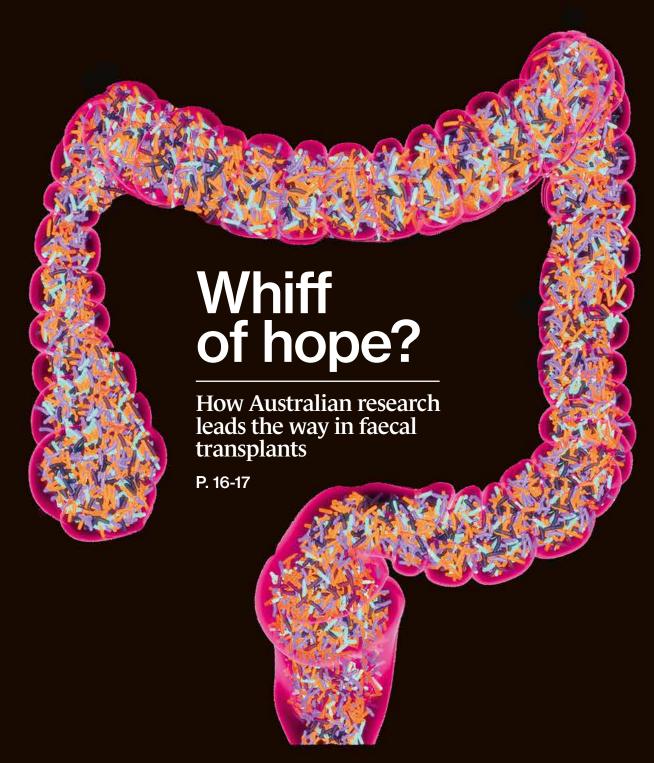
Australia OSTOMY Connecting the Ostomy Community

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Contents

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In this issue

Nutrition advice	5	President's column	13	News of the world	27
Letters	7	All about YOU	19	Associations	29
STNs there for you	11	Book review	23	Support Groups	30

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The ACSA Journal Ostomy Australia was established in 1992 through the inaugural sponsorship of ConvaTec Australia. The journal is published three times per year and is available free to every member of an Australian Ostomy Association.



Awareness helps to fly right

WITH more people travelling by air following the lifting of Covid restrictions, a group from the Western Australian Ostomy Association (WAOA) recently met with Perth airport security staff to raise awareness of the problems some ostomates may have when flying.

WAOA secretary Lorrie Gray said a previous visit to the airport by the association in 2019 had been instigated after hearing complaints about the difficulties faced.

"We hadn't had many negative reports after that, perhaps because less people were travelling, but recently our stomal therapy nurse has received a number of complaints, often just in passing," she said.

WAOA asked its members for feedback, which it then passed on to Perth airport.

"We had quite a number of responses, some good, some bad," Lorrie said.

"Some people had been asked to show their bag and they were uncomfortable doing that in a public place; some reported a negative, authoritarian attitude from security staff?"

She said representatives from the airport were helpful and interested to learn more about ostomates, and invited a group from WAOA to again meet with Perth Airport security screening manager Dayel Tovey and his colleagues.

At the domestic terminal, the group went through the screening processes and the procedures travellers must follow to comply with Federal regulations.

All passengers travelling in Australia must go through a metal detector and have a full-body scan. Objects on the body (such as wallets and keys, as well as stoma bags) appear on an avatar on a small screen watched by an airport screening staff member.

If anything abnormal is detected the passenger is read a statement asking their permission to be searched further, which may include touching sensitive areas.

Once the passenger agrees, they can ask to go to a private room or stay where they are as a handheld metal detector is waved over the area of concern outside the clothes.

The passenger is then asked to gently touch their clothing over the area with their hands which are then swabbed with a wand which goes into a machine to detect a variety of substances.

"It was made very clear to us that noone should ask to see your bag, ask you to empty it or even take it off," Lorrie said.

"If you are asked to do so, you need to ask to speak to the supervisor and if you still have concerns, ask to see the duty manager."

The WAOA group raised the issue of ostomates' hand luggage being emptied in view of other people and were told luggage could only be inspected in the screening area.

Daily tools for ostomates, items such as adhesive remover spray and scissors are of particular interest for security staff and always need to be checked.

"We were told the spray cans could

be pepper sprays and sharp implements such as scissors could be used as a weapon," Lorrie said.

"We were advised that our 50ml spray cans of remover or barrier spray are fine to take on both domestic and international flights but it is perhaps wise to have them easily available for inspection and perhaps your ostomy products themselves could be placed in a separate cloth bag inside the hand luggage."

An option for ostomates or any traveller with a condition which is not immediately obvious and which may affect their experience going through airport security is the Hidden Disabilities lanyard and wristband.

The green lanyards and bands feature bright yellow sunflowers and can be shown to all airport staff.

The Hidden Disabilities Sunflower program started at England's Gatwick Airport in 2016 when it was recognised that passengers with hidden disabilities might need extra support or assistance when travelling – but in a busy airport environment, it was difficult to identify who those customers were.

The team came up with the Sunflower lanyard as a way for those customers to subtly identify themselves to airport staff and since then it has become a global symbol which is recognised at airports throughout the world.

Australian airports which utilise the Sunflower lanyard include Adelaide, Brisbane, Melbourne, Perth and Sydney.

The website of each airport has details on where travellers can pick up a lanyard.

It is important to note that wearing the lanyard does not exempt a traveller from normal airport processes like security screening or passport control.

Perth Airport's website says its team has been trained to recognise the lanyard and how to best provide the assistance and support customers may need.

Share your experience

HOW has your travel experience been while flying and going through airports?

The Australian Council of Stoma Associations (ACSA) would like to hear from you.

Share your thoughts, whether the experience was positive or negative, by email to info@waostomy.org.au

The stories gathered will help us to plan and implement any measures which may help ostomates in the future.



Lactose intolerance a dairy dilemma

by Teresa Mitchell-Paterson

THIS article addresses the apparent mystery of your post-surgical intolerance to lactose – you may have noticed or be wondering why you have developed a milk intolerance after stoma surgery.

This is quite a common occurrence after most gastric surgeries and has been reported in scientific journals as early as 1969.

The severity of symptoms can vary in individuals; some people may experience mild symptoms and others have a rapid and sometimes debilitating response.

Not everyone develops the condition because it is dependent on the type of surgery; the extent of intestinal involvement; and the amount of pre-existing lactase, the enzyme that breaks down the production of lactose.

What is it?

Lactose is the sugar component that naturally occurs in milk and dairy products.

Lactose intolerance is a condition where the gastrointestinal tract is unable to completely digest lactose.

Symptoms usually occur within a few hours after consuming milk or dairy products in food and drinks.

Symptoms typically include bloating, cramps and abdominal pain; feelings of nausea or possible vomiting after lactose/dairy; excessive gas, frequent passing of gas (a very common symptom); rumbling

stomach – undigested lactose can lead to grumbling or a gurgling sound from the abdomen; diarrhoea, loose watery stools due to inability of the digestive system to break down lactose; and discomfort, tightness or a heavy sensation in the abdomen after consuming lactose/dairy.

If you suffer any of the above symptoms it is advisable to discuss them with your healthcare professional who will probably administer a simple test to confirm lactose intolerance.

Why does it happen?

Bowel and stoma surgery involves the alteration or removal of parts of the intestine and this can interrupt the normal process of food flow through the digestive system.

This may affect the time available for lactose to be digested and absorbed.

The condition can be a temporary or permanent occurrence.

People who had surgery due to treating underlying conditions such as ulcerative colitis or Crohn's disease already have an inflammation in the intestinal lining which may affect lactase production and it is possible that this may develop into lactose intolerance.

Lactase, naturally produced in the intestine, is responsible for the break down of lactose into smaller components for absorption into the blood stream.

If lactase production is low, the larger components do not breakdown sufficiently and a fermentation process occurs in the bowel.

This is the major cause of the discomfort resulting from lactose intolerance.

Is it an allergy?

No, lactose intolerance is caused by a lack of an enzyme and not the response of the immune system.

What about calcium from dairy?

Milk and dairy are high in calcium, and there are concerns that you may not be receiving enough calcium if milk is not part of your diet.

Usually lactose intolerance gradually subsides, however, some people continue to have symptoms.

Some people may experience a gradual increase in lactase production over time, allowing them to tolerate small amounts of lactose without experiencing symptoms.

This can occur naturally as the body adjusts post-surgery.

Full tolerance may or may not be achieved, but you may reach a 'tolerance level'.

This is when you can trial your ability to tolerate small amounts of dairy and monitor how much you can have without incurring symptoms.

This varies from person to person – it may be that you tolerate a dash of milk in tea or coffee but react to a milkshake or smoothie.

Certain illnesses or conditions, such as gastrointestinal surgery, gastrointestinal infections, or wheat allergy in celiac disease, may lead to temporary lactose intolerance.

Once the underlying cause is addressed and the body recovers, lactose tolerance may improve.

The bacteria in the gut play a role in lactose digestion; in some cases changes in the gut microbiota can occur, leading to an improvement in lactose tolerance.

If you suspect you have a lactose intolerance after bowel stoma surgery, take steps to discuss this with a healthcare professional.

They can evaluate your symptoms, complete diagnostic tests if necessary, and provide guidance on managing lactose intolerance, which may involve dietary modifications or lactase supplements.

Foods rich in calcium

Tofu made with calcium sulfate is a good plant-based source of calcium. The calcium content may vary depending on the brand and firmness. Check the nutrition label. One hundred grams of tofu can provide about 350 mg of calcium.

Non-dairy milk alternatives such as rice milk, almond milk and oat milk, are often fortified with calcium. Read the label to see which brands are enriched with calcium to ensure an adequate intake. Typically, one cup (240ml) of fortified soy milk contains approximately 300mg of calcium.

Sesame seeds: two tablespoons contain roughly 280 mg of calcium. Try the hulled (skin removed) tahini to avoid problematic interactions with the stoma.

Almonds are not only a healthy snack but also provide approximately 95mg of calcium in 100 grams. About two tablespoons of almond butter will achieve about 35 grams of calcium.

Fortified breakfast cereals: Some breakfast cereals are fortified with calcium. Check the nutrition labels to find options that contain added calcium.

Canned fish with bones like salmon and sardines are not only rich in omega-3 fatty acids but also contain calcium because of the edible bones. For example, 100 grams of

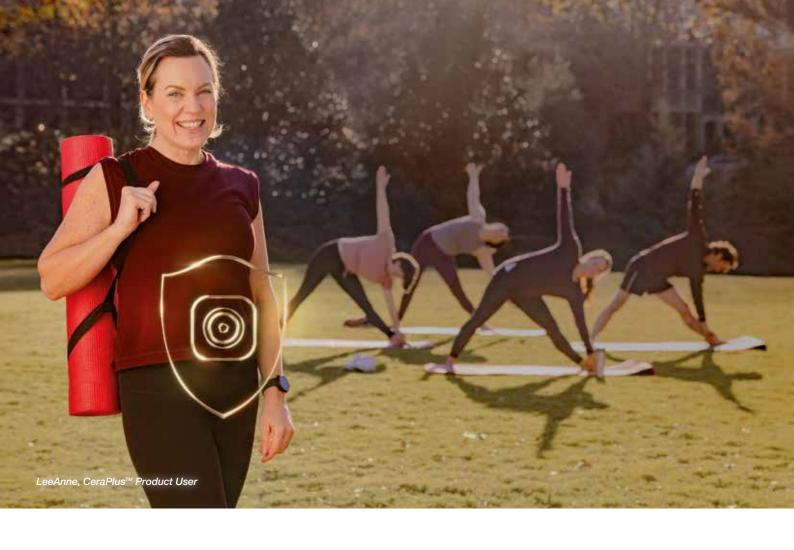
canned salmon with bones can offer about 240mg of calcium.

Lactose-free milk, yoghurt and cheese are widely available in supermarkets. Check the nutrition label for calcium levels.

Lactase tablets can be taken with dairy foods to reduce lactose intolerance symptoms. Speak with a healthcare professional about this approach.

Leafy greens also contain calcium but may not suit a stoma diet.

It's important to note that while these foods are high in calcium, the bioavailability of calcium can vary. Consuming a variety of calcium-rich foods alongside a well-balanced diet will help ensure you meet your calcium needs.



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-LeeAnne^

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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

Handy for travel

I was impressed by the innovative method of reusing plastic bags described by Bob Cooper in the April edition.

.....

Apparently his mate, on a long overseas flight, connected his urostomy bag to a night bag which he in turn covered with an old plastic bag when he went to the toilet. But there is a much simpler and better way of dealing with long flights, car trips or indeed any situation where access to a toilet or convenient tree is difficult. Several stoma appliance manufacturers have available leg bags of varying capacities (probably 500ml is the most practical) and tube lengths. These bags serve as an extension to your urostomy bag and can more than double its holding capacity.

The leg bag is attached to the upper or lower leg by straps with a tube connecting to the urostomy bag outlet. All this apparatus can easily be concealed inside a trouser leg so a trip down the aisle should occasion no curious glances.

An additional, and very real, benefit is that a leg bag's use takes the pressure off the urostomy bag's seal, thus helping to prevent its lifting.

Unfortunately these bags are not supplied under the Medicare arrangement but they are not expensive (between about \$8 to \$13 each) when their benefits are considered and especially if only used occasionally. They are available from several local medical appliance companies and no doubt stoma nurses would also have details about their supply and use.



I just heard the guy gagging as the fellow traveller left with a wink in his eye.
I bet next time he wasn't so demanding



Having lived with a urostomy for 18 years, I can attest to how much easier travel becomes by using these very useful appliances.

.....

David Connah, email

Sunflower travel

THANK you so much for your excellent magazine, I really appreciate the changes you have made to the content. The travel article was really helpful but an experience last October at Melbourne airport left me shaken and upset at the way I was treated because of my stoma – I was asked to lift my top in public to expose the pouch at the screening area. I made an official complaint to the airport security team and the result was less than satisfactory and inconclusive

about the process; the security officer was reported and counselled. Not content to remain fearful about going through airport security screening, I continued my research and this led me to discover the Hidden Accessibility program at Melbourne Airport.

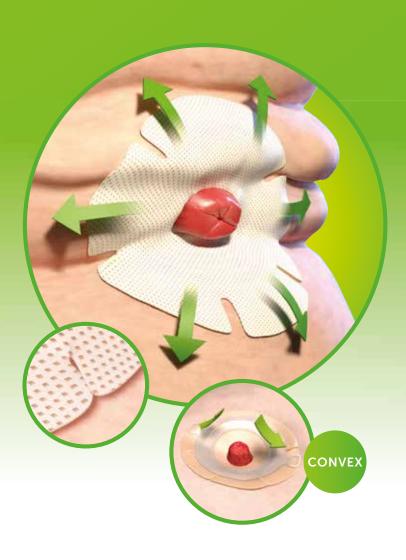
With great trepidation I approached my next flight in April with the Sunflower lanyard I obtained from the airport and wore, and this solved all my screening point concerns. I am hopeful you will consider sharing this advice with ostomates who like me just want to be treated with respect.

Viv Parry, VIC.

Editor's note: See page 3 for story

Continued page 9

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Continued from page 7

What a waste

DO you think that the manufacturers of our ostomy bags would consider optional 'no frills' packaging? I have used products from all of the current suppliers over the past 11 years. Each is somewhat different in their approach to packaging but the one common factor is that I now discard everything but the ostomy bags. I throw away the instructions (not required after 11 years). I throw away the filter stickers (do we really need 15 stickers per box of 10 bags?). I throw away the stoma guide.

I throw away the box that they all come in. All of this waste ends up in the recycling bin but if I had the option of ordering just the bags then waste would be minimal. Maybe just the bags in a clear recyclable plastic bag or cardboard box. How much cheaper would it be to supply? There must be thousands of long-term users

I throw away the disposable plastic

waste bags (as I have accumulated a

that dispose of the unwanted items as I do. If at any time we need any of the items that we currently discard, then we can order the current product.

••••••

I AM always reading about how positive

people are with their stomas, well I am going to be different and tell you like it is.

Greg Vawdrey, VIC.

lifetime supply).

The other side

I have had both hips replaced, a pacemaker installed after two heart attacks and a peristomal hernia which is getting bigger. I have emphysema and struggle every day. I was diagnosed with bladder and prostate cancer which ultimately resulted in the stoma. I have since been told that I have now lung cancer and lymphoma in the tongue. I have just finished the radiation course so hopefully it has been contained. The worst by far is living with a stoma, being woken at all hours of the night in a urine laden bed as the bag has twisted. I change every two days but still get leakage at the side at the oddest of times. I try and play golf but what do I wear? My biggest problem is the stoma is right

where my belt used to go, so I wear braces with shorts. I wear a bag over the plastic catcher and the golf shirt over the top; this means I have access to the catcher without having to disrobe. My entire wardrobe is now obsolete as I need casual shirts to fit over my stoma. So let me tell you life with any stoma is bloody hard! But then I am still on the right side of the ground so that's something, and my hardworking wife still loves me after 55 years married. Anyone who can go on holidays with a stoma is very brave as just living every day is a tough enough schedule.

Trevor Brimelow, QLD.

Anyone else?

I WANT to thank you so much for your journal, I really appreciate your stories. I am a mum to a 25-year-old daughter who was born with multiple congenital abnormalities which included an imperforate anus.

Initially she was given a loop colostomy and at about 10 months old she was given a Malone and a Mitrofanoff stoma.

I would really appreciate if you have any stories or advice for people in my daughter's situation, especially diet advice.

My daughter has a really active life and is very busy with work but she is extremely underweight.

As she has a Malone stoma her bowel is

flushed out daily and due to her anatomy she cannot eat foods that are too oily or rich (for example salmon and avocado) as these cause extreme diarrhoea. I am hoping that you have any advice for people in this situation. I would also love to hear from anyone with both a Malone and a Mitrofanoff who has had a pregnancy. My daughter is not ready yet but one day she hopes to be a mum and we would love to hear other women's stories.

.....

Jo, VIC.

All clear now

I AM celebrating 52 years with my ileostomy after having back in 1971 a rather large operation when my bowel was closing and about to haemorrhage due to ulcerative colitis. It is my best friend and even though I have had some times where I have had to have parastomal hernias repaired, a strangulated bowel and a few stoma resitings, my life has been excellent. I am a proud mum of two wonderful boys and had a great marriage of almost 50 years before my husband lost his battle with the big C. A few months ago I changed my bag to a clearer one; because I have high output, one time I noticed a whole tablet in my bag. I hadn't realised that slow release tablets weren't in my system long enough to even begin to dissolve. For how long and how often this was happening I don't know but once I began to crush this tablet and putting it on my toast the problem was solved (but remember not all tablets can be crushed and must be taken whole so this is something that each person needs to discuss with their doctor).

Pam Gamble, email.

Continued page 10



Continued from page 9

Nutrition for ostomates

THE article on nutrition needs (April OA) by Teresa Mitchell-Paterson was excellent.

It raises a question about who is responsible for monitoring patients' nutritional needs.

You would think it would be covered from the outset but it rarely rates a mention post op, even by the dietitian.

The GP is in an ideal position to assess the situation, as they are aware of all our other health issues and how they might impact on absorption of nutrients. But my GP is dismissive of my pleas for blood tests and insists she needs clear instructions from my surgeon's 'nutritional team' to do this.

He does not have such a team, as confirmed by his surgical resident.
As a result, post-ileostomy operation, I went through most of last year with a very low iron level, a situation only picked up by my gastroenterologist and my cardiac specialist.

The gastroenterologist ordered an urgent iron infusion, which finally got me off the hook.

My stoma nurse is aware of nutrition needs but is already flat out doing the practical chores she is required to do to take up the cudgel. As a result I just take vitamin supplements without consulting the GP. It is a conundrum I am sure ostomates and others with inflammatory bowel issues who are vulnerable to deficiencies may suffer and I just don't know what the answer is.

Could there not be a standard instruction to alert GPs for possible nutrition issues from an umbrella organisation, such as *Ostomy Australia*?

Angela Hardcastle, VIC.

Novel metho(d)

I am 92 and have a stoma resulting from bowel cancer 40 years ago.

•••••

My stoma nurse advised me on all the recommendations to cover skin problems – from leaks, falling off, itches, skin loss.

However, being a farmer and isolated from those medically advantaged, this could prove a problem.

I can tell you what was done when an emergency arrived – methylated spirits. I do not advise or recommend in any way, but for me it worked.

On one occasion my stoma nurse asked about skin itch problems and was horrified when I told her that I used metho.

She asked: "How do you use that?" and was told "I open the bathroom window." She then asked "Why do you do that?"

My reply was: "When you put the metho on, you go through it!"

Ken Spinks, NSW

(Editor's note: Do not try this at home. It is definitely not recommended).

Name of the rose

I CALL it Miranda after her bald head and enormous eyes at birth, It made her look like an alien which is what my stoma looked like at first sight and not the pretty rose depicted in illustrations.

Miranda calls it 'Angel' as it keeps her Nagyi* alive.

But my stoma has decided on its own label, 'Little Squirt'

Appropriate after a shower when it definitely gets active.

This escapist 'wee' is still a novelty coming circuitously from my abdomen not my bladder.

Its colour a reflection of fluids enjoyed from water to juice, to coffee to red wine. A conscience to keep me on track to care for my kidneys.

So regardless of names and tubes, once again I am grateful for this new world granted me via Miranda, Angel and Little Squirt. (*Nagyi is the affectionate Hungarian term for grandmother)

Vali Adoberg, QLD





Hit the spot: Finding the right site for a new stoma is just the start of how an STN helps ostomates.

Nurses have more than a gut feeling

WHEN was the last time you saw a stomal therapy nurse (STN)?

New ostomates are familiar with the reassurance that comes from a healthcare professional providing advice – they encounter stoma nurses regularly before and after their operation as hospitals now recognise the importance of specialist care for those with a new stoma.

Providing guidance, support and education, STNs play a vital role in helping ostomates adapt to their new life.

As time goes on and people gain more confidence, their need for help and advice with their ostomies may diminish.

Unless there is a specific and urgent problem, for long-term ostomates many years can pass between visits to their local STN.

This shift can be attributed to the independence and self-sufficiency that STNs help you to achieve and which comes with experience, but it is worth remembering that the supportive presence of a stoma nurse remains invaluable – and you never know what new tricks they may have learned that

they can pass on to you.

This was highlighted during National Stoma Therapy Week in June with the Australian Association of Stoma Therapy Nurses (AASTN) raising awareness of the important work of stoma nurses and "celebrating the possibilities of ostomates and those that support them."

Nurses were encouraged to publicise and celebrate the national week with a variety of activities to promote healthier living for people with stomas and raise awareness of the role stoma nurses play in this, by providing guidance, education and emotional support.

Deal with new challenges

IF you haven't seen an STN in quite a while, you may be surprised at what they can help with.

STNs are highly qualified registered nurses who continue with additional post-graduate study.

The role of a stoma nurse varies

according to the support required by an ostomate and can include advice on what pouching system would suit you – bearing in mind stomas change over time and new challenges can present to even those who have had no problems in decades – to new ways of thinking about diet and exercise.

Stoma management is, of course, the main concern of the STN and they are trained to spot issues when even the ostomate may not be aware of a problem brewing or actually present.

STNs are trained in recognising abnormalities such as dusky or pale stomas, inflamed or broken skin, swelling and excessive bleeding.

They are also specialists in managing wounds, fistulae and gastrostomies, as well as continence advice.

Other services provided include pre-operative counselling for those considering the surgery, post-operative care and support for patients with a stoma and ongoing long-term education and review.

It is recommended ostomates have a review by a stoma nurse every one or two years, just to check on the state of your overall health relating to your ostomy.

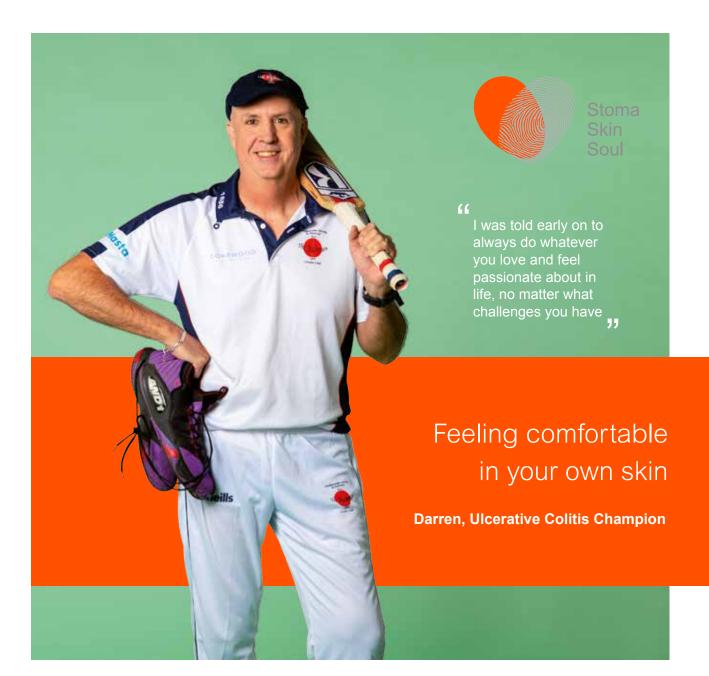
It's best to nurse a stoma

WITH about 50,000 ostomates in Australia and more than 3800 new stomas created each year, demand for STNs is increasing.

Ostomates both new and old may have problems with the skin around their stoma, pouches not staying on or leaking, the stoma changing size or shape, significant weight change, a bulge around the stoma, or a number of other challenges including sexual issues.

Finding a stoma nurse to help is simple – just contact your local ostomy association (the Australian Council of Stoma Associations has details of all societies at www.australianstoma.com. au) or find details on pages 29-31 of this issue of *Ostomy Australia*.

The AASTN website has a very handy tool which shows you where your nearest STN can be found – go to www. stomaltherapy.au. The website also has many helpful patient information pamphlets to download (some of the information in this article was sourced from the AASTN website).



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CE



FROM THE ACSA EXECUTIVE COMMITTEE

A little help for your friend

by Ian Samuel OAM

WITH winter nearly finished and most of us gearing up for warmer weather, now is the time (if you don't do it already) to have an annual check-up with your stomal therapy nurse who is there to ensure that all is well with your friend, your stoma. A healthy stoma helps make a healthy body.

The portal awaits

YOUR Australian Council of Stoma Associations (ACSA) executive has been busy supervising the roll out of the SAMS Portal.

SAMS is the national computing system used by most associations to process orders for members and the portal, once a member is registered, will allow for an easier online method of ordering supplies.

It will also make it easier for your association to process the order.

At present, it has been implemented at the Queensland Stoma Association, the Ostomy Association of Melbourne, Ostomy NSW, and NSW Stoma.

For this I want to thank our administrator, Hermione Agee, and Kevin Barry who we have contracted to implement our IT plans.

Kevin and his assistant Bryan are doing for us what would take 30 people to achieve a smaller result.

We are indeed fortunate to have them and their dedication to our cause.

When your association is ready for the portal, you will receive step-by-step instructions.

Hermione and I are in regular conversation with the Department of Health and Aged Care, under whose umbrella the free Stoma Appliance Scheme sits, as well as Services Australia which processes the claims in a manner similar to the way our pharmacy prescriptions are dealt with.

Save our journal

NOW for the not so good news.

Unfortunately, the very existence of this our journal, *Ostomy Australia*, is under threat.

Surveys indicate that you overwhelmingly want and need OA and we at ACSA think it is the best way of communicating to you, the members.

Until now we have relied on advertising from the suppliers but in recent times that has fallen off.

We need either more advertising or donations from you our members to keep it afloat.

If you want to speak to me about any of this, please contact me either by email at acsapres@australianstoma.com. au or by phone on 0416 044 881.

All hands on deck

I want to once again thank our hardworking and wise ACSA executive.

Lorrie Gray is our vice-president and is also the manager of the Western Australian Ostomy Association.

David Swift is our honorary secretary and is also president of the Ileostomy Association of South Australia.

Adam Keam is our honorary treasurer; he has a full-time position as the chief operating officer of an international bank and yes, there is more – Adam is on the board of Ostomy NSW Limited.

Our administrator is Hermione Agee, who has a sideline of being the manager of the Ostomy Association of Melbourne.

I, as president, don't have any other current ostomy involvement, having retired as president of OAM.

However, my love and dedication is for our unique Stoma Appliance Scheme.

Under the scheme, the only payment required is an annual membership fee along with postage charges.

Everything else is paid for by the Commonwealth which pays to the associations 2.75 per cent on the amount dispensed to the members.

I would be happy to hear from you on any of the matters raised or indeed on any other issues.

SOCIETY NEWS

Round up the troops

A DISAPPOINTING turnout at meetings has prompted the Benalla-Wangaratta ostomate support group to encourage members to spread the word to local GPs.

As only five people attended the meeting in April, the support group suggested members speak to their doctors to express the importance of informing new ostomates about the group meetings.

Meet for support

THERE has been no such problem with the Queensland Ostomy Association reporting "overwhelming attendance" at support groups this year.

The group meetings have a company representative and the association's stomal therapy nurse in attendance to provide information on products and stoma care.

The association said feedback from the members had been very rewarding.

The support groups are held on the first Thursday every two months from 1-2.30 pm, with next meeting on August 3.

Afternoon tea is supplied and all ostomates are welcome.

For more information on support meetings across Australia, see pages 30 and 31 of this issue of *Ostomy Australia*.

Under new management

THE office manager of the ACT & Districts Stoma Association, Mel Mason, is currently on maternity leave, with Vicki Kilby stepping in until March next year.

Support Group meetings in the ACT have changed to Thursdays to allow for STN Olivia Dyriw to attend; the next meetings are September 14 and November 16.

Be empowered

IN partnership with the Colostomy Association of Victoria (CAV), an inspirational and educational event will be held in October in Melbourne.

Hosted by Coloplast, the event is for all ostomates to enjoy morning breakfast, mingle with other ostomates, and listen to inspirational guest speakers.

Topics covered will include tips and hints when caring for your stoma, how to accept the unaccepted, and what foods to eat and what to avoid.

To register your interest in attending or to find out more, go to coloplast.to/ostomyevent or contact CAV.

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44920	Midi Clear 25mm	30m	10	615ml				
44922	Midi Clear 30mm	30m	10	615ml				
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UROSTOMY								
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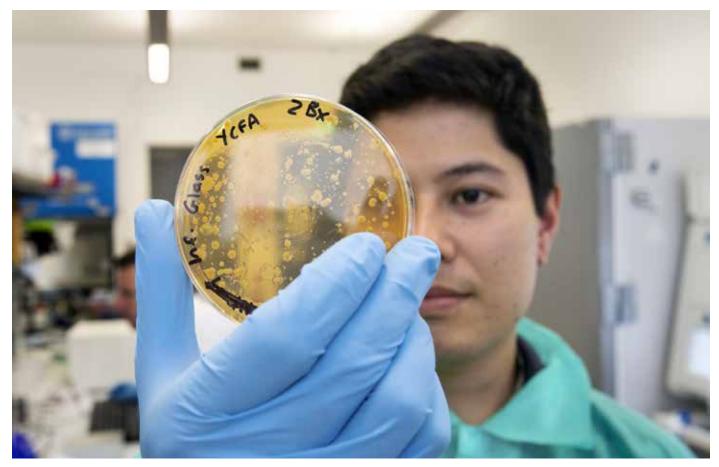
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What a dish: Adelaide's BiomeBank was the first company in the world to gain approval for cultured microbiome-based therapies (Photo: BiomeBank).

Research harnesses the power of poo in faecal transplants

IT may be an improbable source, but human faeces could hold the key to an effective remedy for a wide range of diseases and ailments.

A faecal microbiota transplant (FMT) introduces faeces from a healthy donor into the colon of a recipient.

FMT products are manufactured from fresh or frozen stool, and are introduced to the bowel for therapeutic use by a range of methods including rectal enema, sigmoidoscopy, colonoscopy, and nasogastric or nasoduodenal tube.

The stool contains beneficial intestinal bacteria and yeasts, with research

suggesting mixing more diverse healthy microbiota with a recipient's current gut microbes gives them a new microbiome constitution which could better cope with bowel diseases.

The human body is inhabited by trillions of microscopic organisms; too small to see with the naked eye, microbes inhabit almost every part of the human body and are collectively called the microbiome.

The majority of the microbes live in the gastrointestinal tract, especially the large intestine.

The use of FMT to treat medical

conditions has been studied in medical literature since the 1950s but it is only in recent times, following extensive clinical trials, that it has been approved for use.

The procedure has been tested on people with conditions ranging from Crohn's disease, irritable bowel syndrome (IBS), ulcerative colitis, and chronic diarrhoea and constipation, with promising results.

Its use as a treatment for neurological conditions such as multiple sclerosis and Parkinson's disease continues to be studied but has yet to be found conclusively effective.

Australian research is at the forefront of the FMT field, with \$2.5 million in state government funding announced in May for a WA facility, one of the nation's first manufacturers of FMT licensed by the Therapeutic Goods Administration.

The funding will significantly increase production at Australia Red Cross Lifeblood's Perth microbiome facility.

The facility collects samples from eligible donors and processes the microbiota for use in approved clinical trials and for transplant into patients suffering recurrent gut bacterial infections of Clostridioides difficile (C. diff).

An infection of C. diff can produce toxins which cause vital organs to shut down and is particularly dangerous following bowel surgery.

WA health minister Amber-Jade Sanderson said the ground-breaking health initiative was "a gamechanger for many people suffering with a recurrent, debilitating condition that, for some, can be fatal."

Research at Perth's Fiona Stanley Hospital has shown FMT is a safe and effective treatment with a 70 to 90 per cent cure rate for recurrent C. diff infections, which affect more than 6000 Australians every year.

The next step in Lifeblood's clinical trials is to develop a tablet containing faecal microbiota, which will then be used to support research into clinical uses for conditions such as ulcerative colitis and Crohn's disease, depression, and cancer.

To do this, the facility has called for more Perth residents to "make a life-changing donation with a difference"—instead of giving blood, to make a poo donation.

Lifeblood microbiome manager Elizabeth Connolly said although it might seem like an unusual request, people already rely on FMT to improve their dayto-day lives.

"Recurrent C. diff is a terrible, debilitating condition," Mrs Connolly said.

"Where traditional treatments like antibiotics haven't helped, FMT effectively treats this infection for more than 90 percent of patients.

"Often all it takes is one treatment – for those people, FMT can transform and in some cases even save lives."

Mrs Connolly said people were needed to sign-up as microbiota donors to help patients in need.

"Saving lives takes guts, and while we already have some wonderful donors, we

are looking for more donors to join us so that we can supply FMT to more patients in need," she said.

"We know there are people out there who have the power to change someone's life, but at the moment all that potential is being flushed away.

"If you're aged over 18 and under 50,

feel healthy and live in Perth you may be eligible to donate."

Chief executive officer of Lifeblood Perth, adjunct professor Stephen Cornelissen, said the facility now offered FMTs Australia-wide to hospitals.

"Witnessing the positive impact for patients has been an absolute privilege and

we are excited for the opportunities this will enable us to pursue," he said.

Once a stool donation is collected at Lifeblood, it is tested and processed, then frozen below -70C.

Most of the FMT products are then sent to hospitals across the nation.

In Queensland, the product is being trialled at the Royal Brisbane and Women's Hospital for severely ill blood cancer patients who have developed reactions following bone marrow transplants.

Bone marrow transplantation specialist Dr Andrea Henden said graft reactions were particularly hard to treat in the gut, with patients often hospitalised for long periods of time where they were dependent on hospital care and intensive immune suppressing medications.

Conventional immune-suppressing steroid medication failed to work in half of all patients with graft reactions.

"FMT is a really exciting new approach that could save lives," Dr Henden said.

If we can restore a healthy gut microbiome in these patients we can

"We know there

are people out

there who have the

power to change

someone's life,

but at the moment

all that potential

is being flushed

awav."

potentially influence immune function in the gut and treat the reaction in a safer way that preserves the patient's immunity."

In South Australia, biotech firm
BiomeBank became the first company in the world to gain regulatory approval for donor-derived microbiome therapy when the TGA

approved its use in November of FMT products for the treatment of C. diff.

Managing director Sam Costello said the approval was a an important advance for microbiome therapeutics globally.

"We are excited to progress the development of our cultured microbiomebased therapies with the aim of alleviating microbiome mediated disease on a much larger scale," Dr Costello said.

The microbiome-based product will first be launched as a frozen syringe formulation for colonic and enema delivery with oral delivery capsules for improved patient access to be made available in the future.

As research projects continue across the country, it seems the power of poo is only just beginning to be realised.



Surprise pill: FMT introduces faeces from a healthy donor into the colon of a recipient (Photo: Samelog).





A day of education calms the mind

By Bonnie Crowe

ON March 4, Young Ostomates United (YOU) hosted another education day at the Nurses Memorial Centre in Melbourne.

This time, it was a mix of mindfulness and education on childhood bowel issues.

Rita Doherty started the morning by taking attendees through the principles of mindfulness and meditation, followed by a guided mindfulness session.

As many of us know, emotional health is very strongly linked to gut health, and things like stress can cause a flare up or other problems with our bodies.

My personal take away from the session was that you can be anywhere to practice mindfulness and we have the ability to calm ourselves quickly and quietly – no one would even know you are meditating.

Next we had another fantastic session, this time led by Judy Wells, who is a stomal therapy nurse and continence specialist at the Royal Children's Hospital in Melbourne.

Many of the members of YOU are carers for young people with chronic bowel issues, and it was very interesting to hear the kind of issues that are seen in children and how they can be treated. Both sessions were recorded and can be accessed on the be accessed on the YOU Facebook page for members.

Judy's PowerPoint presentation is also available by contacting YOU.

The primary way YOU reaches the ostomate community is through our Facebook Community Group.

The group currently has 624 members, who are a mix of ostomates, carers, and support people.

It is a closed group, as the privacy of our members is very important. It is a place to share stories, ask questions, and have a community of people who may have experienced the same situations as each other.

YOU also uses the platform as outreach, donating cute stoma bears to young ostomates and touching base with members and sometimes sending flowers or something else to brighten the days of people going through a hard time.

The group advocates for ostomates to hospitals through stomal therapy nurses, and wants to help educate ostomates on how they can live their best lives with their stomas.

Recently, YOU sent another box of stoma supplies to Uganda, something the group does periodically to support ostomates in Uganda, where appliances are not readily available.

Upcoming events include a casual lunch/get together on October 7 (venue to be decided) and a Christmas lunch/get together on December 2 at Blackburn Lake, in Blackburn.

For more information about YOU or to be involved in upcoming events or the committee get in touch through the website or join the closed Facebook group Young Ostomates United Inc.

You can also get in touch with the secretary of the group, Helen, at helshae@hotmail.com.

Focus on calm

by Lilian Leonard

THE workshop, Mind and Body Focus using Meditation, by Rita Doherty was a great introduction to YOU's education day.

Sitting in a circle after brief introductions, Rita emphasised how important mindfulness is, recognising how important the mind is in coping with life and everyday challenges.

By learning to relax our mind it helps to reduce stresses, relieving anxiety and can assist pain control.

Rita demonstrated the benefits of 'belly breathing' which will help to relax our body and mind and is helpful to do at least five times a day.

This can be done anytime and anywhere: holding your belly breathe in slowly, if possible close your eyes, hold that breath, then exhale slowly, repeat.

Now relaxed, Rita helped us to mediate: eyes closed and sitting in a quiet atmosphere, focus on something restful in your mind, exclude other issues from your mind and concentrate mentally on something positive, breathing slowly and deeply

Rita quietly moved around the room using the restful tones of crystal sound bowls. Following mediation it is important to slowly get back to reality. Thank you Rita for educating us in relaxation techniques and the importance of mindfulness when coping with life's challenges.

Childhood issues

YOU Inc. is always grateful to our friend, stoma therapy nurse Judy Wells, who over so many years continues to shared her stomal knowledge with us.

After working in the field of continence the past few years, Judy has recently moved to stomal therapy, although the stoma departments have now been divided the other members of the team have shared their knowledge for Judy's presentation.

Ninety-seven per cent of paediatric stomas are performed on children under two years of age and are temporary.

The reasons for paediatric stomas are varied and include necrotizing enterocolitis (inadequate blood supply to the gut, more common in premature infants); Hirshsprung's disease (scant or absent nerves in a section of the bowel); meconium ileus (sticky meconium or first poo causes a blockage in the bowel); imperforate anus (where the anal opening is not formed); and inflammatory bowel disease (although this is not common in children).

Congenital birth defects include narrowed sections of the bowel, gastroschisis (a hole on the abdominal wall with protruding bowel), slow transit constipation/chronic constipation, childhood cancers, trauma, and intestinal transplant.

Types of treatment apart from stoma surgery can include use of a Transcutaneous Electrical Nerve Stimulation (TENS) machine which can be used to treat certain types of pain,and is effective in some children with chronic constipation or slow transit.

Rectal or anal washouts can be quite effective and are welcomed by many children.

Surgery such as appendicostomy, Malone, or a Chait button can all be used with regular washouts.

Another type of treatment is a Mitrofanoff, or bladder stoma. For dietary considerations, it is recommended to increase fluid intake and roughage, and to consult with a dietitian.

Total Parenteral Nutrition (TPN) is a method of feeding that bypasses the gastrointestinal tract; excessive TPN can cause liver disease but is invaluable to allow the bowel to heal.





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Creative outlet gives quality to life

by Jacky

I HAVE always had bowel problems growing up, with either bad constipation or too loose, cramping, bloating and bleeding from the bowel.

I always put the bleeding down to pushing too hard and popping a few haemorrhoids.

About 13 years ago I had trouble walking five steps before I would lose my breath and get dizzy; this went on until I finally started to worry and went off to the hospital.

I passed out at the door and woke up on a bed with the doctor trying to find a vein to take blood – he finally got a little squirt out of one somewhere.

When the results were in he came back and said my haemoglobin had dropped to .7 per cent, meaning my body had only 50 per cent of the blood it should have.

They started infusions straight away.

About six months later a similar thing happened but this time I went to the hospital a lot earlier.

After just two pints of blood and an iron infusion they started to investigate other reasons for the blood loss as my mother had died two years earlier from ischemic bowel.

After a trillion tests (my least favourite being pooping out porridge stuff behind a curtain to see how fast or slow the bowel worked) they started to discover lots of problems.

It turns out I had inflammatory bowel disease, as well as slow transit and my bowel muscles wouldn't work properly, meaning I would have accidents anywhere at any time.

I got to the point where I wouldn't leave the house.

I gave up my daily walks with friends because pooping accidents were becoming too regular. So for three years I became a recluse.

I fell into a very bad depression; I would go to the shops, start my grocery shopping, get half way through and then leave my groceries in the aisle, due to panic attacks and the fear of having a bowel accident.

I would go home, cry and feel more depressed.

Eating food made me sick and I would end up in severe pain from the simplest of meals, so I basically stopped eating and ate as little as I could tolerate.

Finally, I was asked to undertake a study for a pacemaker in my bowel – I was keen to try anything at this point as I had cut myself off from all my friends and I was just existing every day in a bubble of pain and depression.

However, the pacemaker didn't work and after a year my symptoms became more severe.

I had an appointment with a specialist who referred me to an amazing bowel doctor who told me about a Chait tube trial they were doing, and once again I agreed to give it a go.

It didn't want to work for me either, so it was back to the drawing board.

A year later again I had a loop ileostomy performed. It all went well for about six months but then the large bowel that was left was blocking up with mucous; this is common and it usually easily passes through the rectum once every so often with no problems but it wouldn't pass through.

For 18 months we tried several alternatives with a lot of hospital stays, painful procedures, fun and games.

Finally, the decision was made to remove the whole large bowel and I now have a permanent ileostomy.

After about five years of not leaving the house, and basically not living any kind of life out in public, I had to try and get myself back out into the world again.

It was tough going, and my mind was quite scattered.

I had forgotten how to socialise, and pretty much forgot who I was as a person before I became sick.

I started to go regularly to the support group held every second month down in Wollongong. The stoma nurses were so supportive and always so nice.

The people in the group were amazing and a couple of the ladies would message or call to see how I was going.

I attended counselling and slowly started to get a little less scared about leaving the house.

As time went on, I became so courageous I opened an op shop down the south coast to try and help people.

It was a huge success for 12 months but I just couldn't keep doing it on my own and had to eventually shut shop.

I felt myself slipping back into my recluse state again and knew I had to find something, so I started volunteering one day a week.

I also started painting classes one day a week and started spending time with family and friends again.

Last year I was looking forward to getting back to Ostomy NSW for my volunteer work, and back into a new year of adventures, and I broke my wrist in three places.

Time stood still for a couple of weeks, then I had a crazy idea that I didn't want to stop doing. I had dabbled in making waistbands to wear at night time for the occasions when my bag sprung a leak, and I would try a thousand different ideas to waterproof my bag in the shower. I had started aqua aerobics and started making bags to cover my ostomy bag, so other people wouldn't feel weird seeing me in the water with my plastic bag.

At one of our meetings, a gentleman mentioned that he carried his supplies around in a plastic bag, and would like someone to make a pouch for men to put their supplies in.

I couldn't sew a straight line but
I wanted to make things for ostomates
– I asked a friend to teach me how to
sew and after a lot of messes, I started to
create

Every day I am learning new sewing skills and coming up with new ideas; I have an Etsy shop and sell my little inventions, and I am proud to say that people seem to like them.

I have even had a couple of stalls at ostomy events now and hope to keep going all over the place so I can share the love and help make other people with a stoma feel a little bit more attractive with my bits and bobs.

My life in the past 13 years has gone from non-existent to amazing, worthwhile and wonderful.

I thought having a stoma and a permanent bag would be the end of any quality of life, but it has given me back a better quality of life, and one with much more meaning.

Tricky subject makes for an entertaining read

by Amanda Haines

ANYONE who is or ever has been a teenager will know the importance of fitting in and the excruciating, end-of-theworld feeling that comes from being just a little bit different.

When the thing that makes you special is connected to a societal taboo, as well as being the source of much long-standing comedy, it can be a tricky thing to navigate.

This is the scenario faced by Freya, the young protagonist of Xena Knox's newly-released paperback novel *Sh!t* Bag.

Freya is a typical modern teen – she wears cartoon undies (ironically, of course) and the biggest drama in her life is whether she will go to the school ball with her on-again, off-again boyfriend.

After a medical emergency, she wakes up in hospital with "a poo bag on my belly".

She's never heard of an ileostomy, and now she has one.

Like all of us pre-ostomy, no matter our age, Freya's behavioural immune system has hard-wired her brain to think of anything related to bowel movements as disgusting.

Her schoolmates are no different and unsurprisingly, given the scatological tendencies of teens, she is given a new nickname - Sh!tbag.

Freya has to overcome her own instinctive reaction so she can deal with this interesting new situation she finds herself in - and she does so by reappropriating the obnoxious name and turning it into a badge of honour.

The language used in the novel is, of necessity, coarse and sometimes confronting but it is realistically so - the idea of what is suitable language for any given social context changes over time and thanks to the internet, it changes rapidly.

The publishers (Hachette Australia) have, however, chosen to mitigate the swear word in the title of Knox's book so as not to offend readers too much (and just the right amount).

They hail it as "a taboo-breaking novel" and in its specific subject matter it certainly is.

Presenting what can be sensitive issues such as ostomies in a light-hearted and entertaining manner goes a long way towards removing any old-fashioned stigma that may be associated with them, and adds a normative aspect every teen would embrace.

Knox's writing style is fluid and easy to read and captivating enough to hold even the shortest attention span.

Although it is aimed at the young adult (YA) market, Sh!t Bag is a light read suitable for all adults – not just those with a poo bag on their belly.



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Being stubborn leads to a better life

by Molly Dunn

I AM 84 and feel alive and very lucky, a stubborn old lady who has had to take life in my own hands as I was born with a bowel condition.

I have had an ileostomy for 44 years; for folk who don't know about ostomies, I tell them I have had my plumbing rearranged.

I lived in the UK for 17 years and then immigrated to New Zealand, living there for 37 years – now for seven years I have been a very proud Australian living in Queensland.

I wear a bag on my tummy; I had all my large bowel and half my small bowel removed in a series of operations.

I lead a near-normal life, I know my restrictions and can eat most foods.

I had my plumbing rearranged in 1981 after a lifetime of bowel problems from birth to adult following many doctors' visits.

At 17 years of age I had to give myself daily enemas and pain was a way of life.

I was in and out of hospital; doctors, specialists – no-one knew what was wrong: "It was all in my mind" was what I was usually told.

Finally, it was revealed that I had Hirchsprung's disease, which is a very rare malformation of the nerves and muscles between the gut and the brain.

The matron at the hospital advised me at 31 years of age to never have an ostomy bag as "they were terrible things and dirty" so that idea was out.

My first operation was to cut out a large piece of the bowel; this was unsuccessful and it was followed by numerous operations of "we'll take a bit more".

More blockages occurred from which I nearly lost my life twice.

I had 14 operations in all and hospitals were a way of life, as was pain for the next 10 years.

My life was pretty poor and the pain left me housebound with no quality of life, which was hard on my family.

The last bowel operation left me with the opposite of constipation; I was housebound going 24 times in a day.

By then I had severe ulcerative colitis. By reading and a lot of talking I never gave up hope that one day I would be okay.

I made a decision and my husband Archie supported me (as usual) when I chose to have an ileostomy; Archie always made me feel I was like anyone else, he was a wonderful man.

I made it very clear to my long-suffering surgeon I had to have an ileostomy or I couldn't go on.

The operation went well – I had a few problems but that was natural after so much surgery.

It took a year or so to get used to such a change but things improved beyond all hopes and expectations.

Archie and I learnt a sense of humour, tolerance and to feel good about oneself.

Nothing is perfect and ostomy pouches are no exception, accidents will happen; it is rare but this is when a sense of humour comes in.

I joined a bushwalking group and went kayaking, abseiling, horse riding and ice skating and we both played competitive indoor bowls

Archie and I had a four-month trip around the world and I managed fine, taking with me a huge supply of appliances.

Life was a ball, I was free of pain and I learnt all new things that I could never do before, such as art classes and embroidery at night school.

I joined the workforce for a while but an ostomate cannot tolerate stress, just a side effect one has to live with, so I avoid it.

It's like any condition one has, you have to be in charge of yourself and not let any condition be in charge of you.

It is a hard thing to do and I guess we all slip up at times.

I have been a volunteer with many organisations and have tried to help folk get back on their feet but sadly you can only help folk who want to help themselves, some don't.

Archie and I had three children together; he died eight years ago so my life has had to go solo since then.

It is hard but so far I am still alive and enjoying my crafts and the garden.

I have got this far.



IMPORTANT NOTICE



Support Garment Briefs and Pants are coming off the scheme

From 1st October 2023 Support Garment Briefs and Pants are being removed from the Stoma Appliance Scheme.

This means that after 1st October, Support Garment briefs and pants will no longer be reimbursed by the government for ostomates. This includes:



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Order your full pants allocation from your association before 1st October!



News of the World

DJ busts a move



ENGLAND: Adele Roberts has become the fastest woman to run the London Marathon with a stoma bag.

The Radio 1 DJ set the record less than 12 months after stopping chemotherapy for

bowel cancer.

The 44-year-old, who ran the marathon in 3hr 30min and 22sec, was quoted as saying "up yours, cancer" after her achievement.

The official Guinness World Records' social media account shared a picture of Roberts with her certificate.

Roberts had a tiny replica medal made for her stoma, which she has named Audrey, and which she shared in a video posted on her Instagram story.

"We've just set a world record for the fastest marathon with an ileostomy, less then 12 months since I stopped chemotherapy – anything is possible," she said.

www.theguardian.com

Implant trials begin



SWEDEN: A medical technology company has progressed to patient trials with an innovative device which it says will "transform the lives of people with a stoma".

The company, OstomyCure, has for the past decade been developing an implant known as TIES.

The titanium port is implanted within a stoma and used to attach a lid to open and close the stoma at the user's convenience.

According to the company, 20 patients have now been implanted with the device with participating hospitals in the UK, Sweden, Poland, Austria, and India.

The patients will be monitored for a further six months to fully assess safety and performance.

The analysis of the clinical data from the patients will be included in regulatory submissions under the EU Medical Device Regulation, the next step in making the device available for ostomates.

www.ostomycure.com

Jubilee celebrations



RUSSIA: The 30th anniversary of the ostomy patients' association ASTOM and the ostomy patients' rehabilitation service was held in April in Moscow.

 $\label{eq:more than 10 thousand people with a stoma} \\ live in Moscow.$

ASTOM cooperates with healthcare and government authorities as well as producers of ostomy care products in the organisation of the rehabilitation system for people with stomas and the free supply of ostomy appliances throughout Russia

Opening the conference, ASTOM president Dr Viatcheslav Sukhanov listed the main reasons hindering the process of medical and social rehabilitation of stoma patients as being the lack of a regulatory framework for the rehabilitation of stoma patients; the lack of compulsory medical insurance tariffs for stoma patients, both adults and children; the lack of special medical education for nursing staff in the rehabilitation of stoma patients; and the lack of consultative rooms for stoma patients in most regions of Russia.

astom.ru/en/magazine-astom

Therapy useful



IRAN: A study of the role of cognitive behaviour therapy for ostomates has found it can improve their "hope and happiness".

The authors of the study, published in the *Journal of Wound Ostomy and Continence*

Nursing, evaluated the effectiveness of group cognitive therapy in a single-group before-and-after study.

The sample comprised 30 patients living with an ostomy for at least 30 days; most were male and with a mean age of 64.5 years.

The study incorporated two validated instruments: the Miller Hope Scale and the Oxford Happiness Inventory.

Researchers found that, following 10 therapy sessions, the happiness level of patients with an ostomy increased significantly from their pre-therapy levels.

jwocnonline/Abstract/2023/03000.aspx

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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 2601

Open: First and second week of the month: 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

F: (07) 5571 7481

A: 8 Dunkirk Close, Arundel QLD 4214

Open: Tuesday

and Thursday 9am to 3pm

NORTH QUEENSLAND OSTOMY ASSOCIATION

E: admin@nqostomy.org.au

T: (07) 4775 2303

F: (07) 4725 9418

A: 13 Castlemaine Street, Kirwan, QLD 4817

Open: Monday and Thursday 8am to 4pm, Wednesday 8am to noon

QUEENSLAND OSTOMY ASSOCIATION

W: QLDostomy.org.au

E: admin@QLDostomy.org.au

T: (07) 3848 7178

F: (07) 3848 0561

A: 22 Beaudesert Road, Moorooka QLD 4105

Open: Mondays 9am to 2pm, Tuesdays and Thursdays 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

F: (07) 4636 9702

A: Education Centre, 256 Stenner Street, Middle Ridge 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: 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 10.0am 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 to 1pm

VICTORIA

BENDIGO AND DISTRICT OSTOMY ASSOCIATION

W: bendigo-ostomy.org.au

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

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 Monday and Wednesday

GEELONG OSTOMY

W: geelongostomy.com.au

E: goinc@geelongostomy. com.au

T: (03) 5201 0844

F: (03) 5201 0844

A: 6 Lewalan Street Grovedale VIC 3216

Open: Monday, Wednesday, Friday 9.30am to 2.30pm

OSTOMY ASSOCIATION OF MELBOURNE

W: oam.org.au

E: enquiries@oam.org.au

T: (03) 9888 8523

F: (03) 9888 8094

A: unit 14, 25-37 Huntingdale 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

OSTOMY ASSOCIAT

W: waostomy.org.au

E: info@waostomy.org.au

T: (08) 9272 1833

F: (08) 9271 4605

A: 15 Guildford Road Mount

Lawley WA 6050

Open: Monday 9am to 4pm

Tuesday 9am to 4pm

Wednesday 9am to 1pm

Thursday 9am to 4pm

Friday 9am to 1pm

Fourth Saturday of each month 9am to 1pm

National Directory of Ostomy Support Groups

ACT

Canberra: ACT support group, 10am to noon, second Tuesday of every month. Next: September 14, November 16. 2nd Floor, City Health Building, 1 Moore St (cnr Moore and Alinga), 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). 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). 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: Sept 5 and 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.

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 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@ramsay health.com.au; or Julia Kittscha CNC STN Wollongong Hospital 0414 421 021 or 4255 1594 or julia.kittscha@health.rsw.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. qov.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: 11am1pm, 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, 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

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

Barossa: Either 2-4pm 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 Maureen O'Donnell 0434 051 375.

Fleurieu: 10am-noon on first Monday of March, June, September and December at Grosvenor Hotel Function Room, Victor Harbor. Contact Phillip 0408 831 774.

Mount Barker: Opening in 2023. Contact Maureen **0434 051 375** to register your interest.

Murraylands: 10am-noon first Monday of February, April, June, August, October and December. Murray Bridge RSL, 2 Ross Rd. Contact Maureen 0434 051 375.

Northern: Elizabeth Playford Lions Club, Hilcott Street, Elizabeth North. Fourth Tuesday of the month 2-4pm. Febuary, April, June, August and October. There will be a product rep at every meeting. Email northernostomygroup@ gmail.com

Port Lincoln: RSL, 14 Hallett Place, Port Lincoln. For dates and time contact Maureen 0434 051 375.

Riverland: 10am-noon, first Thursday of January, March, May, July, September and November. Renmark RSL, 91 Fifteenth St. Group begins on September 7. Contact Maureen 0434 051 375.

Southern: 2pm on first Wednesday of February, April, June, August and October at Elizabeth House, 112 Elizabeth Road, Christie Downs. Contact stoma therapy nurses Lyn Sandford 0421 000 960 or Sharmaine Peterson 0438 853 082.

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 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 s0481 484 347.

South East: 10.30-12.30 Thursdays in February, April, June, August, October and November. St Martin's Church, Edward St, Mt Gambier. Please phone to check date and venue. Contact Barbara Wardley 0415 477 978 or Leeanne Paterson 0418 733 111. Yorke Peninsula: 1.30pm on third Wednesday of February, April, June, August, October and December at Senior Citizen's Hall, Verran Terrace, Moonta (next to Bowling Club). Call Helen Colliver 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, three days a week. AGM last Wednesday of November at 12pm. 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 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.

Missed something?



www.australianstoma.com.au/resources/ostomy-australia