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Volume 26 Number 2 August 2017

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# An inspiring centenary

Melbourne conference preview

Sex? There's always a first time

## National Directory of Ostomy Associations

Please contact your association (from the list below) for all ostomy issues relating to membership, appliance supply and/or Ostomy AUSTRALIA journal distribution.

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President's

Conference

Ileostomy

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Your say-

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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.

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# PRESIDENT'S MESSAGE

#### SAMS, a better way of working

Work is moving quickly to introduce the Stoma Appliance Management System (SAMS) computer application in associations around Australia. SAMS, which has been developed by ACSA, is a multi-faceted software application that will save time, effort and money. Lessons from implementation are also helping us to improve the system during roll-out.

SAMS lets associations manage the distribution of products listed on the Stoma Appliance Scheme (SAS) to their members. It also handles the lodgement of claims made by associations to the federal government for reimbursement of product costs. As well, SAMS is able to manage member details, including membership fees, and can also process sales of products not listed on the SAS.

SAMS has been less than three years in the making. The 2014 ACSA national conference approved the development of a national system to be used by all stoma associations. The meeting agreed that the system that had been developed for Ostomy NSW Ltd (ONL) by Innovent Business Solutions provided the best basis for a national system. The meeting agreed to ACSA acquiring the intellectual property (IP) for the system from ONL and developing it to meet the requirements of all associations.

The acquisition process was completed in April 2015 and development commenced in August 2015. Ostomy Association of Melbourne (OAM) was selected as the development site because it had suitably gualified staff and facilities.

Development has been a painstaking and thorough process. Initial activities involved a detailed analysis of the requirements for a system that would be suitable for all associations to use. This involved reviewing the way the JANT and SAMSON systems used by most associations worked.

This information was then compared with functionality provided by the ONL system and a plan prepared for developing the functionality that would be needed. Work on the project was on a part-time basis and so development was at times slow.

OAM moved to SAMS in April this year and the implementation went extremely smoothly. This was largely due to the efforts of Hermione Agee, who had managed the development and conducted extensive testing. ONL will be next to move to SAMS.

The first round of enhancements has begun and by the time you are reading this, associations will have been asked to provide suggestions on how the application can be improved.

Other associations will move to the new system over the next 12 months.

#### **Benefits of SAMS**

How will the introduction of SAMS improve things for ostomates? A single system supporting all associations provides a number of benefits to both the associations and the government, who are responsible for the delivery of the SAS.

Associations will be given regular updates to the application and will not have to worry about implementing any changes to the SAS processes. They will receive updates to the SAS Schedule of Products, as well as updates for any changes in the way government reimbursements are claimed.

The cost of managing and maintaining the system will be shared by all 22 associations, which will charged proportionally, based on the number of members they support. For most associations, the cost will be less than their current support costs.



The government will benefit by having to interact with a single system when handling product reimbursements lodged by associations. ACSA will also provide the government with statistical information on product usage. This will then be available to the Stoma Product Assessment Panel that recommends which products should be added to the scheme and monitors their subsequent usage.

ACSA also expects that ostomates will benefit from associations being able to be more responsive to members because the administrative effort required to deliver services will decline.

I will keep members informed of the progress in implementing SAMS through this report

#### **Association structure**

As I noted in my April report, at our 2016 annual conference associations agreed to establish a working party to identify alternative organisational structures to provide a platform for a formal contract with government. The working party has identified the type of structure that it believes would be most appropriate for ACSA and is currently reviewing how other not-for-profit organisations operate.

The committee had intended to circulate a firm recommendation on its preferred option to associations at least two months before the 2017 ACSA AGM. This now seems unlikely as the detail required cannot be assembled in time. However, conference will receive an interim report.

#### Universal access to stomal therapy nurses

The Executive continues to explore how ostomates might be able to access stomal therapy services when they need them, and also be reviewed by a stomal therapist on a regular basis.

We still need to address a number of issues, including obtaining government support, determining who would run such a service, how it would be structured and where we would recruit the stomal therapists to operate the scheme. Like all new ventures, it would have its challenges, but it offers the opportunity to introduce the next major improvement in a scheme that leads the world in supporting ostomates.

We will continue to work with government, the Australian Association of Stomal Therapy Nurses and stoma product suppliers to establish the service.

Geoff Rhodes PRESIDENT

# **2017 ACSA Conference** Springtime in Melbourne



Above: Federation Square illuminated by a brilliant light show (picture: Nils Versemann). Top right: Street art, central Melbourne (Visions of Victoria, Mark Chew). Below: Tasty coffee at a Fitzroy café (Visions of Victoria, Mark Chew).



igcap pring in Melbourne brings out  $\mathbf{J}$  the very best of a beautiful city. It is with this background that the Melbourne ostomy associations welcome members from around Australia to the annual ACSA Conference, which will be held at the Novotel Hotel in Melbourne from 13 to 15 October 2017.

The Novotel is situated in the centre of Collins Street between Swanston Street and Elizabeth Street.

Apart from great conference facilities and excellent affordable hotel rooms for delegates and other registrants, the hotel is conveniently located in the shopping centre of the central business district.

For those accompanying delegates or during times when the conference has adjourned, a short walk or tram ride along Swanston Street and St Kilda Road leads you to the National Gallery of Victoria and nearby recital halls. Across the road from the National Gallery are the wonderful gardens surrounding the Shrine of Remembrance. A bit further past the shrine are the Royal Botanic Gardens, laid out in 1846 as directed by Governor Charles La Trobe and further established under the direction of Ferdinand von Mueller.

The agenda for the three-day conference will follow the established





Street art, central Melbourne (Visions of Victoria, Mark Chew)

precedent of a welcome function on Thursday evening and the Annual General Meeting on Friday morning. It is expected that the conference will be opened by the Governor of Victoria, the Hon. Linda Dessau, AC.

On Saturday there will be further sessions of ACSA conference business

On Sunday we have organised a breakfast outing on the famous Tramcar Restaurant. The trams will travel around Melbourne and its suburbs at a leisurely pace for a couple of hours.



National Gallery of Victoria (Visions of Victoria, Peter Dunphy)

We hope that delegates and other observers have an enjoyable and fulfilling time with us at the 2017 ACSA Conference. Hotel bookings and conference registration can be done with registration kitsregistration and hotel forms are available on the conference website, www.australianstoma.com.au.

## **Ileostomy Victoria - 60 years of achievement** By Terry Carver

**T** n May 1957 colorectal surgeon Mr E S R Hughes— Later to become Sir Edward Hughes—contacted 28 ostomates and invited them to a meeting in a lecture theatre at the Royal Melbourne Hospital.

While studying in the United States he had seen the benefits of having ostomates gather together where they could exchange ideas on managing their stomas, how they could tackle problems with the very basic appliances then used and managing problems with skin around the stoma.

Waste collection from a stoma was very basic in those days, with pouches made of either gum or compounded rubber, with no skin barrier to protect the skin around the stoma.

The meeting in 1957 agreed to form the first stoma association in Australia. It was called QT Association of Victoria, 'QT' being the two wards for ostomates where Hughes had studied in the US. Some other associations that were set up interstate also used the QT initials in their names at the start. The Victorian association changed its name to Ileostomy Association (Vic) Inc when it was incorporated in March 1988, to better reflect its local affiliations.

The original association's role was as a support group and a co-operative. All supplies (what there was of them) had to be purchased by ostomates, with no help from the government of the day. Significant savings could be made by buying supplies in bulk from the manufacturer. These savings could be passed on to association members.

In 1959 the association decided that it needed a home other than a member's garage and took a room in the Block Arcade building complex at 98 Elizabeth Street, Melbourne. We have leased several rooms in our 58 years at the Block-Room 8 (25 years), Room 6 (five years), Room 324 (six months, totally unsuitable), Room 226 (three years), Room 127 (nine years), and Room 322, where we soon will have been for 16 years.

In 1960 colostomates from the Ileostomy Association formed the Colostomy Association of Victoria. As other Victorian associations opened, our members took the opportunity to transfer to the new associations that were nearer to their homes or work.

It is noteworthy that, of the 28 ostomates who attended that first meeting, two are still active. One remains a member of Ileostomy Association (Vic) and the other is a member of Peninsular, having transferred when that association was formed.

The association has also played a national role. In 1963 the president of QT Association of Victoria was among the association leaders who came together in Sydney with the thought of forming a national body. A few years later that led to ACSA being formed.

To commemorate our 60th birthday, a luncheon for the volunteers was held in May 2017 at the Langham Hotel.

While we have very good records of all the people that have served the association at the committee level, many of



Volunteers at Ileostomy Victoria's 60th anniversary lunch: from left, Janice Halling, Julie Hose, Tatsuo Katsumata, Loretta Cassani, Sandra Rose, Roger Reid, Kerry Bird, Geof Easton, Susan lovenitti, Gil Langfield, Barbara Thom, Wendy Taylor, Carlo lovenitti and Terry Carver. Those who were unable to attend were Leah Turna, Lyn Mc Kelvie and Dean Iovenitti

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whom have also worked in the rooms dispensing goods to the members, we do not have a register of all the unsung volunteers who have worked with us. As president, on behalf of the association, I would like to thank them and all who have given their time as volunteers for all they have contributed over the last 60 years

Committee statistics shows that over the last 60 years

we have had 13 presidents, 25 vice-presidents, seven secretaries, 12 treasurers and 11 minute secretaries, from a total of 85 committee members. Committee members have served 577 years in total.

Long-serving committee members include Mrs J Williams and Mr T Carver (each 28 years), Mrs W Taylor and Mr P Taylor (27 years), and Mr J Cummins (25 years).

## Put on a furry face for a good cause

Decembeard was launched in Britain in 2012 by the charity Beating Bowel Cancer, and the idea has caught on internationally, with Decembeards now up and running in Canada, Ireland, New Zealand and Australia.

In Australia, Decembeard, run by the 100 per cent community-funded charity Bowel Cancer Australia, has been going from strength to strength. More than 300 fundraising Web pages were set up last year and the number is expected to increase in 2017.

The event encourages

men to grow a beard in the final month of the year to raise awareness and much needed funds for bowel cancer. That growth can be anything from a few days' stubble to a 'full set', though participants aiming for that kind of bushy creation might be well advised to set aside their razors before November.

And it's not just men who can take part. Women and children are also encouraged to join in—though their face fuzz is synthetic—to raise funds and encourage their fathers, brothers, husbands, boyfriends, partners and male friends to find out about bowel cancer. The emphasis is on 'real people' and their stories.



Ashleigh, who took part in the 2016 campaign, did so as 'a nurse and a midwife, a daughter and a sister', after her brother, Dean, died of bowel cancer at the age of 26, only eight months after diagnosis.

'People often think that bowel cancer is an "old person's disease," but bowel cancer affects people of all ages,' Ashleigh says.

After Dean's death, his friends joined together and created Deano's Bearded Stallions to commemorate their friend's life and raise awareness about bowel cancer—and Ashleigh has been a strong supporter.

'In place of something so tragic, they have created a meaningful way

to celebrate and honour Dean's life and his untimely passing,' she says.

Bowel cancer affects men of all ages, and risk increases with age. In Australia, one man in 11 will develop bowel cancer during his lifetime.

Around 55 per cent of all Australians diagnosed with bowel cancer are men. The illness is the nation's third leading cause of cancer deaths in men.

Bowel Cancer Australia is the leading communityfunded charity dedicated to prevention, early diagnosis, research, quality treatment

and care for everyone affected by bowel cancer.

Bowel Cancer Australia reckons that anyone can make change happen. Beards aren't just for hipsters, those with tattoos, men who ride motorbikes or blokes who can't find time to shave. Anyone who promotes their facial hair for Decembeard can help to achieve Bowel Cancer Australia's vision where no one dies of bowel cancer and all those diagnosed receive the support they need.

There are plenty of ways to get involved. To find out more or to register to grow your own Decembeard, visit www.decembeard.org.au.

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# Your say – Letters to the editor

Ostomy AUSTRALIA does not endorse the contents of readers' letters nor do we vouch for the accuracy of any claims made in those letters. Readers should not rely on any such claims in the absence of medical advice and should consult with their treating doctors prior to embarking on any course of treatment.

#### Dear Editor.

I would like to suggest a method of placement of overnight drainage bags for people who have a urostomy. The photos on this page show the concept.

A thin plastic cutting board (approximately 20cm x 30 cm) was cut in half, making two pieces of about 20cm x 15cm. The two pieces were then joined with duct tape to enable them to be folded. Four hooks were then stuck to the board so that the overnight drainage bag could be attached to the board. A plastic clip was added for more convenience in securing the hose.

The idea is for half of the board to be slipped between the base of the bed and the mattress. By placing a plastic tray or suitable container underneath the bag the whole contraption can be located easily and unobtrusively beside the bed.

This allows placement of the overnight bag without fixing metal or wooden appliances to the bed and also means that it can be moved easily to other beds without transferring fixtures. This system also makes for easier travelling because it folds into a small package.

I hope this system may be of assistance to fellow ostomates.

James Wallace. NSW

#### 

#### Dear Editor.

I have had a stoma for 10 years and generally have managed fairly well. I am only a size 12 but clothing at the waistline has been a problem. That improved a little once I started wearing the (free) briefs supplied by the association. Recently I had a bowel obstruction which resolved without surgery but I now have a problem with abdominal bloating. I need to wear slacks that are loose at the waistline with a front zip and are not elasticized over the tummy but I cannot find suitable garments in the shops or on line. I have had to endure considerable discomfort until recently I thought of trying maternity slacks. I now have three pairs and I would recommend them to other women with a similar problem. Sorry that I haven't got an answer for men with a similar problem.

If anyone has other ideas about how to solve this problem I would be pleased to hear. For 10 years I have put up with waistbands cutting across the appliance, interfering with the filling of the bag, and this problem is worse when away from home.

Katherine Kingsbury, Victoria



AUSTRALIA



Top: The general layout of James Wallace's drainage bag arrangement and, below, how the unit can be held in place by fitting between the mattress and the bed base

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#### Dear Editor.

I am a new ostomate since September 2016, a situation brought about by a hernia mesh getting loose and rupturing the bowel—a long story, but I am hoping in the near future to have a reversal undertaken.

Like everyone else I went through the learning curve of adjusting to the bag and, yes, I suffered leaks and on a number of occasions forgot to secure the drain.

One thing I did learn was that certain foods produce hostile enzymes that burnt and irritated the stoma. I was changing bags just to solve this difficult problem. There was a way around it—open up the drain into a tube and fill the bag with warm fresh water. I use the water container that is used for filling our iron. Slosh it around for 30 seconds and problem solved. Additional benefits are a clean bag and reduced odour.

I hope this proves to be of assistance to someone.

Alan Wenlock, Western Australia

#### Dear Editor.

For many years now I have suffered from an annoying eye condition called blepharospasm for which, as yet, there is no cure. There is a website devoted to it, part of which encompasses a bulletin board which I have found to be a most useful tool from the point of view of educating, contacting like members, passing on tips and advice, answering questions and in general keeping up with advances pertaining to one's condition. The bulletin board is in the charge of an able bulletin meister, who is given the power to vet input, grant yea or nay and to interject with advice when necessary. Given this, it occurred to me that ostomates may well benefit in a similar manner from having a bulletin board they can use.

As an example of the sort of thing I'm thinking of please try www.blepharospasm.org and navigate to the bulletin board.

Tony Lanning, Queensland

#### Dear Editor,

I have been an ileostomate for over 20 years. Last year I began experiencing a problem with leakage from the bag filter-not all the time but often enough to be a concern. This resulted in wet and stained clothing so I began *always* to cover the filter with waterproof padding-very inconvenient. Then I tried covering all the filters with plastic-type bandaids, with some success. But still I often woke up with wet clothing, sometimes to the extent of needing to shower and change clothes in the middle of the night.

I put up with this situation for several months before

contacting the company to alert them to the problem and sent back two unused bags to be tested. When I hadn't heard anything after three months I rang and was told that I would be receiving a letter. The result was that they didn't consider it a serious enough problem to bother about unless they received many more complaints.

I just wonder if I am the only one with this problem, or are other ostomates experiencing the same problem with leaking filters?

Joan Hiscock. Queensland

#### Dear Editor.

I enjoyed reading the letter from Sarah Larcombe in the April Ostomy Australia and wish her good luck in the future.

I have been an ostomate for 50 years. I had surgery after suffering from ulcerative colitis for 18 months. I can remember lying in hospital thinking, 'How am I going to contend with this?' But I started thinking positively. What if I had lost an arm or a leg? Like this, I can still do everything. I had my husband and two small children to think of.

Back then there was no help, no stoma therapists. You were on your own, and the appliances were unbelievable. The base plate, if that's what you could call it, was like a rubber sink plug which had to be adhered with sticking plaster. The bag was placed on to the rubber base plate with an elastic band, so you made sure you had a few rubber bands in your handbag, as well as extra supplies. All these supplies you paid for-nothing free!

Can you imagine if you lived with an ileostomy in a thirdworld country? You probably wouldn't have access to any supplies. We don't know how lucky we are to be so well looked after for just \$55 a year.

Marg C, Victoria

### We want to hear from you!

Ostomates tell us how much fun and information they get from Ostomy Australia-but the journal is only as good as members make it. For contributors, here are a few simple guidelines:

- · for preference, send your item as a email or attachment;
- · don't identify medical professionals unless they have agreed;
- avoid naming companies or products;
- · remember to include your full name, address, and contact details.
- · photographs should be JPGs at least IMB in size.

Email contributions can be sent to:

Journal@australianstoma.com.au

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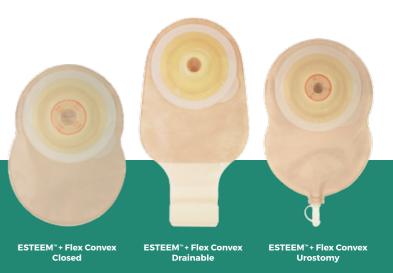
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Ostomy Care Solutions

# Celebration for an inspiring centenary By Peter Batson



The newest Albury Wodonga Stoma Support Group member, Sophie Gifford, 5, helps Isabel Webb to blow out the candles on Issy's centenary birthday cake. Photograph: Peter Batson

Pentenarian cattle breeder Isabel Webb will long Cremember April 2017 as a month of fond memories and a major milestone.

Not only did Miss Webb celebrate her 100th birthday, on Anzac Day, but she joined fellow members of her local stoma support group at a special 100th birthday morning tea they organised, sharing a rich lode of memories from a long and productive life on the land.

Also marking Isabel's special day was the group's newest member, five-year-old Sophie Gifford, of Albury, who was attending her first stoma support group get-together.

Known simply as 'Issy' to her many friends, Isabel was a founder member of the Albury Wodonga Stoma Support Group when it formed in 2012, not long after she received a stoma following a bout with bowel cancer.

The support group meets for informal monthly meetings in Albury and serves Albury-Wodonga and district ostomates, ostomates-to-be and their family members and friends.

Alongside about 20 of her fellow stoma group members, two relatives and Border-based stoma nurse Letitia Harrington, Isabel tucked into a cup of tea and a generous slice of an elaborate strawberry-topped 100th birthday cake organised by support group foundation member Liz Landy.

At the morning tea on 11 April, foundation member Alex Watson described Isabel—the oldest of the group's members by a country mile—as an inspiration to all.

'The fact that today at our meeting we have a 100-year-old member in Issy, and a five-year old, Sophie, demonstrates the age range of those our group, and the many other groups like ours around Australia, provide support to,' he said.

'Whether people choose to come along to our group once or turn up 30 times, it doesn't matter-it's up to them. There's no pressure and our get-togethers are totally informal and non-judgmental.'

Obviously moved, the softly spoken Isabel thanked the group's members for recognising her centenary and praised them for their support and friendship.

Born on Anzac Day 2017 in Traralgon in Victoria's Latrobe Valley, Isabel shifted with her parents in the 1920s to a sheep property at Morven in southern NSW, near Culcairn, where she now lives.



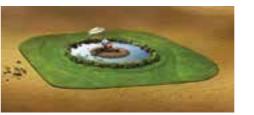
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life. Until he used CeraPlus.



Watch Christopher's story^ isit vimeo.com/hollisterostomv



Hereford cattle became the family's main focus in 1939 and remain of vital interest to Isabel, who is believed to be Australia's oldest registered commercial Hereford cattle breeder.

An astute breeder and buyer, she began managing the family's 'Boongarra' property and its stock in 1975, a job now the responsibility of her niece Cecily Trickett, who accompanied her aunt to the birthday morning tea.

Together, Mrs Trickett and Isabel run about 400 quality Hereford cattle on 'Boongarra'.

Isabel is the aunt of champion Australian Olympian equestrian rider Andrew Hoy, who won three gold medals and one silver spanning a remarkable seven Olympic Games appearances.

Hoy's mother Dorothy, Isabel's younger sister, also enjoyed the support group's birthday celebration.

In February, Cecily told *The Land* newspaper that she often took her aunt by car to inspect their livestock.

'She takes a keen interest in what is going on here and is very attached to her cattle,' she said.

Cecily described her aunt as courageous, stubborn, determined, loving, very supportive of her family, blessed with a strong constitution and quick-witted.

'She beats me in Scrabble; I have great admiration for her,' she said.

'She really appreciates being part of the stoma support group and that you're able to go along and share, and the members know what you're going through.

'It's given her much-needed support and she is so pleased to be a part of it.'

Isabel reckons she was right to stick with the Hereford breed her family opted for almost eight decades ago.

'I have seen a lot of people move away from Herefords, particularly to Angus, and I really don't know why ... because our Herefords have performed as well as any other cattle I have seen,' she told The Land.

'They are a quiet breed, and we often get ribbed by how quiet our cattle are.'

Isabel's own quiet disposition masks a sharp mind and a keen sense of humour, shown by the mischievous twinkle in her eye.

'I want to thank everyone for this celebration today,' she told her fellow ostomates.

'The group has been a real support to me and I thank you all for that.'

\* The Albury Wodonga Stoma Support Group meets at 10am on the second Tuesday of every month (except January) at the Hilltop Centre boardroom, 600 Keene Street, Albury. Contact: Alex on 0428 578.385.

# Young ostomates connect with Facebook From YOU Inc.

he Young Ostomates United (YOU Inc) Facebook page now has 177 members and is growing slowly but steadily.

We began our Facebook page about three years ago, when we felt it was time to join the social media world. Though we were coming from an era where everything we did had a 'hard copy' to one where everything was in cyberspace, transition was really easy. We knew the basics of social media and learned very quickly as we went along.

There is such a need for communication between ostomates. This was something we had tried to achieve. and we did so successfully, without social media. However, we have found that using social media is a way to bring together many ostomates, carers and people pre-operatively, allowing them to share their experiences and receive an instant reply to their concerns.

We have found that people need a hand in many areas, whether it be work, clothing, relationships, sport or just getting used to having a stoma.

A range of questions often asked are: How long will I take to recover from surgery (often there is more than one)? Can I wear my usual clothes? What products are available to use? How do I tell prospective partners, and when do I do so? Will I ever have a babyor another baby? Can I play sport? is it safe? Do I need to tell my boss? If so, how and when? Can I travel, and how do I find travel insurance?

We always try to answer these questions and give the person several alternatives, as we know there are usually no right or wrong answers, given that everyone is different. We try not to answer medical questions unless Lilian Leonard, our 'retired' STN and the founder of YOU Inc, is able to provide an objective answer.

It has been wonderful having our 'closed' Facebook page available. Many other great personal ostomate Facebook pages are available to view. With 27 years' experience as a support group, along with our web page (www. youinc.org.au) with all its information, we believe YOU provides a great opportunity to help those going through one of the biggest and scariest changes in their lives.

All ostomates have the right and a need to feel 'normal' and we believe this can be achieved by the support, friendship and knowledge we all willingly provide.

Thank you to everyone who participates!



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# **Sex? There's always a first time**

# Keep your toes away from the edge

By Eloisa Ballard

 $\mathbf{X}$ /ell, not first time EVER—I am a 65-year-old widow and have had a child.

I met a widower who had lost his wife about six months earlier. We hit it off, as they say, and after a first dinner out started seeing each other several times a week. The widower-let's call him John-is 75 years old, but fit and active and plays 18 holes of golf four times a week.

John early on declared himself in love and our goodbye kisses turned into caresses. I was in heaven as I had not had such affection for at least 10 years. My late husband, who was a good man, had prostate cancer surgery in 2007, making him impotent. The subsequent hormone treatment left him with no desire for intimacy or sex.

I could see that the potential for intimacy with John was coming up and I was concerned about how he would react to the presence of a urostomy bag. I ordered a Between You and Me urostomy bag cover but it was taking weeks to arrive (something about a storm in Adelaide and power cut putting them back several weeks of orders).

Meanwhile, I thought it wise to tell John about my medical history (long) and the urostomy. Along the way he asked 'What is a urostomy exactly?' He listened carefully till the end of my medical history-no mean feat of concentration-and asked two pertinent questions and made one statement:

Question 1: 'So can you have sex or not?' Don't you just love how men get to the point of the matter? I responded in the affirmative that yes I could have sex. He paused and digested this information. Wide-eyed and genuinely puzzled he asked question two as a follow-on.

Question 2: 'So what is the problem?' I responded that I was shy about him seeing the urostomy bag and was waiting for a fabric cover to come from Adelaide. Another pause while John considered this response. He then reckoned that if it was important to me then he would wait-but for how long? If it were a week or two then OK—if it were a month or two then he would like to go ahead regardless of the cover!

The statement was that he was afraid I was going to say I had had breast surgery and had no boobs! I had not thought of that one.

The cover was delayed over a week, and nervously I finally prepared for the 'event' with a smaller, shorter urostomy bag with no tap and a matt flesh-coloured cover rather than the transparent plastic clear covers that I had been wearing.

> So we went ahead and made love. John made no mention of the bag except to ask if everything was OK for me and had he hurt me? (Yes to the first and No to the second). Everything was very good.

> > Joyfully for me, the fabric cover arrived the next week and I used it over my normal bag from then on. This was a good step as the closed non-drainable bag can only hold a small cup of urine and it did get annoying getting out of bed and changing the urostomy bag when one would rather be cuddling up and chatting quietly instead.

Our sex life has continued to be a joy, a special delight, a great treasure and source of bonding between us. When we recently progressed to overnight stays at each other's places. I had to tell John about the overnight catheter bag which I would need to use. He took this in his stride with no fuss in much the same way as he had the urostomy bag.

I have since ditched the fabric cover and use a urostomy bag with matt flesh-coloured covers and a tap. The fabric covers do tend to rub off a bit. If John has noticed this change then he has not said anything. It has not affected his ardour.

I have been amazed by the stories in this magazine of some ostomates who have trekked up the Himalayas and done their ablutions in a cup of cold water and others who have coped with primitive toilets in India. My story is of more modest proportions and closer to home but nonetheless life-changing.

A final tip-throw out your cold and sticky gel. Get a pump pack of the warm and wonderful silicone rubs available from supermarkets. John thinks that this emollient should have been awarded the Nobel Prize for chemistry, and I tend to agree. 



Keren Hampshire: don't be an ostrich

**T** don't have a terminal illness.

- I don't have the big 'C'.
- I don't need a transplant.

I just happen to have been born with a debilitating condition. It's a very long story but I will make it as short as possible.

At the age of 21, after a very pleasant sleep which involved a particular scope, a doctor told me I had a bowel condition—ulcerative colitis.

For three years after my diagnosis, I tried naturopathy. I tried mild medication. I tried changing my diet. I was given steroids to stop inflammation. I even ended up trying cytotoxic immunosuppressant drugs usually given to people with cancer. Nothing could keep my disease under control. So after three years of trying to convince it to heal, I was told it had to come out. And as the saying goes, If it's causing you pain, have it out. At least it's a saying I've heard before.

So I had all of my colon removed. I choose not to recall the operations very often, but since that day I have had eight different abdominal surgeries. Every time I am told that I need more surgery, I face the 'grave' again—my toe stretching out to just touch the dirt.

Obviously, as you are reading this article, it must mean I am still here. I'm pleased to report that all of my ten toes are attached to my feet, which are attached to my legs, which are attached to my abdomen, albeit quite an empty one. And the rest of me is pretty much as it should be.

I did find, after the removal of my large bowel, that my diet had to change. I was advised to eat

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#### By Keren Hampshire



bulking types of food and to steer clear of food that would increase my output. Bananas, peanut butter and marshmallows have become my best friends. What a combination!

Dehydration can become a big issue if I don't keep an eye on that, especially in winter. This may come as a surprise but you can still become dehydrated in winter. I have found that certain rehydrating drinks from my local chemist would help me to keep sufficiently hydrated. It's a daily effort to keep vigilant about my health but there is no choice if I want a good quality of life.

My story is not uncommon. However, if you have been given the diagnosis of ulcerative colitis, it does not mean you will have the same story as me. I've found that joining a support group and talking to others who have travelled a similar journey can benefit you in the long run. And my advice to all of you out there with either ulcerative colitis or Crohn's disease—please seek the best help that you can and don't be an ostrich by sticking your head in the sand. It is not worth it—and it can help keep your toes away from the edge.





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# The best is yet to come By Shantel Payne



To be honest, my first stoma was **L** probably the easiest. I had been sick for three years with ulcerative colitis and would always joke that the next step would be a bag. I guess I never really thought it would happen. But when a surgeon walked up to my hospital bed and said, 'We will be taking your bowel out,' leaving me in tears, my new reality began. When I used to say that I could end up with a bag, I didn't really understand what it meant because, as I said, I never really thought it would happen to me.

After my first surgery I had an epidural and couldn't feel my stomach for a few days. When the epidural was removed, I remember asking if everyone could leave me alone and give me some time just to get used to the bag touching the side of my leg, and feeling its weight as it filled up. I believe this was an

important time for me; it allowed me to accept my situation.

Once I'd recovered from surgery, I remember feeling amazing because I wasn't in pain and wasn't running to the toilet every few minutes: before, I used to go about 30 times a day. I was so happy within myself, but very shy and embarrassed about having it. Of course I told my friends, but I wasn't really open about it with new people. I was so worried that no guy would ever love me or accept me. This took its toll on me.

I was adamant that I didn't want another operation and told the doctors at every check-up. That was until about a year later, when I met a guy I thought I liked, and I thought liked me. I eventually told him and showed him because I thought it was safe to do so. This didn't turn out verv well for me. He didn't understand why I would want a bag hanging off

me when I had the option of getting it removed. I believe his exact words were, 'Having a scar is better than having a bag.' He wasn't interested in me after that, which made me feel more insecure and embarrassed—so much so that I changed my mind and made an appointment with a colorectal surgeon.

So a little over 18 months on from having my first stoma, it was reversed and I was given a J-pouch. This led to more difficulties than I ever thought would be possible.

First, I had fevers which doctors couldn't explain; the fevers would come and go.

Second, my bottom hadn't been used in over 18 months. The muscles would cramp up every time I went to the toilet, and the skin around that area was so sensitive that toilet paper was worse than sandpaper. I would cry every time I went to the toilet.

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Third, I never fully recovered and less than four months later ended up in hospital again— quite unwell, and leaking poo from my vagina. I knew that I might have to have some type of surgery, but not in a million years did I think I would have to get the bag back.

Then one afternoon a bunch of doctors came to my bed, pulled the curtain around me and said, 'You've got a tunnel from your J-pouch going to your vagina; we've made arrangements, you'll be transferred to Brisbane where you will get an ileostomy again.' This time it was just me, by myself, and I have never cried so much in my life!

My second stoma was by far the worst! Even though I knew what I was in for and that it wouldn't be so bad, and was looking forward to feeling good again, I still felt devastated. I remember thinking that I'd missed my chance to find someone to love me. I was too sick in those four months to go out and meet someone, and that scared me the most. Looking back now it feels silly, but at the time it was all I could think about.

'A scar is better than a bag.'

This time with the bag I wasn't as shy, and didn't feel embarrassed. I actually took a photo of it and decided to raise money for Crohn's and Colitis Australia, and plastered the photo all over Facebook and Instagram. The cat was out of the bag, everyone knew!

I was comfortable in my skin, so guess what happened? I met a guy who wasn't afraid of what I told or showed him. He actually loved me more because of what I had been through, and how I still managed to be so positive and happy about life. We ended up dating, and a few months later I was told the tunnel had been fixed and that I would be booked in to get it reversed again. It didn't seem to matter as much this time because I'd found someone who loved me for myself and had told

me that once the bag was removed. it wouldn't change the way he felt about me. This was one of the nicest things anyone has ever said to me.

So off I went down to Brisbane to have my loop ileostomy reversedmy fourth surgery.

I remember thinking 'Yay, I can't believe all of this is behind me and I can finally move on.' Life was great for the following nine months or so. I was healthy and happy, but soon realised that the only reason I was still dating the guy was because he loved me even though I'd had the bag. That reason alone wasn't a good enough reason to stay.

So off I went down to Brisbane to have my loop ileostomy reversed-my fourth surgery.

I remember thinking 'Yay, I can't believe all of this is behind me and I can finally move on.'

Not long after that I got sick again. I went to the toilet and lost a lot of blood, and knew immediately that something wasn't right. So back to hospital I went. When I was sitting in bed waiting for my flexi sigmoidoscopy, my doctor asked me if any poo was leaking from my vagina, and I said very proudly, 'Nope'. No more than five minutes later, just before it was my turn to go in, I went to the toilet and poo had started to leak from my vagina. I was devastated and started to cry hysterically. Once I'd been wheeled

into the procedure room I told the doctor what had just happened, while bawling my eyes out. I was so upset, that they quickly put me to sleep. The last thing I remember was crying and crying, but feeling more and more sleepy. I woke up and knew my fate—that I would be having my fifth surgery, and would be getting the bag back yet again.

I would still say my second stoma was the worst, because even though I'd become unwell quite suddenly, when the doctors came and pulled that curtain, I already knew what they were going to say. I cried, but knew that I had no choice: for whatever reason my strength was going to be tested yet again.

So now I have had five surgeries; three more than I would have had. had I not listened to a silly boy. With hopefully only one more surgery in the future, I can finally say I don't care about having a bag, nor about finding someone to love me. I honestly couldn't care less. If the next guy I meet can't deal with me having a bag, then too bad for him! And if he is supportive, but I fall out of love, I know that just because he'd loved me though I had a bag, I'll be strong enough to leave and not stay in an unhappy relationship.

This is a long story, so thank you for hanging in there. I wanted to share my story with people (or 'friends'-it sounds nice) who have a colostomy bag or anything similar which they are embarrassed about, and don't believe anyone could ever love them. I am here to tell you that you will find someone, and they will love you for who you are as a person, not what you look like. I know your friends and family have probably told you this over and over again, but they don't get it. They haven't experienced it, they have no idea what it feels like or how it makes you feel.

Me, I have some idea and it's true-you deserve only the best, and it's coming.

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# GOLD COAST SEMINAR **Transplant experiments could help ostomates**

ransplants using material from animal organs could be used in future to improve clinical outcomes for ostomates if biological and ethical questions could be resolved, the audience at the Gold Coast Ostomy Seminar in April was told.

The possibility was canvassed during a wide-ranging medical panel discussion at the seminar, held by Gold Coast Ostomy Association at Southport.

The seminar audience heard that experiments were being conducted into the feasibility of transplanting pig bladders. Pig valves had already been used in human heart surgery. However, immunological and physiological difficulties, as well as ethical questions, would have to be resolved before xenotransplantation—as the practice is known—is adopted.

In another experimental development, some experts were also conducting fecal transplants for people with recurring infections.

This procedure, known as fecal microbiota transplants (FMT). involves introducing fecal bacteria from a healthy person into a recipient. The process is designed to restore colonic microflora by introducing healthy bacterial flora through an infusion from a donor. It is carried out by enema, orogastric tube or by mouth in the form of a capsule containing freeze-dried material.

Panelists were asked if fecal transplants could be effective in the treatment of Crohn's disease and ulcerative colitis, and replied that these infections might be

helped by changing an individual's microbiology.

A limited number of studies have shown FMT to be an effective treatment for patients suffering from Clostridium difficile infection (CDI), whose effects can range from diarrhoea to pseudomembranous colitis.

FMT also has been used in experiments to treat such gastrointestinal diseases as colitis, constipation and irritable bowel syndrome, and even neurological conditions such as multiple sclerosis and Parkinson's disease.

The seminar panel was chaired by Professor Les Bokey, Clinical Dean and Professor of Surgery at the University of Western Sydney, and comprised Scott McClintock, the Director of Urology at The Gold Coast Hospital; colorectal surgeon Dr Isabella Mor; Dr John Edwards, director of the Irritable Bowel Disease Clinic at Gold Coast University Hospital; and stomal therapy nurse Sheryl Waye.

The seminar included an extensive discussion of preventing, managing or treating hernias.

The condition is more common in large people, the audience was told, and was also more likely in people who had been on steroids for a long time. People with colostomies had a 60 per cent greater chance of developing a hernia than ileostomates because colostomies tended to be in place for longer.

Exercise after surgery could help ostomates to avoid hernias. Pelvic floor exercises, walking and swimming were recommended,



Professor Les Bokey

but it was important to avoid abdominal exercises soon after surgery.

However, some hernias required surgery, which might involve repairing them with surgical mesh or relocating the stoma.

To avoid hernias, people needed to manage them by maintaining good health, wearing supportive clothing and supporting the area when coughing or sneezing.

In covering surgical questions, participants heard that outcomes were generally the same whether keyhole, laser or robotic surgery was employed. Some technologies gave better access than others to the organ concerned.

However, the key to successful surgery lay with having a good surgeon using the technology with which they are most comfortable.

Nerve damage from surgery is very common because the nerves in the pelvic area can be difficult to see. Radiation treatment and X-rays can also damage nerves, as could heat damage in cauterized areas.

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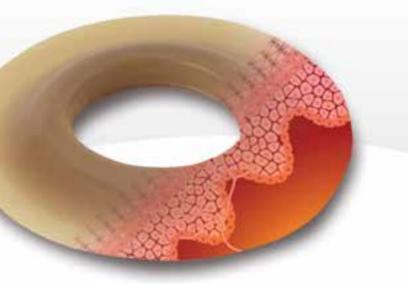
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89530	30 mm – can be stretched to 35 mm	10	30
89540	40 mm – can be stretched to 45 mm	10	30
	Adapt CeraRing – Oval Convex Rings		
89601	20x25 mm	10	30
89602	30x35 mm	10	30
89603	40x45 mm	10	30
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	Adapt CeraRing – Oval Convex Rings			
89601	20x25 mm	10	30	
89602	30x35 mm	10	30	
89603	40x45 mm	10	30	



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after surgery was around 30 per cent, due to adhesions being created during an operation. Recurring obstructions could be repaired by further surgery, but management was also important. To that end, ostomates who were at risk should adopt a low-fibre diet, take smaller bite sizes, chew their food thoroughly and eat slowly. In some instances, surgery could affect a patient's sexual function, though this aspect of life differed from person to person. Questions and concerns were best discussed with a stomal therapy nurse.

Panelists were asked for advice about skin care around stomas. Where the skin had been damaged or was sore and tender, people were advised to change appliances less often, and to try different products to find the appliance most suitable to their needs. Bleeding around a stoma could be caused by granulomas. In all instances it was best to talk to an STN about topical treatments and ointments.

#### •

# **Ostomates should reject stigma**

Ostomates should aim to be positive role models to help remove the stigma that too often attached to having a stoma, Ken Aukett, co-founder of the United Ostomy Associations of America, and UOAA director Millie Parker, told the Gold Coast Ostomy Association's seminar in April.

While ostomates saw their new condition as a victory over disease and a personal rebirth, some people still saw it in a negative light, Aukett said during a joint presentation.

Aukett argued that there were four types of stigma the 'public stigma' held by those in the wider community who saw stomas as 'socially unacceptable'; 'self-stigma', when ostomates themselves suffered low self-esteem

because of their situation; 'family stigma', the relatives' reaction when a spouse or parent had a stoma; and finally 'medical stigma', reflected in some members of the medical profession showing scant regard for an ostomate's needs.

The presenters identified a range of factors that contributed to these attitudes. Some of these were shaped

by public constraints, such as communal or public swimming pools prohibiting ostomates from using the facility, or restrictions on some sporting, adventure and leisure activities.

In popular culture, the image of ostomates was undermined by entertainers using the condition as an opportunity for comedy, and by occasional denigration by celebrities and other public figures. In some countries stomas were seen as culturally unacceptable, and regulations failed to support people with stomas. For example, there might be no legal obligation for schools to be advised when a student with a stoma needed special assistance.

The public at large, the presenters said, knew something about colostomies but was little aware that there were other types of stomas. Their view was restricted to the belief that people had to use 'that horrible bag'.

There were only limited opportunities to challenge the generally negative view of ostomies in the community. While personal knowledge of someone with a stoma tended to change attitudes, public and media organisations often declined opportunities for informed discussions when they were offered, they said. The problem was

> compounded by entertainers making jokes about the subject and public figures who rejected ostomy surgery as a medical option.

The UOAA was pursuing a number of strategies in the United States to improve understanding of ostomies and change attitudes to ostomates. They included activities built around National Ostomy Day and an annual

Ostomy Awareness Day campaign. Effort also went into World Ostomy Day, held every three years on the first Saturday in October. Positive social media campaigns and informative websites like the UOAA's own (http://www. ostomy.org/Home.html) could also play a part.

Ultimately, however, changing perceptions was a task to which every ostomate could contribute, they said. They could do this by taking a positive attitude in their day-today lives and refusing to accept widespread stereotypes.

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perceptions is a task to which every ostomate can contribute.

Changing







Sam Moss: When it's time, it's time.

On 11 November 2017 my colostomy, affectionately known as Rudolph, will be turning four, and as that date comes around so do a flood of memories.

My stoma story starts on 1 November 2011. It was the day that stopped the nation. It was Melbourne Cup Day. It was also the day that stopped me in my tracks...literally.

I was working full-time as an executive manager for a large bank, heading up the National Contact Centre. It was my dream role. One of my human resource strategies was to create a culture for my employees that was fun. Melbourne Cup Day was one of those events that we made the most of. Morning teas in every team, Fashion on the Field competition, and so on. It was a full day.

On the day I woke early, as usual, to get ready for work, well aware that this was an important day for my staff and that it was going to be a good but busy day. Mornings were getting harder and harder for me as I have rheumatoid arthritis, which causes incredible morning pain, making the very act of showering and dressing difficult. For some reason I felt particularly bad that morning. Thankfully my husband drove me to work every morning, so I was hopeful that the car trip into the city would give me time to start feeling a little better

At 10am, while sitting at my desk in my office, I suddenly felt the most intense abdominal pain I had ever experienced. I didn't know if I was going to be sick or if I had a stomach upset. I rushed to the ladies' room as fast as I could and went into a cubicle before anyone could see me ... or so l thought. I couldn't vomit, I couldn't go to the toilet, I just had so much pain and bloating. Even standing straight was difficult. I opened the toilet door to return to my office, hoping that maybe sitting quietly and sipping water might make it all go away—and I was greeted by my support leader. She had seen me leave my office and knew something wasn't right. She took one look at me and immediately said, 'I'm ringing your husband, and you're going home'.

My husband arrived with a very worried look on his face. I gathered up my things, still thinking about work and what needed to be done for the rest of the week. I was still talking business with my support leader all the way to the car. I loved my job; I was passionate about the people, the customers and the company I worked for.

I had no idea as I left the building that day that I would never return to my office. While 1 November 2011 was not my last day working, it was actually my last day in that building. Any work from then on, until I medically retired in 2014, would be done from home. My life was changing faster than I realised.

My GP saw me that afternoon and after an examination he felt that I needed a CT scan straight away. The scan revealed that my bowel was completely blocked. Possible appendicitis was mentioned.

I had an urgent appointment with a colorectal surgeon a few days later and then the real fun began. He took one look at the CT scan and said straight up that my bowel was non-functioning. After listening to my history of a previous hysterectomy and my confession to having had painful bowel movements for guite some time (although clearly I had been in denial about that until then) he told me I needed to have a test called a defecography. I remember thinking that it couldn't be that bad. I really wanted to find out what was going on so I enthusiastically booked the test appointment.

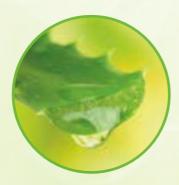
If you have to have one of these tests, you really need to leave any inhibitions at home. It's full on! I arrived one hour before the test, as requested, and was asked to drink a cup of thick white glug. I was allowed a hot cup of tea at the same time and the staff at the radiology department were just beautiful. I felt so well cared for and they worked hard

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through the whole process to protect my dignity. The gluggy drink is what allows the X-ray to see the functionality of the bowel. After an hour a barium paste is injected into the rectum. This is actually the most uncomfortable part of the whole procedure. I was then quickly moved to a portable toilet which was attached to the x-ray machine and I had to try to pass the paste. I thought I was doing really well so I began to relax and think that maybe I just had a bad case of constipation, and that a whole heap of laxatives would be the answer.

After the test my husband and I went straight up to the colorectal surgeon's office to discuss the test findings. His first comment was, 'You're stuffed'. Yes, he did mean literally, as my entire colon was stuffed with ... well, you know what.

I had the following issues:

1. A severely abnormal anorectal angle (congenital condition apparently ... who knew!)

2. A rectocele—this is where the anterior rectal wall bulges forward into the vagina. Mine was incredibly large and one of the reasons why my bowel wasn't emptying.

3. Rectal prolapse with internal intussusception-basically my rectum was telescoping into itself when I was trying to have a bowel movement, making it impossible to accomplish.

Put all these three together and he was right. I was stuffed.

So I started a long surgical path that began on 19 December 2011. The first procedure was a laparoscopic rectopexy which restores the rectum to its normal position in the pelvis so that it no longer prolapses. This procedure also fixed the rectocele. I was home for Christmas, hopeful that 2012 was going to be the start of some real improvement on the health front and that I would be able to return to work in the New Year.

That hope started to diminish due to surgical complications and by mid June 2012 I again had a non-functional

bowel—so much so that my husband would need to hold my hands so I could squeeze them to cope with the intensity of the pain when trying to have a bowel movement. It was horrific. I could feel that hope of returning to a normal life running away at high speed.

We returned quickly to my colorectal surgeon. He was seeing me fairly regularly as healing from the rectopexy surgery had been complicated by infections and a pelvic haematoma. Unfortunately the only way to find out what was happening was to have another defecography.

'I needed to know that I had tried every single avenue. If that failed I would know I had no choice, and I knew that would help me accept the outcome'

The test results showed my rectum had prolapsed again internally, my rectocele had returned and my anorectal angle was even more severely abnormal than before. Surgery had failed. We were devastated. My first question was, 'So what do we do now?'

It was at this consultation that the word 'stoma' was first raised. My surgeon said this was an option I needed to seriously consider. He also said that we could try repeating the rectopexy, this time with a perineum approach and internal mesh to have a better chance of holding everything in place.

I felt sick. I wasn't ready for a colostomy. Normally I would research the life out of something but I couldn't even bring myself to do that at this

stage. I had the option of a repeat rectopexy and I needed to know that I had tried every single avenue. If that failed I would know I had no choice, and I knew that would help me accept the outcome.

September 2012, I had my repeat rectopexy. Once I recovered, early in the New Year, I did begin to enjoy a healthier bowel again, but it was short-lived. I had by this stage stopped working. It was a hard decision but I knew it was necessary. My body was failing me on so many levels and my doctors were encouraging me to medically retire.

In mid-2013 I went again to see my colorectal surgeon, fearing my latest surgery had failed. It had! This time he spoke to me in more detail about the likelihood of needing a permanent colostomy.

I was now starting to have bowel incontinence because my body was trying to eliminate waste by watering it down and moving past the constipation. It was time!

I was ready. I was so ready. I was over all the pain and discomfort, the surgeries, the tests, the disappointments. I needed this and I was actually looking forward to it.

On 11 November 2013, my perfect little stoma was formed.

Sam's full story can be followed on her blog <u>My Medical Musings</u>



The regular feature by Carmen, our stomal therapy nurse, will reappear in the December issue of Östomy Australia.

Kylie McGrory's column with news about ACSA and the Stoma Appliance Scheme will return in the same issue.

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## As an ostomate, are you losing confidence?

Margaret Allan is a nutritionist who advises both ostomates and the general public on diet and health-related matters. She is the director of the consultancy Nutrition for Ostomates.



∧ common theme I am  $\boldsymbol{\Pi}$  noticing with many of my ostomate clients at the moment is a lack of confidence. Not a lack of confidence in themselves as such, but a lack of confidence in pursuing normal dayto-day activities, such as shopping, socialising and

even going to work. And this lack of confidence is stemming from issues with stomal output such as leakages, accidents and unpredictable events which can all cause ongoing embarrassment and fear.

Having a stoma is a new way of living, and learning to cope with it can be more challenging for some, due to a variety of reasons. But eventually, all going well and with support from family, friends and the medical community, everything settles down and returns to a semblance of normality over time. Life goes on.

However, if this doesn't occur, or if problems arise down the track which result in leakages and/or accidents, it can lead to restriction of daily activities and reduction in enjoyment of life.

This is not an ideal way to live long-term if a solution is possible. Being able to move freely about in the local or wider environment is important socially as well as mentally. It is also necessary in order to fulfil many of the day-to-day activities that are a mandatory part of life, such as grocery shopping, routine errands, doctor's visits and so on. To address this issue

there are several factors that should be examined in the search for a solution.

#### Is it the appliance?

One of the first options to consider when leakages or accidents are restricting daily activities is to consult a stomal therapy nurse to see if the leaks or accidents are related to the appliance.

This is relevant for all ostomates-that is,

for urostomates as well as colostomates and ileostomates. For a range of reasons the appliance may not be fitting correctly or adhering sufficiently so there is not a good seal around the stoma. There may be an alternative appliance that suits your current situation more appropriately.

#### Is it food related?

If leaks or accidents are related to gastrointestinal output rather than bladder fluids, then a second option in these circumstances, for colostomates and ileostomates in particular, is to evaluate dietary intake to determine if there is a particular food or foods that are causing the issue.

Fat, fibre and lactose are common problems for some people that result in diarrhoea, and the rapid and excessive output that ensues can put pressure on the appliance that results in leakage. This situation is compounded if the appliance is not fitting correctly in the first place. Examining dietary intake over a period of time and correlating it with the timing and frequency of accidents can shed light on whether any of these foods are the problem.

Unfortunately, however, the solution may not be as simple as this.

The fact is that it may not be one food in isolation that is the cause of the accidents, but possibly a

combination of foods together that are the culprits. More extensive dietary evaluation is required in this case to determine what particular food combinations could be causing the issue, and professional assistance is recommended.

This is the level that I have been working on with particular clients in an effort to provide some clarity and resolution. These clients are monitoring their dietary habits and stomal output over a period of time and providing feedback so that I can then search for links between

the two and identify the culprits or issues. There is a lot of variation in people's food tolerances and limits, especially after stomal surgery, and so the findings are often very individual.

#### Is stress a factor?

A third option to consider when leakages or accidents are becoming a problem and interfering with quality of life is factors outside of the appliance and food intake. The gastrointestinal tract is a

sensitive organ that is easily prone to being upset by variables such as stress, lack of sleep and fatigue.

Each of these factors can affect the delicate balance and harmony within the digestive system, resulting in abnormal bowel function. This may manifest as diarrhoea, accidents, unpredictable bowel habits, loss of tolerance to certain foods and/ or excessive flatulence.

An increased level of stress in particular is a common theme for many ostomates, often without the individual being aware of it. A question I always ask my clients when we are exploring this issue of recent onset of leaks or accidents is-what has been going on for them lately? Have there been any events in their life that have triggered an increased amount of stress that may be upsetting the normal rhythm of their life and therefore their gastrointestinal function?

As mentioned earlier, adapting to becoming an ostomate can be more stressful for some people than others, and so a degree of stress may stem from this factor alone. However, for others it could be completely unrelated. Spending some time identifying if there are any current stressors in your life can be valuable.

If it turns out that stress is a factor in the situation, then there are dietary and supplemental strategies that can provide support to both mind and body. Additionally, applying lifestyle measures that also calm the mind and reduce the impact of stress on the body is important. Gentle exercise, deep breathing, relaxation techniques, enjoyable activities and good quality sleep can help to alleviate some of the problems and restore efficient and effective digestive function.

Leaks and accidents can be caused by many factors, of which dietary intake is certainly a major one. There may be a simple and obvious culprit that can be easily identified and restricted in the diet, or more extensive evaluation may be required. Either way it should be considered and explored, ideally with professional support and guidance. Stress may also be playing a role, and this should be addressed and alleviated as well.

You should seek professional help if, like some of my clients, you feel you are losing confidence due to unpredictable stomal output and would like assistance to address this concern, either from a food perspective or in relation to the impact of stress, lack of sleep or fatigue. You can contact me regarding consultation options at www. nutritionforostomates.com.au/contact.

Wishing you good health and happy days,

Margaret •



Stress, lack of sleep and fatigue can easily upset the gastrointestinal tract.

## Your chance to take a look inside ...

Stomates around Australia will have an opportunity to learn about some of the inner workings of the human body when Bowel Cancer Australia's Big Bowel arrives in their area.

The Big Bowel—a seven-metre long, 2.4 metre high inflatable educational exhibition piece-is a larger-than-life resource designed to extend Bowel Cancer Australia's work in education, prevention, diagnosis, research and treatment of bowel cancer.

The Big Bowel made its first successful 10-day tour through southern NSW, Canberra and northern Victoria in June. Other tours are planned that will take the great colon all around Australia over the next few years. In Canberra, the inflatable was set up on the lawns at Parliament House-a place well known for its hot air. In future the Big Bowel will appear at community centres, shopping malls, health expos, outdoor events-anywhere that has the space to accommodate the exhibit.

Bowel Cancer Australia plans to target locations that are notable hot-spots for bowel cancer, aiming to encourage people to be aware of their bowel health, watch for warning signs of bowel cancer, and to see a general practitioner if they have concerns.

But the Big Bowel isn't just about cancer. As visitors walk through the gigantic colon, they will see many of the pathologies that can develop. The three-dimensional exhibit features representations of healthy bowel tissue, pre-cancerous polyps, advanced polyps, mild and severe colitis, and Crohns disease, as well as malignant, cancerous tumours.

Bowel cancer is the second most common cancer in both men and women in Australia.

In 2013, 14,962 new cases of bowel cancer were diagnosed nationwide. The risk of developing the disease increases with age, and becomes more common from age 50. One man in 10 and one woman in 15 will be diagnosed with the disease by the time they reach age 85.

In 2014, bowel cancer caused more than 4071 deaths in Australia, making it the second-highest cause of cancer deaths after lung cancer. Yet more than 90 per cent of cases can be successfully treated when detected at the earliest stages.

Awareness is important, so keep an eye out for the Big Bowel near you. Step inside—your visit will be another step in helping to beat bowel cancer.

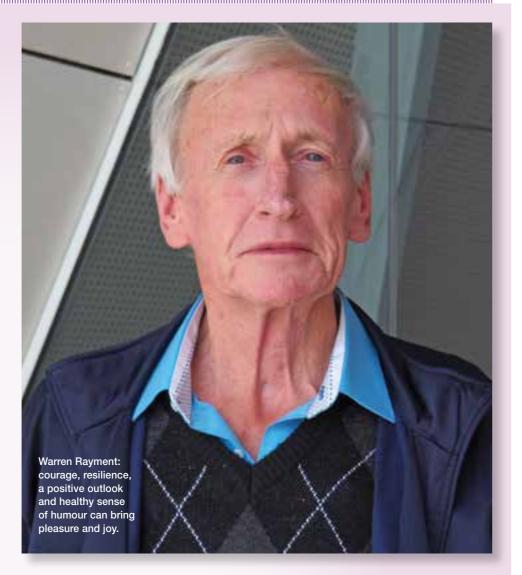
# The pain and the pleasure (Part 2)

In our April issue, in the first article in a two-part series, **Warren Rayment** looked back on his 50 years as an ostomate. The article closed with Warren at the end of a long period of ill health. Then, as he tells readers in the concluding part of his recollections, things began to change.

To say the next two years was a L life-changing adjustment is a gross understatement. Problems with appliances persisted, as did my reclusive state. I became withdrawn, depressed and had a fear of dealing with the complexities that confront normal 20-year-olds. Pleasingly, and with help from various sources, I was achieving some success with the Downs Bros appliance from England. Remember, this was well before today's marvellous Stoma Appliance Scheme was introduced. Appliances, creams and accessories had to be purchased. This really tested my parents: Dad was a very capable carpenter, but with a limited income.

Unlike most other 20-year-olds, my social life was non-existent. Occasionally I summoned the courage to catch a bus to a nearby suburb and take in a Saturday night movie. Even this bold move was fraught with fear of the appliance coming adrift. It was always with a relieved sigh that I returned safely to the sanctuary of my parent's home.

But at 20, I had to find some form of employment. Although I had not sat the final-year exams, a benevolent school principal had given me a pass based on my performance. This was some comfort, but in the early 1960s nearly all government departments and large companies in Sydney had their own medical practitioner to assess the fitness (or otherwise) of potential employees. Believe it or not, virtually every doctor I encountered



had no knowledge of stomas. Consequently, they settled for the safe option of declaring me unfit for employment. This additional frustration was demoralising and heart-breaking.

After months of rejection, fate intervened in the form of a caring uncle who knew a fellow Rotarian with links in Goodyear Tyre Service, a company then setting up stores across Sydney. A sympathetic hearing saw me employed as a clerk in their Hurstville store. My first job was a 20-minute bus ride and a short walk from home to the store—a pleasing start to my professional life.

I spent six years at Goodyear, progressing from office clerk to office manager at one of the newer stores, then some time as deputy accounting office manager in their Sydney office. I proudly purchased my first car. At long last appliances were sticking, promoting greater confidence in my daily life and morale. It seemed that my faith was finally being vindicated.

My confidence was boosted by a dozen or so Sydney ostomates who had formed a group called the Ileostomy Association of NSW. I joined their Saturday afternoon meetings and by pooling our finances we were able to purchase imported appliances at reduced cost. We stored them in a member's garage and produced them for collection on Saturdays.

It was increasingly evident that my story had moved into pleasure mode, but my social life was still stagnant, and embarrassingly I was still a virgin at the age of 26—a sad admission for a young man in the mid-'60s, a decade of free love, pot and flowers in the hair. My illness, surgical ordeals and the associated misery had severely dented my confidence with girls. This was strange, given that Wollongong High School was co-ed and that I used to mix confidently with female students. Although a couple of attractive girls had appeared at the tyre store over the years, my negative mindset was such that I made no advances. One attractive lass caught the same bus to work each morning, but I was always too shy to make an approach.

The gods continued to smile, however, as I visited my Dad's church and met a friendly group of young people who invited me to their Friday night social tennis evenings. I overcame my fear of the appliances failing and resumed physical activity. I looked forward to these evenings and through them a romance with one girl blossomed. We married when I was 27. Around that time I joined the Shell Oil Company as a marketing administration officer. This led to a very happy and productive career over 26 years. It was a marvellous company and work was a joy.

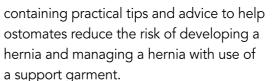
Marriage followed a normal course, we purchased land to build a new home and adopted a son in 1973. Around the same time a mate got me into playing baseball in the St George district, a sporting activity that lasted some 12 years. I had a strong throwing arm from my cricket days and this made playing both active and satisfying. The change rooms did cause occasional embarrassment, with good-natured comments like "Who's that old bag you're hanging around with now, Wazz?" often in the air. Mostly the guys were understanding. At the same time I was playing evening squash once a week with a work friend.

After 16 years or so with a stoma, I dared to think that life was rosy and the upward swing was permanent.

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I was managing the appliances easily, the stoma was functioning well and my social and working life were progressing nicely. That illusion vanished when I suddenly suffered a massive bowel obstruction. When it cleared it left a legacy of excruciating abdominal pain and discomfort that plagued me for almost two years. The gastroenterologist followed up with a barium meal-being the mid-'70s, there were no CTs, MRIs or ultrasound and diagnostic imaging tools available. 'It's all in your mind Warren. There's nothing adverse showing up. Just take Di-Gesics for the pain.'

Eventually, after two years of agony, I told the surgeon: 'Something is wrong. I need you to fix it.' So in I went for another bout of surgery at Royal Prince Alfred. This time modern anaesthesia was used, and the kinked bowel was remedied—

Continued page 38





but post-operative recovery did not go well. I developed septicaemia and was bouncing off the bed with rigours and fevers. I was lucky to survive but to my dismay the pain intensified. Again I was confronted with more medical patronising: 'It's all in your mind, Warren. Just take painkillers and get over it.'

In desperation I consulted another surgeon. This time the X-rays revealed gall stones, and the decision was made to remove my gall bladder. The six-hour surgery to remove the gall bladder, divide numerous small bowel adhesions and remove a stone stuck in the bile duct was done at the newly-opened Westmead Hospital. The surgery went well but, as we know, adhesions can create more adhesions and these have plagued me ever since. It has been so distressing at times that I have since had numerous other surgical interventions to divide the adhesions, but none has produced any lasting relief.

Sadly, my wife and I divorced in 1990. This led to a move to the Gold Coast for a fresh start with a lovely partner and a new happy existence. But even then the pain cycle persisted. It was so debilitating that as a last resort I sought the thoughts of the Gold Coast Ostomy Association's medical patron. He decreed that further surgery would be high risk, with no guarantee of alleviating the pain. So on with life I went, trying to accept and manage constant pain as part of my life.

In January 2015, though mindful of the risks, I agreed to another operation in my desperate quest for relief. As with earlier interventions, this surgery did not go well. A large part of the small bowel was so scarred that the surgeon could not salvage it and as a consequence I have been left with short bowel syndrome, chronic pain and an abdominal fistula that will not heal. Life in this state is confronting and I now rely

on a strong pain medication regime. Reluctantly, I have to accept that my condition is unlikely to change.

So we've arrived at the present, and the point in my story where some analysis is appropriate.

I've described my near-death encounters but I want readers to remember that a number of them occurred in past decades (in the last century, in fact) when surgical and medical knowledge, nursing care and the nature and quality of

In the final balance of my life's story, I think it fair to say that the achievements, successes and accomplishments probably hold the advantage.

ostomy appliances were far from the sophisticated and effective systems ostomates enjoy today. In those bygone years there were no guarantees of survival. I am indeed fortunate to be alive and able to relate my tale.

But no life is all bad. Many pleasurable achievements, successes and satisfying times have intersected and illuminated the dark times.

In the final balance of my life's story, I think it fair to say that the achievements, successes and accomplishments probably hold the advantage. They are my 'great comebacks' that emanated from often dark and frightening episodes.

Of all the events that fall into the 'great comebacks' category, I think the greatest were a successful 25-year career in the oil industry as an administration and marketing officer and as social director in the later years; a return to active sport-squash, baseball and tennis-and a college diploma in business management.

I also achieved public speaking diplomas in the '80s. I worked as a committee member, then president of the Ileostomy Association of NSW from the 1970s through to late '90s. I have also acted proudly as president of ACSA, president of the South Pacific Ostomy Association, vice-president of the International Ostomy Association in the '90s, and more recently as president of a very vibrant Gold Coast Ostomy Association.

Although no longer active in this domain, I have also been busy over the past 15 years in the simulated patient programs at Southern Queensland, Bond, Griffith and Queensland universities and acted in many training videos for their medical and physiotherapy faculties.

I believe all of these successes and achievements are glowing testimony to the 'great comebacks' that are possible for anyone with a stoma, despite the many challenges it presents. I have learned that courage, perseverance, resilience, endeavour, spirit, a positive outlook and a healthy sense of humour, underpinned by the love and support of strong social, medical and family networks, can bring a life of great pleasure and joy.

It is indeed worth daring, and worth striving, to be more than your illness, to move beyond the fears, frustrations, pains and often roller-coaster fluctuations in your health to claim life's many pleasures and rewards. My story is indeed one of darkness and challenges, illuminating 'great comebacks' and achievements-and in the end, of deep gratitude that I have made it through.

#### **NEW SOUTH WALES**

#### ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec. Venue: Hilltop Accommodation Centre. 600 Keene Street, East Albury NSW Contact: Alex Watson 0428 578 385

#### BATHURST

Meet on the first Tuesday of March. June, September & December at **Daffodil Cottage** Contact: Louise Linke (02) 6330 5676

#### **BROKEN HILL**

Meet: Every 3rd month or as required. Venue: Broken Hill Hospital Conference Room Contact: Tarndra (08) 8080 1333

#### **CENTRAL COAST**

Meet: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting. For further information, phone the Stomal Therapy Service on (02) 4320 3323

#### **COFFS HARBOUR**

Meets 2:00pm to 3:30pm 2016 meeting dates to be advised. Venue: Sawtell RSL Club, First Avenue, Sawtell. Ostomates & friends welcome. Contact Mandy Hawkins STN on (02) 6656 7804

#### EUROBODALLA REGION

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

#### FAR NORTH COAST

Meet at Lismore Workers Club 225 - 231 Keen St. Lismore. 11.30am - 2.00pm 1st Saturday March, July, December. Contact: Marie: (02) 6686 7248

#### FAR SOUTH COAST

**Bega & Surrounding Areas** Meets second Sunday of Feb - Apr -Jun - Aug - Oct - Dec at 11.00am at a different venue each time. Flvers are sent to Ostomates 10 days beforehand Inquiries: Eileen. Phone: (02) 6492 2530 Geraldine. Phone: (02) 6492 2366

#### **GRAFTON & DISTRICT** Meets first Thursday of each month from 9.00 am to 11.30 am

Contact: Anne: (02) 6641 8200 **GRIFFITH & DISTRICT** Griffith and the surrounding areas

(100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally) Enquiries: Barry (02) 69635267 or 0429 635 267 Email: ann.bar@bigpond.com Karan: 0434 785 309

HASTINGS MACLEAY Meet: The Old Hospital at 10am to 12 noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec. Inquiries: Neil 0427 856 630 or Glennie (02) 6583 7060

#### **ILLAWARRA**

Meets: 10.00 am to 12 noon. 2017: 26 April. 14 June. 30 October. 13 December (Christmas party) Jun - 17 Aug - 19 Oct -14 Dec. Venue: Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525.

For further information contact Helen **Richards CNC STN (Wollongong** Private Hospital) (02) 4286 1109 or Julia Kittscha CNC STN (Wollongong Hospital) 0414 421 021

#### MANNING/GREAT LAKES

Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug -Oct - Dec. Venue: Skills for Life Building. 5-9 Elizabeth Ave. Taree NSW (wheelchair accessible) Website: www.mglostomy.co.cc Contact: Karla MacTaggart on (02) 6592 9469

#### **NEWCASTLE DISTRICT**

Meet at 1.30pm on the last Saturday in Feb - May - Aug (AGM) - Nov. Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton. Enquiries: Geoff (02) 4981 1799 or Diane 0409 156 325 or Maree (02) 4971 4351

#### **ORANGE & DISTRICT**

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

#### SHOALHAVEN

Meet: 2.00pm. 2016 meeting dates to be advised. Venue: Nowra Community Health Centre, 5-7 Lawrence Ave, Nowra. Contact: Margaret or Tracey on (02) 4424 6300

#### SYDNEY - LIVERPOOL / **CAMPBELLTOWN AREA**

Meets: Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden) 2016 meeting dates to be advised.

For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

#### SYDNEY - PENRITH AREA

Nepean Educational Support Group will meet from 2.00-3.30pm on 28 April, 23 June, 25 August and 3 November 2017. Venue: Sydney Medical School. Clinical School Building, 62 Derby St., Kingswood. Family and friends welcome, afternoon tea supplied. Enquiries: Naomi Houston (stomal therapist) (02) 4734 1245 SYDNEY - NORTHERN AREA

Meet: First Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital,

## National Directory of Ostomy Support Groups

185 Fox Valley Rd. Wahroonga. Contact: San Cancer Support Centre (02) 9487 9061

#### TWEED

Meets: third Tuesday of March, June, September and December from 12 to 2pm.

Venue: South Tweed Sports Club. Contact: Jane Bright on 0409 671 162

#### **WAGGA & DISTRICT**

Meets: first Wednesday of each month from 10:00am to 11:00am. Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga Enquiries: David (02) 6971 3346 or 0428 116 084 Baz (02) 6922 4132

VICTORIA

#### **BAIRNSDALE & DISTRICT**

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

#### **BALLARAT & DISTRICT OSTOMY SUPPORT GROUP**

Meets: 2pm 2nd Wednesday of each month Venue: Barkly Restaurant, cnr Barkly St and Main Road. Contact: Graeme on 0400 979 742 or David Nestor on (03) 5339 4054

Emails: david.nestor2@bigpond.com or graob44@gmail.com

#### **BENALLA / WANGARATTA**

Meets 2.00 pm on the third Monday of each second month. Venues: Wangaratta Masonic Centre. 99 Appin St. Wangaratta in Apr - Aug Dec and Benalla Masonic Centre, Cnr Benalla St. & Walker St, Benalla in Feb - Jun - Oct. **Contact: Rex Nankervis** (03) 5762 2080

Email: rexmarn@bigpond.com

#### MILDURA

Meet: Every third month Venue: Mildura Base Hospital Conference Room Contact: Tarndra (03) 5022 3333 or Norma 0409 252 545

#### SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on (03) 5655 2628 for more information.

#### SUNRAYSIA / RIVERLAND

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

#### WARRNAMBOOL & DISTRICT

Meets at 10.30 am on the second Friday of the month in Feb - Apr - Jun Aug - Oct - Dec.

Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool

Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093

Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

#### **WESTERN AUSTRALIA**

#### ALBANY

Meets at Albany Hospice conference room, 9.30 am to 11 am on the first Friday every three months. For details, contact Terry (08) 9847 4701 or 0428 502 530

#### GERALDTON

Meets: 2.30 pm last Saturday every second month. Venue: Bluff Point CWA Rooms Contact: Dawn Hall: (08) 9921 8533

#### PERTH (WAOA)

Venue: 19 Guildford Road, Mt Lawley Weekends: third Saturday of every month 11-1pm. General: fourth Tuesday of every month 2 - 4pm New Members: second Tuesday of every month 2 - 4pm.

#### QUEENSLAND

#### BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre, 10 -18 Mt. Warren Bvd. Mount Warren Park OI D Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107

#### BRISBANE

**Brisbane Ostomate Support Visitors** Service (BOSVS) is a new ostomate visitor service operating in the Greater Brisbane Area. Phone: (07) 3359 6500. Website: gldstoma.asn.au/bosvs.htm Operating Hours: 7 days, 8am to 8pm. Operated by Qld Stoma Assn and Qld

Ostomy Assn.

#### LOGAN

Meets 10am - 12noon on third Monday of each month at Logan **Central Community Health Centre** Corner Wembly & Ewing Roads Contact: Logan Hospital Stomatherapy Unit, (07) 3299 9107

#### MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan -Mar - May - Jul - Sep - Nov). Venue: Meeting Room, Mackay Mater Hospital Contact: Graham Stabler for further information on 0428 776 258 or email.

grahamstabler@bigpond.com

#### REDCLIFFE

Meets first Tuesday each month at 10.00 am in the Shillam Room, Redcliffe Cultural Centre - off car park Irene Street, Redcliffe, **Enquiries: Dorothy Douglas** (07) 5495 1335

#### ROCKHAMPTON

Meet: 1.30pm third Saturday, Feb - May - Aug - Nov. Venue: Community Health Centre, Bolsover St. Rockhampton Contact: Frank & Marge Nov Phone: (07) 4921 0728

#### SOUTH BURNETT

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

#### SUNSHINE COAST

Meets at the Small Meeting Room, Library Support Building, Cotton Tree, Maroochydore on the second Monday of every month from February 2016, commencing at 10am. Enquiries:

Winifred Preston (07) 5476 6313 or presto1849@hotmail.com Evon Fuller (07) 5447 7158 or eful@bigpond.com Laurie Grimwade (07) 54459008 or sid.and.laurie@gmail.com

#### TOOWOOMBA

Insideout Toowoomba Stoma Support Group Meets: 2.15pm on the second Wednesday of each month (except December and January) Venue: Dr Price meeting room, Little Street, Toowoomba. **Contact: Margaret Brabrook** (07) 4635 1697 or Pam Brogan 0408 848 590

#### WIDE BAY

Meets from 1.00pm to 3.00pm on the third Thursday each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West. For information please contact Heather James: 0406 472 486 or leave a message on (07) 4152 4715

#### **TASMANIA**

"SEMI COLONS" - a support group for men and women affected by colorectal cancer with or without ostomies. Meets in Hobart on the third Thursday of every month, from 2pm to 4pm. Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania, on (03) 6169 1915

#### **NORTH & NORTH-WEST**

North: Meets 10.00am on the second Wednesday of June, September and December at the Cancer Support Centre, 69 Howick Street, Launceston, North-West: Meets 10am on the second Wednesday of March, June, September and December at Ulverstone Senior Citizens Club, 16 Edwards Street. Contact: Adrian Kok (03) 6326 4664

#### **SOUTHERN TASMANIA**

A new group for southern Tasmania began on 8 March 2017 at Glenorchy RSL, 320 Main Road, Glenorchy. Meetings will be held on the first Wednesday of June, September and

December, from 10am till noon. Further information: Adrian Kok (03) 6326 4664

#### SOUTH AUSTRALIA

#### CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov. When: 2pm. Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End. Information: Val: (08) 8381 1646

#### FLEURIEU

2016 meeting dates to be advised. Meet: 10.00 am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor. Please contact Sue McKay STN for further information on 0412 692 418

#### SOUTHERN

Meet: First Wednesday of Feb, April, June, Aug, Oct, Dec. When: 2pm. Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs. Information: Val: (08) 8381 1646

#### **NORTHERN TERRITORY**

#### DARWIN

Meet: 5.00-6.00pm on the first Tuesday of every month. Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810 Contact: Marg Lavery: (08) 8944 1800

#### YOUTH GROUP

Doris Steyer, Telephone: (02) 4296 5354

#### YOUNG OSTOMATES UNITED (YOU)

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

#### **BOWEL GROUP FOR KIDS** INC

Tel: (02) 4659 6067 or 0431 857 188 Email: enquiries@bgk.org.au Web: www.bgk.org.au

#### PARENTERAL NUTRITION **DOWN UNDER**

Secretary on (02) 9987 1978 Email: contactpndu@gmail.com Web:

www.parenteral-nutrition-downunder webs com

#### **MITROFANOFF SUPPORT AUSTRALIA**

PO Box 256, South Melbourne, Victoria 3205 Email: info@mitrofanoffaustralia.org.au Web:

www.MitrofanoffAustralia.org.au

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PO Box 5013, Burnley, Victoria 3132 Freecall: 1800 819 274 Email: info@omnigon.com.au Website: www.omnigon.com.au

#### **3M Australia**

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

#### Statina Healthcare Australia

3/30 Leighton Place, Hornsby, NSW 2077 Toll Free Number: 1300 365 404 Email: sales@statina.com.au Website: www.statina.com.au

