overseas which goes wrong – Bethany ends up with an ileostomy.

Following the botched operation, she develops sepsis and is informed she'll have to live with a permanent stoma.

Data from a 2023 study published by The British Association of Aesthetic Plastic Surgeons indicates the number of people requiring hospital treatment in Britain after having surgery abroad had risen by 94 per cent over three years.

In the UK, about 200,000 people (one in 335) live with a stoma.

Coronation Street collaborated with Colostomy UK to portray its stoma storyline with both precision and care.

Giovanni Cinque, the marketing and campaigns manager for Colostomy UK, said even though public awareness had grown considerably over the past few years thanks to a number of celebrities revealing they have had stoma surgery, the challenges that people faced living with a stoma were less known.

"This means that we as a society and as individuals are not as aware as we should be of the choices that we can make to positively improve ostomates' quality of life," he said.

"We really hope that Bethany's journey will go a long way in helping to educate the audience, and thus help to create a more Stoma Aware UK. It's also been a pleasure for us to work with the behind-the-scenes teams at *Coronation Street* on this story."

Ostomies appear to be the topic of the month in soap operas, with the UK's Channel 4 soap *Hollyoaks* also introducing a storyline.

A character, Mercedes McQueen, has been diagnosed with bowel cancer and fitted with a colostomy and stoma bag.

Hollyoaks producers worked with Bowel Cancer UK to research the story.

- *Source: www.colostomyuk.org and www.msn.com*

Knives out for teens not wanting ostomy

ENGLAND: Surgeons in London are turning to extreme methods to deter teenagers from knife crime, including using ostomies as a cautionary tale, after a surge in knife crime across the metropolis.

A group of medical staff at Imperial College Centre for Engagement and Simulation Science wants to make young people understand the consequences of stabbing someone so they've created an immersive role-play for teenagers, getting them to stuff swabs around the organs and look for injuries below the peeled-back skin of an anatomical model.

Wearing operating theatre masks and gowns, and surrounded by screens and monitors, the participants have to hunt through the guts and gore to find where a blade has caused damage.

Professor Roger Kneebone said the priority was to make young people think before picking up a knife, by showing how a split-second stabbing can end a life or have consequences that last a lifetime.

Prof Kneebone once worked as a surgeon in Soweto, South Africa, and says it was plagued by knife injuries, many of which resulted in the creation of life-saving ostomies, and as a result victims had the benefit of some of the most experienced and skilled medical staff.

He said warning teenagers about the risks of knife injuries might not really have that much impact.

"Instead, what really connects is to show them that many stabbing victims end up with a colostomy or stoma bag," he said.

"Wearing one of these plastic pouches, used to collect waste from the body when the bowel or rectum is damaged, is not how teenagers want to see themselves."

The simulation takes young people through this process and Prof Kneebone said they ask questions such as how wearing such a pouch would affect sex lives or whether it would smell.

The interactive display is currently touring schools across the metropolitan area, with plans to extend it nationwide.

- *Source: bbc.co.uk*

News of the World

Intelligent 3D bags

CHINA: Researchers claim that 3D customisable ostomy bags with sensors and stimulators significantly reduce skin complications, leakage rates, and wearing time compared to traditional ostomy systems.

A study funded by the Wuxi translational medical centre investigated the potential benefits of 3D, customisable ostomy care for patients undergoing colorectal cancer and intestinal obstruction surgeries.

The study aimed to address common issues with traditional ostomy bags, such as skin allergies, inflammation, and leakage, which can greatly impact patient quality of life.

The researchers conducted a trial in 113 patients with a resulting stoma after colorectal cancer or intestinal obstruction surgery, to determine if 3D-printed ostomy bags, tailored to the patient's stoma shape and equipped with sensors, could improve patient outcomes.

The team used handheld 3D scanners to analyse stoma shape, and printed custom ostomy bags with an intelligent device adhered for monitoring and adjustment.

> “... better acceptance of (the) condition

The analysis found there were significantly shorter wearing times in the 3D group compared to the control group; the leakage rate in the 3D group was also much lower than in the control group.

Additionally, patients using 3D-printed bags had lower discoloration, erosion, and tissue overgrowth, indicating fewer skin complications, and higher acceptance of illness scale scores, suggesting better acceptance of their condition.

The study recommended future research should focus on broader clinical adoption and long-term impacts on home care, potentially transforming ostomy management in clinical practice.

• *Source: European Medical Journal (www.emjreviews.com)*

Stoma card initiative

SINGAPORE: The Ostomy Association of Singapore (OAS) has introducing a new medical identification card aimed at improving accessibility and communication for people living with stomas, as well as highlighting the life of ostomates.

Launched on Ostomy Awareness Day on Oct 5, the card provides ostomates with a discreet way to communicate their condition, allowing them to request priority access to restrooms or handicap facilities without the need for explanation.

Ellil Mathiyan Lakshmanan, president and co-founder of OAS, said the OAS medical identification card is expected to benefit about 6000 people living with ostomy bags in Singapore.

Retiree William Chong has resorted to using the disabled toilet several times, but often gets a “dirty look” from strangers because he is able-bodied.

He says the card would give him the confidence to use a handicap toilet in times of need.

The 74-year-old, a former welding engineer, has been living with an ostomy bag after he was diagnosed with rectal cancer in 2017.

“We need facilities with enough space to manage our stoma pouch, including sinks, a bidet and trash bins for disposing of used ostomy bags,” he said.

“Unfortunately, cubicles in public restrooms lack these essential features, forcing us to navigate our condition in less-than-ideal circumstances.”

One area where the card will be particularly beneficial is at immigration checkpoints like the airport, Mr Lakshmanan said.

“Many people feel anxious or embarrassed about their ostomy pouch being exposed or touched during security checks. They also often carry extra ostomy supplies in their carry-on bags, which might not always be understood by security staff,” he said.

Presenting the card will allow people to communicate their condition discreetly, thus avoiding embarrassing or awkward situations.

Mr Lakshmanan says this initiative places Singapore alongside other countries like the United States, United Kingdom and Australia, which have introduced similar cards to help individuals with ostomy bags in accessing handicap toilets and during travel.

Dr Chew Min Hoe, a senior consultant specialising in colorectal and general surgery at colorectal clinic The Surgeons, said the card will benefit patients and caregivers.

“While it is not meant to be viewed as a disability, it does provide some convenience especially for travel and the need for areas like handicap toilets,” he said.

“It reduces some of the potential communication difficulties that our patients may encounter and eases various frustrations.”

• *Source: www.straitstimes.com*

‘Diet’ pills to blame?

USA: A woman from Pennsylvania is suing the manufacturer of prescription drugs Ozempic and Wegovy, claiming the drugs were responsible for leaving her with an ileostomy.

Juanita Gantt said her doctor prescribed the trendy weight-loss drugs, produced by pharmaceutical giant Novo Nordis, because she had a higher risk for diabetes and wanted to shed 10 kilos.

Gantt said she was initially feeling fine for the first few months of her treatment until her husband found her unconscious on the floor in October, 2023.

Doctors discovered that sections of her large intestine died and needed to be removed – her colon was removed as a result and she now has a permanent ileostomy.

Gantt claims the labels don't properly warn users and doctors about serious side effects like gastroparesis, stomach paralysis, or even bowel obstruction.

Novo Nordis said the allegations in the lawsuits were without merit and it will “vigorously defend against these claims.”

The drugs are prescribed for treating diabetes but have become popular as an aid in weight loss.

Semaglutide and liraglutide – the key ingredients in Ozempic, Wegovy and similar drugs –are GLP-1 receptor agonists, which can delay food digestion if taken for extended periods of time.

• *Source: nypost.com*

Stoma
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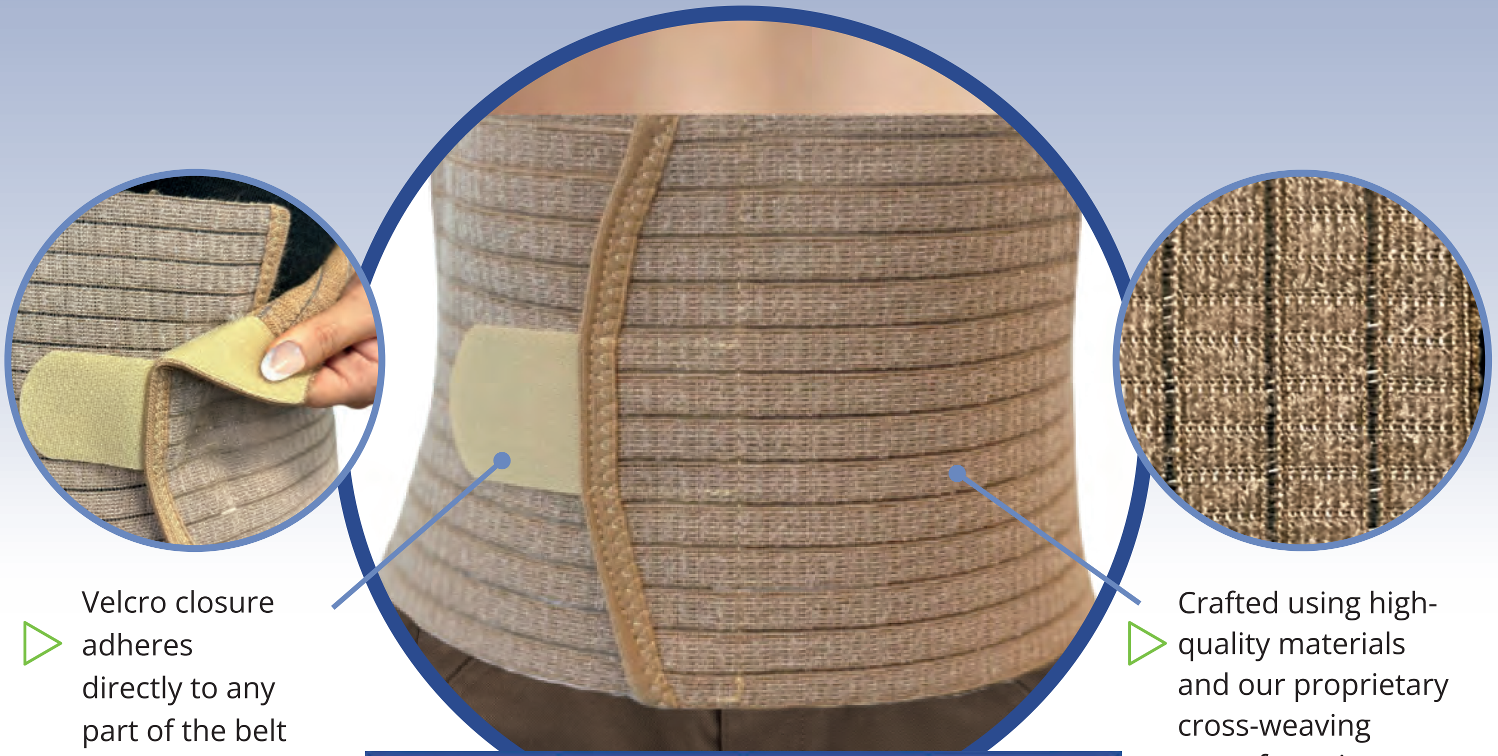

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National Directory of Ostomy Associations

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: wbostomy@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.

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@homemail.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 Jingerri Meeting Room, Logan Hospital. Bldg 3, Level 5. Dec 16, 10-noon Chrstmas 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 Chermside Bowls Club, 468 Rode Road, Chermside. 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 stomal 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, Maroochydore. 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 Czynski, 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 Sharmaine 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 Kok 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: Stomal 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: Stomal 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, stomal 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 Kununurra: 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).

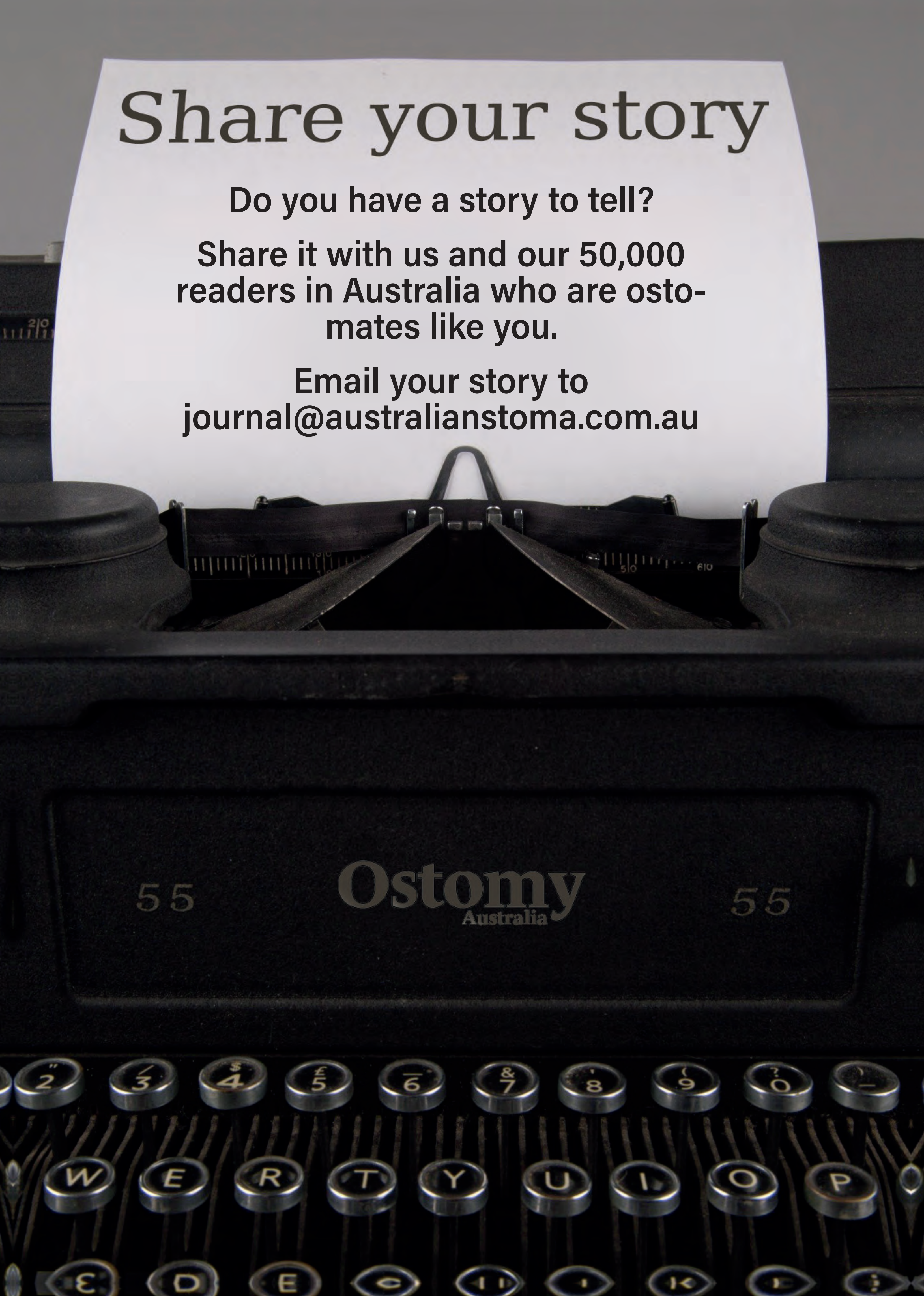
Narrogin: First Wednsday quarterly. 12-1.30pm, Senior Citizen's Centre. Contact Lorraine 0429 812 552.

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.



Share your story

Do you have a story to tell?

Share it with us and our 50,000 readers in Australia who are ostomates like you.

Email your story to
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