# Australia OStomy Connecting the Ostomy Community

Volume 32 Number 01 April 2023



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1

# Bags out and proud

The body positive issue 🔊

ALSO IN THIS ISSUE

Vitamin vitality P3

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Nurse on the run P5

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#OstomyAwareness

# Contents

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Connecting the Ostomy Community

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Sam's on the run	5	Brendan's story	11	Terry's story	22
Letters	7	Spotlight on Darwin	13	Mental health	25
From the executive	10	Social media star	16	The Magic Pastry	27

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#### In this issue

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# Could a multivitamin help?

#### By Teresa Mitchell-Paterson

DO you need a multivitamin?

Unfortunately, there is no scientific literature or developed guidelines for supplementing the ostomy patient.

However, there are some things that empirical observation and patient experience have taught us since the inception of ostomy surgery.

The dietary constraints for an ostomate are often far removed from the Australian guidelines for healthy eating.

The general population is told to consume five serves of vegetables, two serves of fruit, and whole grains and legumes daily.

As many of these foods are reactive for an ostomate, causing high stoma output or blockage, possibly the stoma patient's diet may be lacking in vitamins and minerals falling lower than the recommended daily intake of nutrients.

A high-output stoma increases the risk of malnutrition.

Taking a multivitamin is not a substitute for a healthy diet but may be indicated for where the diet is inadequate or limited.

A healthy diet includes protein, carbohydrate and fats.

However the addition of a variety of leafy green vegetables, broccoli, cabbage, raw vegetables or fruit with peel, nuts, whole grains, and legumes may cause complications for the ostomate such as wind, odour, leakage and blockage.

In a large review on the use of multivitamins, it was found that they may assist patients who cannot meet all the requirements of a healthy diet.

The low-dose (also known as food grade) multivitamins are generally safe for most people. Current smokers or ex-smokers should not consume multivitamins and minerals due to possible high doses of vitamin A which may increase the risk of lung cancer. Colostomy patients are generally able to consume a wider range of foods, whereas ileostomy patients may face a more restrictive diet.

Ileostomy patients can react to fats; when an ileostomate consumes large amounts of fat the decrease in fat digestion (due to removal of part of the bowel) can cause higher output with greater losses of sodium and potassium.

The ileum is where B12 absorption occurs; in ileostomy surgery, this part of the intestine is compromised.

There may be a reduction in vitamins K, and B, folic acid, and short-chain fatty acids produced by this part of the bowel microbiota.

For stoma patients with the above mentioned issues it is important to be specific about supplementation so discuss this with your specialist.

Nutritional requirements will vary based on the amount of bowel remaining and the overall health of the patient.

This applies in particular to B12 and vitamin K.

B12 may assist in reducing the risk of anaemia and nervous system dysfunction.

Vitamin K helps to strengthen bones and is a preventative

for heart conditions such as heart failure, arterial stiffness and hypertension.

A blood test and subsequent analysis by your GP can help determine your current level.

Post-surgery, some patients may experience lactose intolerance,

however, calcium intake is still required; a simple solution is to consume lactose-free products to replace the usual dairy foods.

If large amounts of antibiotics have been administered in the post-operative period the patient will require additional vitamin K.

In nursing protocols, a low-dose multivitamin and mineral is suggested for patients with suspected inadequate nutrient intake or known deficiency.

#### Tips to improve diet

- Keep a food diary and try to add one new food at a time and observe any reaction and avoid or continue eating that food for a few days before introducing another food.
- Be patient, it can take 6-8 weeks post-surgery for the swelling in the bowel settles before more foods can be added to your diet.
- Eat regularly don't skip meals or consume larger than usual meals to compensate for lost calories, this is likely to increase gas and frequent bowel evacuation.
- Chew your food well a practice called mindful eating can be a way to achieve this
- If your bowel is reactive to dairy, you can swap dairy for lactose-free dairy or calcium-enriched plant milk, such as almond or soy milk.

One scientific review on supplements suggests the consumption of a multivitamin-mineral for a year after recovering from surgery.

There is a close relations ship between nutrition and appropriate wound healing – adequate vitamins and minerals are vital to healing.

The proviso is that along with vitamins and minerals adequate calories for protein, carbohydrates, fluids and electrolytes are consumed to maintain tissue integrity and regrowth. Ensuring the diet is wide and varied before surgery can improve the post-operative outcome.

In a nutshell, do you need a multivitamin-mineral supplement?

If you eat a varied vegetable and fruit diet with the appropriate fibre for your stoma you may not require one.

If you cannot eat a varied diet consider a multivitamin supplement in the recovery year after surgery.

#### Teresa Mitchell-Paterson is an associate professor at Torrens University

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## On the run with a second chance at life

By Sam Lawrie

MORE than 16 years ago I began working for the first time as a registered nurse on a surgical ward.

Colorectal surgery was one of the specialities on the unit; this included patients following bowel surgery who need a faecal stoma, either ileostomy or colostomy.

I enjoyed looking after the patients with stomas, I found it sometimes challenging but rewarding caring for them.

I was sympathetic for what they were going through but could never imagine needing a stoma myself.

In 2012 while pregnant with my first child I began experiencing bleeding from my rectum.

The doctors thought it was just haemorrhoids and blamed pregnancy as the cause.

Months went by and my symptoms increased to abdominal pain, lethargy, urgency and frequency of bowel motions, mucous discharge and further bleeding.

The doctors continued to put this down to hormonal changes in pregnancy but did say that they would perform investigations if my symptoms continued after giving birth.

In July, 2013, I gave birth to my daughter and at first felt great with a post-birth high, then slowly the symptoms returned.

I had a colonoscopy which confirmed ulcerative colitis, an inflammatory bowel condition where the inner lining of the colon becomes ulcerated and inflamed and causes these uncomfortable and sometimes unbearable symptoms.

I commenced treatment which included strong steroids, then added an immunosuppressant tablet months later when the steroid wasn't enough.

Also added in were rectal medications ranging from small suppositories to 100ml steroid liquid enemas, sometimes twice a day.



Positive change: Sam Lawrie embraces life again after stoma surgery.

These all caused a number of unpleasant side effects such as mood swings, bloating and insomnia just to name a few, all of this on top of trying to be a mum for the first time.

I often felt stressed and like a complete failure at everything.

In 2015 I became pregnant again, which probably wasn't the best time as my bowel disease was not completely under control.

I started to have accidents; incontinence of my bowels gave me terrible anxiety on top of not feeling well.

It would happen anywhere at any time. It was often worse in the mornings

so I would leave for work early in case I needed a toilet stop on the way to work, which was either service stations or McDonald's, and one thing you realise with faecal incontinence is that there are never enough toilets.

My mental toilet radar was always on and the anxiety I suffered was awful.

After giving birth to my second daughter my condition worsened when I never thought it could.

I was in almost constant pain, rushing to the toilet or having accidents, struggling to eat, losing weight (I was down to 45 kgs) and constantly lethargic, all while trying to care for a new baby and toddler.

I was trapped in my own body.

I fell to a new low, my lowest yet, and even contemplated ending it all – my girls didn't deserve a mum like me, my husband didn't deserve a sick and useless wife like me.

So, after encouragement from close loved ones (yes, sad to say sometimes even us nurses don't have the insight to question their treatment plan and doctor) I saw another gastroenterologist who was more proactive and tried me on intravenous biologics to stop the inflammation.

These gave me some signs of hope with less symptoms however, it was short-lived and I got worse.

A poo transplant was discussed: faecal microbiota transplantation.

This is where another person's stool is transplanted into your colon and your gut microbiome changes to theirs.

I told my husband Shane that I would like to use his stool, he has guts of steel!

I needed an admission to hospital in the week before Christmas of 2016.

Here I chatted with our hospital stoma nurse, Julia, who I knew well from work.

She discussed stoma surgery as an option for me.

This hadn't really been discussed before, if it had it was spoken about as a last resort and I assumed I would never need one from the minimal discussion about it by the medical professionals.

I started thinking of this option of having a stoma.

I was able to research and find other people on social media of a similar age who have stomas and chatted online with a female ostomate in another state who I found on a Crohn's and Colitis Australia Facebook page.

This world opened my eyes to the possibility of getting a stoma and made it all feel less daunting.

I felt fortunate to go through this in a time with access to social media, I didn't feel alone.

Continued page 6

#### Continued from page 5

On April 4, 2017, I had my stoma surgery, I'm sure everyone with a stoma understands we never forget that date.

My surgeon was able to remove my colon and form an ileostomy under keyhole surgery, laparoscopically.

The first couple of days were a bit of a nauseated blur but once the anaesthetic drugs wore off, I began to feel human again and I can still remember the moment that I realised the horrible cramps my colitis caused had gone.

I felt free; free of the pain and suffering I had put up with for the past five years, it was amazing.

Seeing my stoma for the first time was a bit surreal.

I had been in this moment so many times but I was the nurse and someone else had the stoma.

Now it was my turn, I was actually a bit nervous; I had so much experience caring for stomas but when it is your own stoma it is so different.

The fact that I couldn't feel anything on my stoma was weird for a while (stomas have no nerve endings) and it was pretty swollen but that is normal at first and it shrank, however they are daunting enough in those early days as many of you know, especially being so big and swollen.

My whole abdomen was swollen for weeks after, low hanging elastic trackies and baggy tees were life.

Once home I continued to improve and I appreciated the little things in life so much more.

Simple things like taking the kids to the park to play were now stress-free and enjoyable with my stoma.

Before I would panic about where the nearest toilet was and become impatient from my constantly tired and in pain body.

I remember my first support group for ostomates, it was on only a few weeks after my surgery.

This is run in the Illawarra where I live, by both Julia from the public hospital and Helen from the private.

I will never forget the feeling walking in the room and realising that we are all just normal people.

We didn't look or smell different and it immediately put me at ease.

I enjoyed the sharing of advice from their lived experience with stomas.

I am so grateful for this group and have met some amazing people through it. When I was in hospital after my surgery, I saw an ad for the Sydney City2Surf, a charity run from the city to Bondi.

Four months following my stoma surgery I took part in the run with Shane and my brother-in-law Wade.

We raised money for Crohn's and Colitis Australia and wore shirts to share our cause.

I have run in the event every year since.

I was pretty lucky with my stoma and only encountered a few starting out leaks.

I soon found confidence and was ready to get back to work.

I wasn't sure if I would mention my stoma to patients but found that I would just say it and once I saw the positive effect on the patients, I knew it was a good thing to share.

I was encouraged by friends and family to complete my post-grad studies in stomal therapy nursing.

I had never imagined doing further study but this just made sense.

I completed my course at the end of 2018, with thanks from Ostomy NSW, my stoma association which kindly donates funds for a scholarship each year and helped immensely with reducing my HECS debt.

In 2019 I started working as a stomal therapy nurse on a fill-in basis one day a week and continued a few days a week of my ward work.

I loved it – I have found having the day to day, living with a stoma experience I have so helpful with teaching new patients and helping existing ostomates.

We can relate and share stories; it is a special club to be a part of.

Speaking of special, stoma nurses are all amazing.

I was lucky to attend a National Stomal Therapy Nurses conference in Sydney in 2019 and met most of the stoma nurses from around the country.

They were all so kind, encouraging and welcoming me as a new stoma nurse.

The presentations were so informative and inspiring.

And I can confirm that stoma nurses party as hard as they work.

My stoma has given me so much. Yes, I have the odd day when it can be annoying, like when I don't want to get out of bed early just to empty an aboutto-pop bag, a bit like a hot air balloon.

But it doesn't take long for me to remember how my life was without my stoma.

The histopathology from my surgery concluded that I in fact have Crohn's disease not ulcerative colitis; the inflammation was found throughout the deeper layers of the intestine. This meant that my stoma would definitely be permanent, I was not willing to risk reversal surgery as this would involve two more surgeries to form a new rectum from my small intestine called a J-pouch.

However, with the Crohn's diagnosis there would be a risk of my J-pouch becoming inflamed and failing and I would have to go back to a stoma.

My children are young so I did not want to try this, which is a very individual decision for every person.

And as I said the adjustment to stoma life was much better than living trapped in a Crohn's flare like I had.

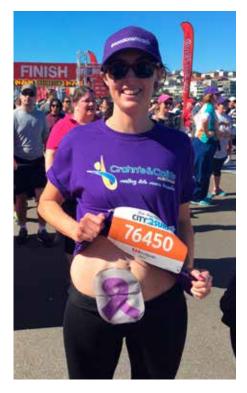
I continue to relieve in the stoma nurse position and love every minute of it.

There are highs and lows in the job but those highs always make up for the lows and I love the satisfaction of helping people, especially understanding what it is like living with a stoma.

My grandmother died in her thirties when my Mum was only two, her bowel perforated from inflammatory bowel disease.

So, I often think of her and how lucky I was having this second chance at life.

I hope to continue working as a stoma nurse more and more in the future and sharing my story with anyone who will listen, to help stop the negative stigma that surrounds living with a stoma.



Fundraiser: Sam Lawrie took part in a charity run and raised funds for Crohn's and Colitis Australia

# 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

#### Connection

MANY thanks once again for providing us with the wonderful journal. While I have met quite a few people with colostomies, I have never until recently met anyone who has an ileostomy like me. I feel quite an emotional connection

.....

when I read the interesting stories of other ostomates.

Val Jack, email

#### Icebreaker

For the first time in seven years since having my colostomy I laughed out loud at my predicament.

.....

The cartoon Cancer Owl by Matthew McWhorter is brilliant and I am sure there are plenty more funnies inside him just waiting to "burst out".

I felt truly understood and could see the funny side for once and I am going to show it to friends as a part of my "coming out".

I have been hiding it and my suprapubic catheter but it is a conversation that needs to be had.

What a great icebreaker for that conversation and I hope Matthew keeps up the great work.

I don't write to magazines but Matthew's work truly needed to be applauded. Thank you for publishing it and thank you Matthew.

Janice Stevens-Rice, Queensland

Inspired by a true story, submitted by: Anonymous



#### Thanks for tips

Thank you for the article on hydration for ostomates. This was very timely as we have been having warmer weather in our area than we have had for some time, and because I am just recovering from another partial bowel obstruction which was probably due to dehydration. I agree with the tip for placing tissue inside the bag to reduce pancaking. You can also squeeze a little lubricating deodorant in on top of the tissue. My other tip relates to swimming, which I love – pool, surf, whatever. If you are going to be out in the surf for a while, you can consider putting a semicircular elastic strip to stick the top of the bag down more securely. This means that even if you're diving under a lot of waves, the top of your bag won't start to peel down. Remember that while the first 12 months with your Mrs Hanky might be tough but you can go on to enjoy a normal, happy life!

#### Anne Kelly, NSW

Continued page 9

## Soft convexity for the **B BRAUN** everyday active ostomate

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#### **Navigation advice**

The travel piece entitled Up and Away (December 2022) was very timely and informative.

For the Hollister travel certificate however the Hollister search function does not work.

You have to go to Ostomy Care, then Clinical Education, then Quick Educational Tools, and finally to Travel Certificates.

You can print in 13 different languages including English so it has good coverage.

.....

#### Joe Duggan, email

#### **Great story**

Loved the December magazine, particularly the story 'More than just a man with a bag'.

Loved reading your story Darren, with your ups and downs and how you conquered them.

I have had an ileostomy for 12 years now and could completely relate to the issues you had with health.

I also have Crohn's disease.

I loved my ileostomy from day one, and I haven't had much trouble with it. Thank you for the read and I wish you and your lovely family all the best.

.....

#### Nancye Turner, Queensland

#### More advice

In reply to Catherine Gavin (Letters, December edition) wanting advice after getting a reaction to many adhesives, I wondered if she has tried no-sting barrier film?

Many skin barriers can be used but the bulk are silicon-based, whereas there is one that is polymer based. I only say this because I had a friend once who seemed to have a milder problem (redness from the adhesive) and after using the polymer-based product didn't have a problem. I myself get the itches from adhesives and this mostly stops them to a degree. I spray it on my skin where my bag will go and let it dry for 10 seconds then put my bag on over it.

.....

#### Bronwyn White, email

#### Skin issues

With reference to the letter 'Advice sought' in the December 2022 edition, I also had difficulties with my skin but not due to the adhesives, mostly caused by occasional leakages.

Thanks to suggestions by the supplier of my products, I now use products to "remove, cleanse and protect" my skin;

previously, I had only used warm water. Companies who develop products must be aware of skin allergies, for example, they make tape for people with allergic reactions.

Find an expert in this field and discover what chemical you are reacting to so that you know what to avoid. There are two parts - protect your skin

and avoid the irritant. Somebody with a chemical background, perhaps a pharmacist with extra

understanding may provide suggestions. Not as easy as it sounds, I imagine.

Isobel Davie, VIC



#### **Goodbye Stomie**

I have written a goodbye poem to my stoma - I'm having my reversal tomorrow. It was in the summer of 2022,

The first time I met you.

The way we met was a bit of a shock, All because of a tumour that was causing a block.

Fit, healthy and having fun,

- I didn't expect bowel cancer at 31. I adapted to you, Stomie, faster than I
- expected,

You saved my life and that has to be respected.

The black bags made you feel like a chic accessory,

Our craft-a-noons cutting bags for you will no longer be.

We've had our moments, that is for sure, Life with you was never a bore. We experienced (more than once) the bag explosion,

And the songs you sang through gas, causing an embarrassing commotion. It's been interesting having you spend time on the outside of my tum, But now it's time for you to go so I can poop back out of my bum.

Steph Do Carmo, TAS.

#### Overordering strains resources

THE Australian Council of Stoma Associations (ACSA) is the peak body of the 20 associations that distribute stoma appliances to their members.

On a day-to-day basis the work of ACSA is handled by its executive who are all volunteers, working tirelessly for the benefit of ostomates.

We liaise with the Commonwealth government through the Department of Health and Aged Care.

We also work with stomal therapy nurses (STN) through the Australian Association of Stomal Therapy Nurses (AASTN).

All of this is to ensure that the 47,000 people around Australia who have a stoma are well looked after and to ensure that ostomates can feel positive about their bodies and can lead a normal, healthy life.

In Australia we are indeed fortunate to have our stoma care looked after by successive federal governments of whatever political persuasion.

The Stoma Appliance Scheme is unique to Australia.

Ostomates in many other countries have to pay for their supplies or make a substantial contribution.

We are fortunate that our associations

are staffed by caring members of the community whether they be paid or are fellow ostomates who volunteer their time and expertise to get your supplies to you.

If you want to be part of this volunteer group approach your association to see if you can assist and if they need your assistance.

One of the issues that concerns us is the proper ordering of supplies by members.

As you will be aware the government allows ostomates to order their needs on a monthly basis.

We urge ostomates to order what they need and to ensure that they have sufficient supplies to meet their needs so that there isn't an urgent need to get emergency supplies because they have used their last bag.

Conversely, we urge ostomates to not over-order supplies.

To do so places a strain on precious resources.

We also urge ostomates to speak to professionals if they have a problem.

Most associations have an STN with whom members can speak to or see if the need arises. With all of this ostomates can live a full enriched life without having to be concerned with the needs of their own stomas.

If you wish to communicate with me or the ACSA executive my email is set out below.

I wish you all a happy and healthy year ahead.

#### Ian Samuel OAM President Australian Council (

Australian Council of Stoma Associations acsapres@australianstoma.com.au

#### READERS WRITE

A new reality

#### By The Gutless Wonder

I expected it would be so foul To live one's life without a bowel, That it would be an awful drag For my output to flow into a bag Through a stoma on my tum Which I refer to as my tummy bum!

He can cause much stress with his leaks And may even utter embarrassing squeaks, He always needs our help to dress And sometimes creates quite a mess But our stoma is our closest friend And can be with us right until the end. Living with a stoma is not so bad I'm without the ulcerative colitis I once had. After suffering a near death plight Followed by a year-long fight. Gone now are the bleeding and the pain I rejoice and celebrate life once again.



# A grand journey as life goes on

OVER the years my wife Joan and I had lived a pretty quiet life with only a few minor health concerns, like a heart bypass in 1993, but life was really pretty quiet and orderly.

I retired from work in 1997 (I was a purchasing officer in a large computer wholesaler in Brunswick) and we had a very happy, contented life with a fair few interests.

We had three grown up children with their own lives, and some lovely grandchildren.

Life was good, really good – and uncomplicated.

In early 2004 I had a minor problem which I thought was probably a haemorrhoid so after a few days thought I should see the doc.

I had the check and rather surprisingly the doctor said perhaps I should have it checked by a specialist.

Not very happy Jan ... but indeed very lucky, because otherwise I probably would not be here now. The specialist said a colonoscopy would be needed and we assumed if they found anything it would be something simple and easy to fix.

We went back to get the results with little, or no real worry at all until he quietly asked Joan – who had been sitting in the waiting room – to also come in "for a chat."

He started his chat and we could not believe our ears.

He said: "rectal cancer."

It's a strange feeling, quite unreal and almost an out-of-body experience when you hear those words.

As a very active person, the specialist's words flooded through my mind: "You will need to have a stoma and wear a bag for the rest of your life ... the operation will never be reversed."

My first thought was: "What's a stoma?" We left the specialist's rooms in a state of shock and disbelief.

In 2004 I had major bowel surgery at Warringal with 10 days in hospital, then visits by a home care nurse for the next five weeks.

From memory all I seemed to do was sleep, however this was followed by a long, long period of recovery due to

#### by Brendon Smith

infections and discharges for more than six months.

I had great difficulty just trying to sit down due to the pain and extreme discomfort.

We went to our first Northern Support Group meeting where I remember Joy Walker telling me that I wouldn't be able to sit down without pain/discomfort until at least Christmas.

And guess what, Joy? You were quite correct!

My own surgeon had never told me that the difficulties and problems I had been facing for three months since surgery could take more than six months before they would cease and be overcome.

At last, after months of daily problems, the discharges suddenly stopped with, I believe, great assistance from salt water, resulting from many trips to the beach.

As the weeks rolled by life began to take on more of its normal aspects and we were kept busy with our usual activities whenever possible and I think this was important for both of us.

The process of diagnosis, treatment and recovery had taken a whole year of our lives (a year we will not forget) but also from which we have learnt a lot.

Since 2005 life has been back to normal where we are both flat out most days keeping busy and involved with a number of community activities.

Our current interests are quite time consuming – I try to play tennis most Tuesday nights, although I watch what I eat very carefully after Tuesday lunch.

You don't want a bag to be filling, or a very full bag, as you chase a ball and run around a tennis court.

Looking back on life I'm delighted to be able to say that I have been most fortunate in life's journey.

I helped to start the local Yarrambat Historical Society in 1990 and have now been their secretary for more than 30 years.

Of special interest is that our historical society works closely with the local Yarrambat Primary School and every year each grade six student gives a threeminute historical speech. Joan and I are the main organisers for this and have been for the past 18 years, and it is a great way to keep in touch with the youngsters and the local community.

We recently finished three nights where 63 students presented their speeches and this year was special because our granddaughter Carly was a speaker.

After all our troubles like a heart bypass and bowel cancer, nights like these are very special.

Over the years we have also helped with packing at the Colostomy Association of Victoria and really appreciate the efforts of this great group of people.

One of our major activities continues to be with the Caravan Club we started back in 1999 – we now have more than 2400 members involved in all states of Australia with about 50 activities each year.

We have now travelled around Australia twice and usually spend at least six to eight weeks away in the van over winter.

Joan and I are popping over to Tassie to attend one of the club weekends at St Helen and in this situation, and especially in a travelling or caravan situation, the colostomy bag is really not a problem.

Indeed in some ways it's quite a help not to be looking for a toilet somewhere in an outback town or location, when Joan might be.

So life is good – in fact, wonderfully good, considering the possible options and alternatives one has faced.

But it is not perfect and I still have lots of concerns and frustrations about the changes which were brought about following surgery and the radiology and chemo treatments.

I had (and still have) questions that I would like to talk over with some other guys.

Hopefully one day, we will – but thankfully, we are all here today and for all of us, life does currently go on.

I believe it is the taking of just one day at a time that enables real life, enjoyment and living to really go on and each day that we do take will hopefully make a special memory for each one of us in the jigsaw of our life's grand journey.



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## Cuppas and chats in the top end

WHILE those in the top end can face additional challenges in dealing with an ostomy, they also know the importance of staying in touch with like-minded people.

With humid weather special care has to be taken to dry the skin around the stoma with a hairdryer so the bag is secure and proper hydration is, of course, essential.

Tips on how to manage a stoma in the tropics are just one of the reasons people enjoy regular support meetings at the Northern Territory Cancer Council.

The only cancer council to provide ostomy services in Australia, Cancer Council NT distributes stoma-related supplies to all Territorian ostomates and provides support services to help them manage their condition and adapt to lifestyle changes regardless of whether their stoma is cancer related or not.

Regular Support Group meetings are held at the Darwin office where people get together over a cuppa to find, connect and talk to other ostomates who offer understanding and peer support.



**Good mates:** David Smith of Darwin, an ileostomate for more than 30 years, enjoys a chat at the NT Cancer Council support group. David's 'mate' is Teddy, from Ostomy Support Bears WA.

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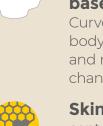
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**Good attitude:** Harrison Kefford credits social media with helping him accept his body shape, both before and after stoma surgery.

# Positive connections with stoma media

**By Amanda Haines** 

HARRISON Kefford knows what it is like to feel isolated.

A series of medical conditions kept the 29-year-old Melbourne man from socialising when he was younger, at an age when all his friends were partying and going to clubs. "It's a time when your life is really about to start," he said.

"I was just too sick and missed out on all of that."

But he is more than making up for it now, thanks to a life-saving stoma and an interest in social media.

Just over a year ago, Harrison had surgery to treat Crohn's disease, resulting

in an ileostomy.

He also has a liver condition and the rare autoimmune disease CIDP, as well as osteoporosis.

He has regular treatment for the CIDP, which keeps it stable, but it is the ostomy which has had the most effect on his quality of life.

"Having a stoma has 100 per cent increased my freedom, not just physically but mentally," he said.

"Having a bag doesn't limit what you can do – if you have a bag, you have the opportunity to see the world and for me I can experience it for the first time painfree."

Seeing the world is just what Harrison has started doing, and he has social media and the internet to thank for that.

Like most people of his generation, Harrison regularly posts on popular video- and picture-sharing sites TikTok and Instagram, detailing his life with chronic disease.

Unlike most people, however, his posts are seen daily by "hundreds of thousands" of people – his most popular posts have attracted millions of views.

Put simply, there are millions of people around the world who know Harrison's name.

And, thanks to his posts, they also know a lot more about Crohn's and about ostomies and stomas than they did before.

Harrison's online presence has attracted interest from ostomy products companies, one of which recently paid for him to visit New York and write about his experiences there.

"As an influencer, I have created content for them, and I try to make ostomy stuff cooler and more approachable," he said.

"I also have a collaboration with [an underwear company] and I would love to design my own range of ostomy-friendly underwear."

As a method of communication, education and making connections, social media is unparalleled and is understandably the weapon of choice for the younger generations.

Due to its inclusivity, many older Australian ostomates in particular are also exploring the benefits of having information and fellowship right at hand via a smart phone or computer.

"My generation is heavily social mediafocussed and using TikTok is a way for me to feel comfortable with myself," Harrison said.

"I think having an ostomy used to be

more of a stigma than it is now, some people think it is really gross but then you just talk about it and people are really interested.

"People say I am an inspiration but I am just like you, learning to adjust and learning how to be comfortable."

The response to his social media posts took Harrison by surprise and he soon realised he had a powerful platform to raise more awareness about stomas for people of all ages.

"I have learnt more about my conditions and other people's through the power of social media," he said,

"It can have a brilliant side, you don't know how many people see your stuff.

"I didn't realise how many people live with ostomies – older people, younger people – it's a lot.

"The more awareness raised, the more people interested, the better."

While the toxicity of social media cannot be denied, with the anonymous nature of posting allowing anyone to make comments they would hesitate to say in a face-to-face encounter, Harrison's experience has been overwhelmingly positive.

As a young man, he has also made great strides in promoting body positivity for males, something that can be overlooked in the superficial glamour shown by so many influencers.

"Social media can be a weird place and people can get uncomfortable but I need

to just worry about myself," Harrison said.

"I don't have the emotional capacity to fight for everyone, I am exhausted just doing my own thing.

"I have never been 100 per cent comfortable with my body, even before the ostomy; I'm tall and skinny, but social media has taught me that every single person feels that way about themselves.

"I find comfort in that – social media has helped me accept my body shape.

"From a male perspective, I feel more comfortable with my body type as I see others who are like me."

The question of just how open to be when there are millions of people watching can be a tricky one.

Harrison said while he would like to be more explicit, he didn't feel the time was quite right to do so.

"That is the number one question I get from people – what does it look like? Can you show me?

"But of course, everyone's is different; mine is pretty small in relation to the rest of me and that's the thing, it's so small but it makes up a huge part of your life."

Along with body positivity, many ostomate social media accounts stress the importance of good mental health.

For Harrison, having a qualified therapist to talk to is just as important as seeing medical practitioners who focus on the physical realities of being an ostomate.

"When you're younger, you can treat



mental health as a bit of a joke and while that may be a coping mechanism, it can also be a way to connect with other people," he said.

"My therapist is awesome in helping me be more comfortable with my ostomy, so I just see the stoma as a way to connect with people."



Online connection: Harrison's social media posts detail his life with an ostomy.

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# News of the World

#### Slammin' Sam



**AUSTRALIA:** SAM Schröder, quad wheelchair tennis star and ostomate, has replicated his 2022 Australian Open success.

The Netherlands player again lifted the

winner's trophy at this year's Open in January in the men's singles division.

While all the drama and publicity for the male players was on the main court where Novak Djokovic (Croatia) defeated Stefanos Tsitsipas (Greece), Schröder was again quietly victorious after beating fellow Dutchman and perennial opponent Niels Vink 6-2, 7-5.

#### Ostomy after cows attack



**ENGLAND:** A RAMBLER suffered life-changing injuries after she was trampled by cows. Janicke Tvedt, 55, came across a herd of about 30 cows while walking her dog in North Yorkshire. The former army officer, who had served in

Bosnia, was pinned against a fence by the cows and stamped on as she lay on the ground.

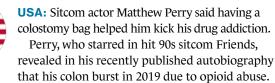
She managed to climb a tree for safety, before paramedics arrived and she was airlifted to hospital.

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She was left with seven broken ribs, hoof marks on her chest and legs and had to have a colostomy bag fitted after part of her colon was removed.

www.dailymail.co.uk

#### Actor beats drugs with bag



The damage was so severe, he was in a coma for two weeks and needed a temporary colostomy for a year. The experience motivated Perry, 53, to quit drugs with the help of a therapist.

"My therapist said: 'The next time you think about taking [drugs], just think about having a colostomy bag for the rest of your life," Perry wrote in his book.

"And a little window opened, and I crawled through it, and I no longer want Oxycontin."

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news.com.au

#### **Diagnosis increase**



**BRAZIL:** THE death of soccer superstar Pele has highlighted the increase of the incidence of colorectal cancer.

The Brazilian player had a tumour removed from his colon in 2021 but died from the disease

in December, aged 82.

According to Brazil's National Cancer Institute (INCA), despite being treatable when caught early, colorectal cancer was on the rise especially among young males, with unhealthy lifestyle patterns one of the key reasons for its occurrence.

In Brazil, colorectal cancer is frequently diagnosed in its advanced stages, with some estimates of the consequent rate of death to have increased by 75 per cent in men and 67.5 per cent in women since 2014.

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There is no nationally organised colorectal screening program in the country.

www.inca.gov.br/en/institutional

#### **Graphic** art



**ENGLAND:** A CONTROVERSIAL artist has turned to social media to share her health journey.

Tracey Emin shared a video of her stoma on Instagram to illustrate her battle with

bladder cancer.

She was diagnosed in 2020 with an aggressive squamous cell cancer and underwent surgery to remove many of her reproductive organs and parts of her intestines and lymph nodes as well as being fitted with a stoma bag.

Known for her art installations such as an unmade bed and a graffiti-daubed tent, Emin stopped painting while she was having treatment.

"I'm not painting because I'm using my willpower to stay alive. That's what I'm doing," she posted in 2021 on Instagram.

Earlier this year, she celebrated news of her remission by posting a photo of her stoma on her social media account.

Emin's art piece entitled My Bed featured an unmade bed with stained sheets, surrounded by the detritus of everyday life, recording days spent in bed in the grip of depression.

The work was nominated for the Turner prize in 1999 and received a mixed response from the public and press. www.dailymail.co.uk

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#### **Toilet** law



**USA:** The state of California has now made it illegal to deny ostomates and others with a medical condition access to toilets in businesses.

As of January this year, any business which is open to the general public for the sale of goods

(including restaurants) must allow those with an eligible medical condition to use employee restrooms during normal business hours, even if the restroom is not normally available to the public.

The statute defines an eligible medical condition to mean Crohn's disease, ulcerative colitis, other inflammatory bowel disease, or another medical condition that requires immediate access to a toilet facility.

Businesses that deny a requesting individual use of an employee restroom are subject a civil penalty of US\$100. www.natlawreview.com

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Do you have any adhesion issues? Ensuring your product sticks securely to your body helps you feel secure, and prevents complications. You can tick one or more issues.	None	Insufficient adhesion when applying	Adhesive dissolves during wear	Adhesive edges roll		
<b>Do you have any skin irritation issues?</b> Your skin around your stoma should look like the rest of your stomach. If not, you can tick one or more issues.	None	At the outer edge of the baseplate	Under the baseplate	Around the stoma		
Do you have any bag issues? It is important that your ostomy bag works for you and that you feel confident wearing it. You can tick one or more issues.	None	Leakage	Odour	Ballooning or pancaking		
For two piece appliance users only It is important your two-piece works for you. Tick on any coupling issues you might have. You can tick one or more issues.	None	Coupling difficult to close or open	Bag falls off	Leakage at coupling		
How is life with a stoma making you feel right now? I am having a difficult time O1 O2 O3 O4 O5 O6 O7 O8 O9 O10 I feel great						

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# A lot learnt in fifty years as an ostomate



His story: Terry Ryan has had a full and satisfying life as an ostomate.

#### by Terry Ryan

I started university in 1967 in the second year of the existence of Flinders University.

Early in the year, I began to experience stomach pains, sometimes causing me to rush out of lectures to go to the toilet.

This mainly occurred in the mornings, a couple of hours after I had eaten breakfast, which in those days was mainly cereal and toast.

Initially, the pains and the resultant toilet runs were sporadic but as

my university life went on, I began experiencing them more frequently, along with annoying discomfort of my anus.

One day, I noticed some blood on the toilet paper but I assumed it was from a possible haemorrhoid.

I cannot recall why I did not go to a doctor during this time.

I managed to complete my university degrees and began my teaching career.

I continued to suffer on and off, sometimes having to leave a game of baseball to go to the toilet.

As things got worse, I ended up

knowing where every public toilet was in Adelaide.

My social life as a young man in my twenties was severely curtailed, although I was an active sportsperson, playing top grade baseball and being a parachutist.

In the end I decided to admit myself as an outpatient at a hospital in Adelaide, where I was seen by a top gastroenterologist.

His answer was to subject me to the cruel practice of a non-flexible sigmoidoscope.

However, he did diagnose ulcerative

colitis and I started on a course of sulphur drugs.

There was no discernible improvement and I still experienced the bouts of pain and then a rush to the toilet.

There were a number of occasions where I lost control of my bowels while driving my car but luckily whenever this occurred, I was by myself.

There were always small amounts of blood accompanying the output but as I said before, I always assumed it was a haemorrhoid.

In 1974, a situation occurred that changed my life for the better.

I was attending a service club (Rotaract) dinner where the guest speaker was a very attractive young woman.

After the event I was chatting with her, and we were getting along famously, when all of a sudden, I had to excuse myself to find the toilet.

When I returned, she had left.

I went home and told my mother I was going to do something about this affliction, so the next day, I went to my GP and told him I wanted to see the top specialist in the city.

He managed to get me an appointment within a week and I had a two-hour consultation with him.

His take was that my disease was probably psychosomatic, which was a common thought at that time.

It is worth noting that I grew up as a kid in Woomera, not far from the atomic bomb test sites. There has been much discussion over the years as to the effect of the fall-out from the bombs causing a higher than normal amount of illness and still-births in Woomera.

Within four weeks, I'd had barium meal x-rays, had seen a surgeon and was admitted for surgery.

I had to wait a week in hospital to build up my strength and then the day of surgery arrived.

I was 25 years old.

I woke up with this giant post-op bag attached to my stomach, had my anus removed and a drain in there, and all my large bowel had been taken.

The surgeon told me that my colon was very close to rupturing and if it had and I was in the community, I would have lasted less than an hour unless I was taken to hospital.

I spent four weeks in hospital, which is a long time compared with how long people spend post-op now.

I was in a ward with five other men,

two of whom died while I was in there, and another who had his arm amputated, so it was a rather depressing room.

The stomal therapy nurse at the hospital was absolutely wonderful and was instrumental in starting the rest of my life with an extremely positive attitude and I can never thank her enough for this.

I had moved back to my parents' place a short time before my surgery, so spent about four weeks recuperating, walking, exercising, but unfortunately putting on weight.

The time came to resume my teaching career and on the first day back, my grade 8 students greeted me

with acclaim. After four months,

I returned to playing baseball, and life was on an upward trajectory.

I am sure recent ostomates would be intrigued to learn of the equipment I used back in those days.

The bags were a bit like the white freezer bags we use in the kitchen today.

They were attached to the hard plastic rings that were stuck on to a base plate.

I used to use two O-rings to attach the bag as they were prone to snapping.

Cleaning the stained plastic rings was a pain, using a solvent and then letting them dry in the sun.

The progress in the development of equipment has no doubt been driven by the increase in numbers of people requiring surgery.

For the past 20 or more years, I have used the same two-piece product and that seems to suit me.

I have tried a couple of other products but have always reverted to my tried and trusted two-piece.

Since my surgery in 1974, I have had relatively few mishaps with my equipment, with most of them occurring in bed as I probably rolled over.

I have had occasional bouts of very loose output, but find that a product like Imodium helps, as does eating a banana.

Just recently I have discovered that I possibly have an allergy to shellfish and even salmon, whereas previously I never had any problems.

Some of the food and drink items that don't like me include peanuts and coconut (tend to cause blockages) and apples, especially the skin.

Tomato juice goes straight through me, and fruit juice in the morning on an empty stomach has the same effect.

As I mentioned, I went back to playing baseball a few months post-surgery and played for many years in A-grade.

After I turned 40, I took up baseball umpiring, making my way through the ranks, to eventually become the director of baseball umpiring in Victoria.

I attended professional umpiring school in the US and back in Australia, I umpired at the highest level here, the ABL.

I also loved playing golf and was able to get my golf handicap down to five.

"I grew up in Woomera, not far from the atomic bomb test sites." However, I have not played golf for more than three years now as I have been afflicted with a condition called orthostatic tremor (you will need to Google it).

This condition has had a severe impact

on my life, restricting me severely from what I am able to do.

Sadly, not much is known about this condition and even the neurologists I have seen admit to having seen fewer than four or five patients with it.

I recently had a total reverse shoulder replacement, the fourth operation on that shoulder. The baseball and javelin throwing from my younger days caught up with me.

I have also had one hip replacement, again the result of wear and tear from sport.

I have been blessed to have two daughters who are now in their 40s.

The younger is a single mum with three young kids and works at a university.

The older one is a doctor who works as a surgical assistant with a number of orthopaedic surgeons.

I have a beautiful wife who I have been married to for almost 30 years.

My role is to do the cooking, washing and cleaning, while she goes off to work.

I feel I have lived a satisfying life, doing most of what I wanted to do with my life – I have had a variety of jobs including teacher, project officer, university lecturer, event manager, golf administrator and intelligence officer.

Obviously I am pleased that almost 50 years ago I went to my doctor asking for a referral to the gastroenterologist.

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**Measure twice:** Correct positioning of the stoma is important to ensure the patient's comfort and wellbeing.

# Mental health support vital for stoma patients

AUSTRALIAN research has highlighted the importance of mental health following stoma surgery.

The study, conducted by a team of medical professionals and health researchers, reviewed the presence of depressive symptoms shown by stoma patients after their surgery. It found some degree of depression occurred in almost half of the number of patients.

Six month after stoma surgery, the prevalence was 39 per cent, and after 12 months it was 42 per cent.

The researchers said patients with a stoma had higher rates and risk of

depressive symptoms compared to patients undergoing surgery without stoma formation.

Dr Joshua Kovoor, a researcher, medical intern and PhD candidate with the University of Adelaide, said a patient's depressive state after stoma surgery could be linked to a few key factors.

"After stoma surgery, many patients struggle physically and mentally postsurgery, especially with a loss of self, intimacy, and body image, in response to multiple psychological stressors," Dr Kovoor said.

"The research highlights how we can improve care to stoma patients before and after their surgery.

"Stoma patients at risk of developing depressive symptoms should be identified early, and have access to mental health services, including psychologists and psychiatrists to assist with their overall care."

Professor Peter Hewett, RACS Fellow and Senior Colorectal Surgeon at The Queen Elizabeth Hospital said when forming a stoma, the surgeon should take care to ensure it had a good position and proper shape.

"A pre-operative visit from a stomal therapist aids in both deciding the optimal position on the abdomen to place the stoma and gives reassurance that help will be available in the post-operative period to manage the stoma," Professor Hewett said.

The team's research was presented at the the Royal Australasian College of Surgeons Annual Scientific Congress in Brisbane.

### Another way of reusing plastic bags

#### by Bob Cooper

WHEN I saw my friend at the Wollongong Stoma Group meeting a couple of years ago, I asked him how his trip to Europe had gone.

He started to tell me a tale of woe. On the plane flight over he had experienced several leaks from his urostomy bag.

He had had difficulty getting his skin completely dry so had not been able to get a good seal. He also said that he had

underestimated just how many bags you finish up using when things go wrong, and to have to be making all of the necessary adjustments in the confines of an airline toilet.

He did sound quite exasperated for a normally cool, calm and collected character.

He said that next time he would have more clothes in his carry on bag as well.

And then just two weeks ago I asked my fellow urostomy mate at the meeting at Frenchs Forest how he had handled his trip to England and Spain.

"Ah," he said, "The plastic shopping bag". "What do you mean?" was my immediate question.

He said he connected his night bag to

his urostomy bag and concealed it in a large plastic shopping bag, down near his ankle.

He went to the toilet a couple of times carrying everything hidden in his bag.

He emptied out the night bag, and walked back to his seat with his plastic bag.

His wife said he had no dramas and everything went smoothly but he did get some funny looks when he took the plastic bag to the toilet.

So two different experiences on a long flight and I can assure you that if I am on a long flight I will be taking a plastic shopping bag to conceal my night drainage bag. INTRODUCING The NEW Omnigon Support Garment

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# Pastry a magical treat

#### by Brian Hunter

If you are true blue, chances are you've heard of the Magic Pudding.

It's a famous children's story – a fairytale.

But this is no fairytale: this is reality. This is a surprising discovery; I will call it the Magic Pastry.

I'm a Queensland colostomate of 84 years.

Twenty-four years ago I lost my sigmoid colon, rectum and anus: a shocking reversal with no warning.

Suddenly, I had no choice – I was an ostomate.

Within days I was forced to submit to the constant dictates of that chemical factory we all live with – a factory that never sleeps.

We all know the plumbing upstream of the cecum is there to extract nutrients to feed into the vascular system, and the downstream stuff (the colon) is a clever de-watering machine.

It's not my intention to preach on diet, except to say that an ideal ostomate seeks an ideal stool (yes, my language will remain refined) and this relies generally on a plain, simple diet with little or no alcohol.

Having said that, let's agree that a messy discharge will challenge flanges and a drier stool makes for better control.

In my youth, I spent some time in western Queensland and was always impressed by the clean discharge of sheep.

Yes, sheep produce small, clean packets of uniform shape and size, and with low moisture content.

For the opposite to these sheep pellets, we have only to look at the dairy cow.

If you have ever stepped in a cow pat you'll know that water content creates the mess factor.

The ideal discharge for an ostomate is therefore a small stool package, of regular size, with a smooth, lubricated surface; that is, it will not stick but it will readily slide.



When this ideal is reached, the stool package will discharge smoothly and will literally drop into the bag.

Furthermore, this discharge will leave no residue on flanges.

So, unless you are a sheep, is this even possible: or is this just pie in the sky?

I always thought so – that is, until recently.

Two years ago, I changed my address and found that I now lived close to a small Vietnamese bakery.

The baker is a remarkable pastry cook so it was inevitable I would try his many options.

Over time, I detected remarkable improvements in my bag performance and, after some experiments, I found the cause was just two products: two vegetarian pastries, one with feta and spinach filling, and the other with feta and broccoli.

Now, I have never been a vegetarian but this got my attention.

After further experiment, I found that a particular dinner at night produced amazing results.

The prime course was one of these pasties, and desert was a simple fruit salad and ice cream.

So what's going on?

Maybe a dietitian can explain. The fillings contain very little feta, so it seems the spinach or broccoli produce ideal colonic control.

Intake for the rest of the day is minimal (you might even call it frugal): breakfast cereal, a sandwich snack for lunch, with coffee breaks mid-morning and midafternoon.

Of course, if I am eating out or visiting, the food (and the results) will vary but the ideal menu, for ideal results, is as above.

And what are the results?

They are remarkable.

I become a sheep: my discharge comes in neat, separate stools that exit and drop into the bag with no fuss – they don't even stain the flange as they pass.

And when I remove the bag, the peristomal skin is clean.

What more can I say?

After 24 years, I have found Shangri-La, not in the Himalayas, but in a humble Vietnamese pastry shop.

Notwithstanding this revelation, I will concede that strict, repetitious diets are hard to endure, and when I am eating out I will always favour a lambs fry or a steak. In our ostomy world however, it seems

that vegetarian is good.

Furthermore, it seems that spinach and broccoli are good for the colon.

But above all, it seems that spinach and broccoli are good for the flange.

Or, maybe it's the feta?

Why? Feta comes from sheep.

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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: Floor 2, 1 Moore Street CANBERRA ACT 2600 Open: First and second week of each month on Monday, Tuesday, Wednesday 10am to 1pm

#### **NEW SOUTH WALES**

#### **NSW STOMA LIMITED**

W: nswstoma.org.au E: info@nswstoma.org.au T: 1300 Ostomy or (02) 9565 4317 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: Ground Floor, 20-22 Yalgar Road Kirrawee NSW 2232 Open: Monday to 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

(07) 5571 7481 F: A: 8 Dunkirk Close ARUNDEL QLD 4214 Open: Tuesday and Thursday 9am to 3pm

#### NORTH QUEENSLAND **OSTOMY ASSOCIATION**

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

#### QUEENSLAND **OSTOMY ASSOCIATION**

W: gldostomy.org.au admin@qldostomy.org.au E: (07) 3848 7178 T: F٠ (07) 3848 0561 22 Beaudesert Road A: MOOROOKA QLD 4105 Open: Mondays 9am to 2pm, Tuesdays and Thursdays 9am to 3pm.

#### **QUEENSLAND STOMA** ASSOCIATION

- W: gldstoma.asn.au admin@qldstoma.asn.au E: (07) 3359 7570 T: (07) 3350 1882 F:
- Unit 1, 10 Valente Close Δ٠ CHERMSIDE QLD 4032 Open: Monday to Thursday 8:30am to 2:30pm

#### **TOOWOOMBA & SOUTH WEST**

- **OSTOMY ASSOCIATION** E: admin@tswoa.asn.au
- Jason 0438 554 064 M:
- (07) 4636 9701 Τ·
- (07) 4636 9702 F:

Education Centre, Blue A: Care Garden Settlement, 256 Stenner Street TOOWOOMBA QLD 4350 Open: Tuesday 9am to 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 4670 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: colostomysa.org.au E: colosa@colostomysa.org.au (08) 8235 2727 T: (08) 8355 1073 F٠ 1 Keele Place KIDMAN A: PARK SA 5025 Open: Monday to Thursday 10:30am to 2:30pm

#### **TASMANIA**

#### **OSTOMY TASMANIA**

- W: ostomytas.com.au
- admin@ostomytas.com.au E:
- (03) 6228 0799 T:
- 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 to 1pm

#### **VICTORIA**

#### **BENDIGO AND DISTRICT OSTOMY ASSOCIATION**

W: bendigo-ostomy.org.au T· (03) 5441 7520 F٠ (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 full week of each month.

#### COLOSTOMY ASSOCIATION **OF VICTORIA**

- W: colovic.org.au
- E: info@colovic.org.au
- P: (03) 9650 1666
- F: (03) 9650 4123
- A: Suite 221 Level 2, Block

Arcade, 98 Elizabeth Street MELBOURNE VIC 3000 Open: Weekdays 9am to 2pm STN 10am to 2pm on Monday and Wednesday

#### **GEELONG OSTOMY**

W: geelongostomy.com.au E: goinc@geelongostomy. com.au

(03) 5201 0844 T: (03) 5201 0844 F: 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
- (03) 9888 8523 T: 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
- (03) 9345 5325 T:
- F٠ (03) 9345 9499

Equipment Distribution A: Centre, Royal Children's Hospital, Basement 2 (green lifts), 50 Flemington Road PARKVILLE VIC 3052

#### WARRNAMBOOL & DISTRICT OSTOMY ASSOCIATION

E: warrnamboolostomv@ swh.net.au

т· (03) 5563 1446

(03) 5563 4353 F:

A: 279 Koroit Street

WARRNAMBOOL VIC 3280 Open: Friday 12 noon to 4pm

#### WESTERN **AUSTRALIA**

#### WESTERN AUSTRALIAN **OSTOMY ASSOCIATION** W: waostomy.org.au

- E: info@waostomy.org.au
- (08) 9272 1833 T:
- F: (08) 9271 4605
- A: 15 Guildford Road MOUNT LAWLEY WA 6050 Open: Monday 9am to 5pm Tuesday 6:30am to 1pm Thursday 9am to 1pm Fourth Saturday of each month 9am to 1pm

# **National Directory** of Ostomy Support Groups

#### ACT

#### Canberra:

ACT Stoma Association. 10am to noon, second Tuesday of every month: April 11, May 9, June 13, July 11. 2nd Floor, City Health Building, 1 Moore St, (cnr Moore & Alinga ST), Canberra. Contact Geoff Rhodes (actual ostomate happy to chat with you) on 0416 206 871 or email grhodes@ homemail.com.au. Everyone welcome but must be double vaccinated to attend. RSVP for meetings is required by ACT Health so we can comply with COVID numbers and restrictions.

#### **NEW SOUTH WALES**

#### Albury/Wodonga:

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

#### **Bankstown:**

10am-noon on the first Wednesday every third month commencing February 8; then May 3, August 2 and November 1. Revesby Workers Club, 2B Brett St, Revesby (close to public transport and free parking) Everyone welcome but must be double vaccinated. 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.

#### **Beat Bladder Cancer:**

The national support group meets on the last Tuesday of every month, 7-8.30pm. Macquarie University Hospital, 3 Technology Place, Macquarie University. Contact: Adam Lynch, president BEAT Bladder Cancer 0421 626 016.

#### **Bowral:**

June 6, Sept 5, Nov 28. Due to current COVID restrictions only fully vaccinated people may attend. Proof will be required upon entry. 1-3pm. Bowral Bowling Club, 40 Shepherd St, Bowral. Contact: Lu Wang & Erin Wagner stomal therapists, Liverpool Hospital

(02) 87384308 or Mariam Elfoul on 0400 921 901, aumael@ coloplast.com. Please RSVP one week prior.

#### **Broken Hill:**

Every third month or as required. Broken Hill Hospital Conference Room. Contact Tarndra (08) 8080 1300.

#### **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, stoma therapy nurse, on (02) 6656 7804.

#### **Continent Urinary Diversion** Support Group:

Meet 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.** 

#### Dubbo:

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

#### **Eurobodalla Region:**

11am on first Sunday of February, April, June, August, October and 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 in February, May, August and November. Contact Gary Tobin 0400 675 277 or STN Jane Kulas 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. April 5, June 21, August 9, Oct 11 Dec 13. 10am-12pm. Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree. Contact: Helen Richards Wollongong Private Hospital 4286 1109 or richardsh@ramsay health.com. au; or Julia Kittscha 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:

10am-noon. First Wednesday in February, April, June, August, October and December. Skills for Life Building, 5-9 Elizabeth Ave. Taree (wheelchair accessible). Contact Karla MacTaggart on (02) 6592 9469.

#### Nepean:

The Nepean Education Stoma Support Group meets at 2-3.30pm on the last Friday every second month: April 28, June 30, August 25 and Oct 27. Medical School, outpatients department, 62 Derby Street, Kingswood 2747. The building is opposite Nepean Hospital's **Emergency Department. Contact** Naomi Houston on 4734 1245.

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:

Feb 22 Ulladulla Community Health Centre, March 29 Nowra Community Health Centre, June 28 Nowra Community Health Centre, August 30 Ulladulla Community Health Centre, November 29 Nowra Community Health Centre. Time: 2pm. Register with stoma therapy nurse Brenda Christiansen (02) 4424 6300 or brenda.christiansen @ health.nsw.gov.au

#### St George:

10am to noon, 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 – 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. Access: The building is opposite Nepean Hospital's Emergency Department. Enter via the side path to the outpatient waiting room. Please wait until 2pm when you will be directed to the meeting 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, April 20, June 15, Oct 19, Dec7. Campbelltown Catholic Club 20/22 Camden Rd, Campbelltown. 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**

#### **Queensland Emergency Ostomate Support Service:**

The service provides emergency non-clinical support to Queensland ostomates outside of their association's standard business hours. Phone 0432 522 311, 8am to 9pm.

Beenleigh: 9:30-10:30am, first Monday of February, April, June, August, October and December (Christmas Function) Logan Hospital, Room 1E. Cnr Loganlea and Armstrong Road, Meadowbrook. Contact Leeanne Johnson stoma therapy nurse (07) 3299 9107.

#### **Bowen:**

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

#### 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 second Monday of every month at Maroochy RSL Events Centre, Memorial Avenue (off First Avenue). Contact Laurie Grimwade (07) 5445 9008, email sid.and.laurie@gmail.com; Janelle Robinson 0409 762 457, email candjrobinson@bigpond. com or Kathy Himstedt (07) 5445 9270, email greg.kath1@ 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. Emergency contact: Jason Miller 0438 554 064.

#### Wide Bay:

Bundy Osto Mates. 10am-noon on the third Friday of each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West. Contact Wide Bay Ostomates (07) 4152 4715.

#### **SOUTH AUSTRALIA**

#### **Adelaide Hills:**

10am-12pm second Wednesday of January, March, May, July September and November. Nairne Soldiers Memorial Hall, Main Road, Nairne. Contact Maureen 0434 051 375.

#### **Barossa:**

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

#### Central:

2-4pm on the third Tuesday of January, March, May, July, September, and November. Hilton RSL, 147 Sir Donald Bradman Drive. Contact Paul 0403 812 469 or Jo 0408 223 352.

#### **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: 10am-noon on first Monday of March, June, September and December,

venue to be advised. Contact Lyn on 0421 000 960 or Susana 0422 571 737.

Northern: Elizabeth Playford Lions Club, Hilcott Street, Elizabeth North. Fourth Tuesday of the month 2-4pm. Febuary, April, June, August, October and December. Contact Jo-Ann 0421 118 962 or Melanie 0401 447 740.

#### Southern:

2pm on first Wednesday of February, April, June, August, October, and December at Elizabeth House, 112 Elizabeth Road, Christie Downs. Gold coin donation for premises appreciated. Contact Lyn 0421 000 960 or Sharmaine 0438 853 082.

#### **Port Augusta:**

Port Augusta RSL, 17 Fulham Road. Meetings 1-2.30pm on the fourth Tuesday of every month, exccept December. Contact Anne Wensley 0429 422 942 or 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 stoma therapy nurse on 08 8638 4536 or 0481 484 347.

South East: 10.30-12.30 Thursdays every six weeks. St Martin's Church, Edward St, Mt Gambier or Coonawarra Soldiers Hall 11 Memorial Drive. Please phone to check date and venue. Contact Barbara Wardley 0415 477 978 or Leeanne Paterson 0418 733 111.

#### York Peninsula:

2.30pm on third Wednesday of February, April, June, August and October, Joyce Olsen Room, Wontama Homes, East Terrace, Kadina. Contact Helen on 0419 839 869.

#### **TASMANIA**

#### Semi-Colons:

10am-noon, third Friday of each month. Southern Cancer Support Centre, 15 Princes Street, Sandy Bay. Contact Support Services 1300 656 585 or Cancer Council Helpline 13 11 20.

#### Tasmania Support Groups: Meet March, June and

September. Contact Adrian Kok 0498 196 059 for dates.

#### South:

Southern Cancer Support Centre 10am-12pm, 15 Princes St, Sandy Bay. North: (two meetings) Cancer Support Centre 12.30-2pm and 2.30-4pm, 69 Howick St, Launceston. North West: Senior Citizens' Club 10am-12pm, 16 King Edwards St, 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:

10-2.30pm on Saturday, August 20. Masonic Hall Appin Street,Wangaratta. Suppliers' Day: 2pm on Monday, October 17. Benalla Bowls Club, 24 Arundel St. 2pm Monday, December 12, Masonic Hall, Appin Street, Wangaratta. Call Graeme Pitts (03) 5762 1721 or 0407 240 943 or mgpwang@gmail.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, two or three days per week. Phone 9650 1666 or email info@colovic.org.au

#### Mildura:

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

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: 10.30am, second Friday February, April, June, August, October and December. Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool. Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093. Warrnambool Ostomy rooms (Fridays) (03) 5563 1446.

#### 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.

#### **Esperance:**

Contact Len (08) 9075 9099. Geraldton, 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).

#### 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 via 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.

# Did you enjoy this issue of the journal?

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

#### We want your stories

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

#### Send your stories to us

All stories, letters and articles are appreciated and valued. Please send them to the editor by email: **journal@australianstoma.com.au** 

#### A few guidelines when sending us your story or article When you send a contribution, we ask that you:

- Send your contribution in electronic form, attached to an email or as an email, where possible
- Provide your full name and contact details. We publish names whenever possible but not contact information
- Please don't identify anyone else in your story, medical professionals or other ostomates for

- example, unless they have agreed to their name being used
- Avoid identifying companies or products
- Pictures tell a thousand words. Please share pictures if you can. Photos should be JPGs and at least 1MB in size. If there are people in the picture, let us know that they agree to publication.

