

# Ostomy

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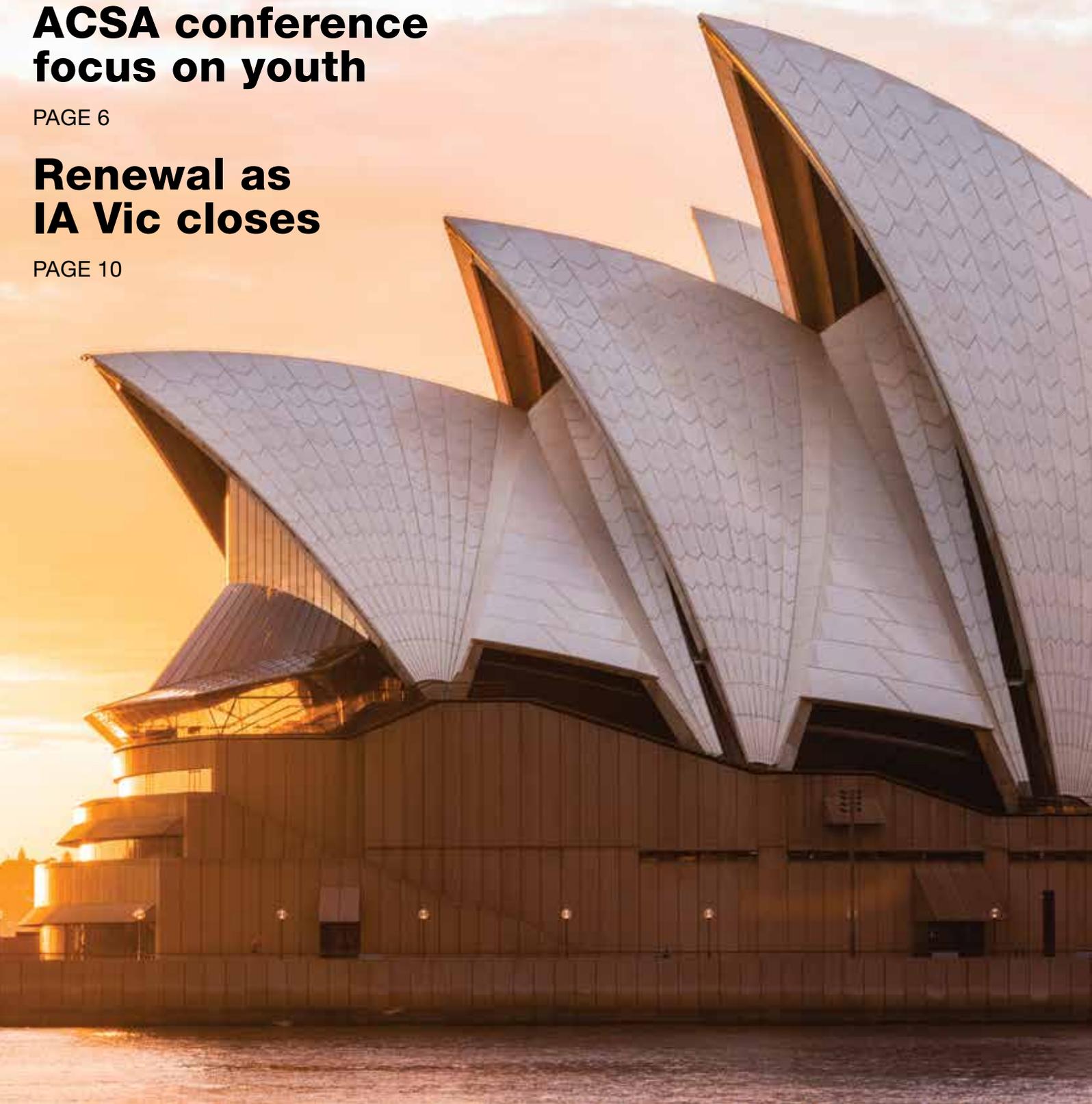
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Readers are strongly advised to obtain appropriate professional advice before using any products advertised.

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If readers do not wish to be contacted further, they are advised to tell the company this. Most companies have said they will comply with such requests. This advice should be taken into account when responding to company promotions.

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## PRESIDENT'S MESSAGE



This will be my final message as President, as I will be stepping down at the October 2018 Conference. This message gives me the opportunity to reflect on the advances that ACSA has achieved over the past four years. They have been accomplished by a dedicated and committed Executive, a dynamic and enthusiastic Administrative Officer and with the support of all associations.

Our primary role, as the ACSA Executive, is to ensure that the Stoma Appliance Scheme (SAS) is managed effectively. One of our key objectives over the past four years has been to ensure that the SAS continues to deliver a range of appliances and accessories to ostomates. Our other major objective has been to ensure that the distribution of appliances under the scheme remains in ostomate control.

Several years ago the Department of Health issued a tender for a small range of products that are available under the scheme. Fortunately, behind-the-scenes lobbying by ACSA and other interested parties saw the tender withdrawn.

I have been the ACSA representative on the Stoma Appliance Assessment Panel (SPAP), the body that assesses and recommends which products are placed on the scheme. In the years that I have been involved, I have seen the panel evolve into a highly professional and effective body that makes considered and clinically supported decisions on the products to be made available. The effectiveness of SPAP's activities certainly helped in the Department's decision not to proceed with the tender. With the Executive's agreement, I will continue in this role, as it is predominantly Canberra-based and I have established a solid working relationship with the SPAP chair and members.

The Council of associations agreed in 2014 to establish a single computer system to manage distribution of SAS products. In April 2015 ACSA purchased the system initially developed for Ostomy NSW and has developed the system over the past three years. The development and implementation of the Stoma Appliance Management System (SAMS) has taken longer than anticipated but by the time this article is published we will have four associations using SAMS and a tested migration and implementation process which will facilitate the speedy migration of the remaining 17 associations. I would like to express my thanks to Hermione Agee from Ostomy Association

of Melbourne and Ian Draper from Ileostomy Association of South Australia for their continued dedicated support to implementing SAMS. Although I am stepping down as ACSA President, I will continue in the role of SAMS program director until we have the system installed successfully in all associations.

One key issue driving the implementation of SAMS is to ensure that all associations have a professionally maintained IT environment that supports distribution of products under the SAS. This system helps to ensure that the Department of Health and Department of Human Services continue to have confidence that the stoma associations that comprise ACSA have the capability and capacity to continue to manage the scheme.

The SAS costs government more than \$90 million each year and continues to grow—a significant government expenditure. In 2017 the SAS Operational Guidelines were amended to allocate to ACSA responsibility for reviewing associations' adherence to the guidelines. This can be considered a positive endorsement of the role of ACSA in managing the scheme. ACSA has subsequently used an automated process to review claims lodged under the scheme by three associations, and continues to follow up any anomalies identified during the review.

It is essential that all associations operate stringently within the guidelines if we are to maintain responsibility for managing the scheme. The SPAP carefully considers the maximum quantities that apply to each group of products listed on the SAS schedule. Those maximum quantities are set by government directive and can only be exceeded or, for restricted products, issued, with the written authorisation of a medical practitioner or stomal therapist.

I therefore encourage all ostomates to seek advice from a stomal therapist if they are unable to manage their stoma within the maximum quantities available under the scheme. Two of the companies supplying products under the scheme are initiating schemes to support ostomates who are unable to see a stomal therapist. One company offers support to its customers whilst the other offers general support. Your association will be able to provide advice on contacting those companies and contact information is also available in advertisements lodged in this journal.

In conclusion I would like to thank all the ACSA Executive team for the support and encouragement they have provided during my time as Vice President and President. It has been a pleasure to repay the support that I have received from fellow ostomates over the preceding 58 years and I look forward to continuing my involvement in different roles.

**Geoff Rhodes** PRESIDENT

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Above: An avenue in Hyde Park, Sydney. The extensive green park is close to the conference venue.

## Youth inclusiveness: ACSA's conference imperative

Involving and supporting young ostomates will be the focus of this year's ACSA national conference, to be held in Sydney from 18 to 20 October.

The conference has adopted the theme 'Youth Inclusiveness', and aims to encourage associations to find ways to allow younger ostomates to play a greater part in their activities.

The conference will be held at the Rydges Sydney Central hotel in Albion Street, a venue close to Central Railway Station and a short walk to Chinatown. It will follow the usual format, with a welcome function on the evening of Thursday, 18 October, and the annual general meeting and general meeting of stoma associations on Friday and Saturday, 19 and 20 October.

In keeping with the conference theme the organisers, Ostomy NSW and NSW Stoma, have made special provision to involve young ostomates in conference proceedings.

A presentation and discussion led by young ostomates Hally Chapman (Ostomy NSW), Kristy Ross (NSW Stoma) and Jenna Brook is scheduled

for the general meeting. Jenna represents 'running for bums', which encourages screening for the early detection of bowel cancer. The trio will briefly present their accomplishments and open the floor to discussion. It is hoped that their involvement will be a step towards bringing more young members to feeling a sense of involvement and affiliation with their stoma association.

Some of the broader discussion is likely to focus on projects and programs that are best suited to involving young ostomates in the work of associations.

Activities that are most effective are those that young people see as being relevant to their lives and backgrounds, and that let them draw on their own experience and enable them to approach issues in ways that answer their own priorities, interests and needs. It is important that they are able to participate in a safe environment, particularly where the issues are personally confronting or challenging.

Whether the opportunities offered are formal or informal, experts agree

### Program

#### Thursday 18 October

**5.30:** Welcome function, hotel foyer, registration, drinks and canapés

#### Friday 19 October

**9.30:** Annual general meeting, Oxford Rooms 1 and 2

Refreshments and supplier displays, Crown Room

#### Saturday 20 October

**9.30:** Annual meeting and annual general meeting (reconvened), Oxford Rooms 1 and 2

Refreshments and supplier displays, Crown Room

**6.30:** Conference dinner, Surry Room. Guest speaker: Luke Escombe. Entertainment: Pink Cadillac

#### Sunday 21 October

**10.00 – 2.00:** Harbour cruise and brunch, MV Magic



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1. Nichols, T. Hannestad, V. and Purnell, P. Supporting stoma hygiene: a cross-sectional survey on the use of Dansac skin lotion tissue (wipes) - Australia, Supplement to the WCET Journal, 2014 April-June Volume 34, Number 2. \* R2 restriction, no authority for an increase in the yearly allocation can be granted.

## NATIONAL CONFERENCE PREVIEW

## Youth inclusiveness: ACSA's conference imperative

that they should give young people a chance for self-expression and creativity. They should also be flexible, and include activities that have a purpose, and that provide chances to socialise and have fun.

In looking to engage young ostomates, specialists in this field say that associations might need to consider drawing on expertise from outside their organisations. They point to the usefulness of getting support from skilled youth workers—something they say is particularly important if a group aims to involve young people who don't normally feel supported or included by the community. It's also important, they say, to determine the best ways to build the mutually respectful relationships that will be essential for any project, program or activity.

The conference will hear that there is a range of different ways by which young ostomates can become involved with their associations. They include through their participation in advisory or reference groups, and through 'community mapping'—that is, by supporting young people to document local resources or activities. Consultations, and commissioning young ostomates to identify local needs and decide how to use available resources to best meet those needs, provide other pathways. So too do collaborative efforts and activities, working in equal partnership with young people to plan, deliver and review services for them.

The conference organisers hope that by exploring these issues, associations will be better placed to work more closely with their younger members.

At the conference venue, two rooms have been earmarked for ACSA—a large meeting room for plenary sessions and a separate room for refreshments.

The refreshment area will also provide a supplier display space adjacent to the conference proper. All the key suppliers will be present and organisers believe this will offer attendees an opportunity to see new appliances, discuss products and meet other ostomates. Organisers also encourage members who are not attending the conference to take the opportunity to visit the displays and meet suppliers. The supplier displays will be open from 10am to 3pm each day.

The conference will open with a welcome function on Thursday, 18 October, in the hotel foyer above the inground aquarium. The conference meeting sessions will be held on Friday and Saturday, 19 and 20.

The guest speaker at the conference dinner on the Saturday night will be award-winning singer-songwriter and comedian Luke Escombe, an advocate for people living with IBD. Luke works in entertainment, health and education and is the creator of *Chronic*, a one-man comedy show about living with Crohn's Disease. In 2017 Luke won a WEGO Health Award in the category Hilarious Patient Leader. An ambassador for Crohn's and Colitis Australia, he has spoken three times at Parliament House in Canberra on their behalf,



A guardian lion at one of the entrances to Sydney's Chinatown precinct, a short walk from the conference venue.

and appeared at events in the US, Europe, Asia and New Zealand.

The dinner will be held in Rydges Sydney Central's restaurant, which offers stunning views across Sydney and the Eastern Suburbs. Music will be provided by the band Pink Cadillac. A Sunday brunch on Sydney Harbour will round out the conference for the delegates attending.

ACSA and the conference organisers have expressed their thanks to appliance suppliers for their support. They say that their contribution to the running costs has helped to keep the conference costs at an affordable level.

The conference also coincides with the Invictus Games, which are being held in Sydney from 20-27 October—so lucky delegates might catch a glimpse of Harry and Meghan when they are around town.

Associations that have not yet finalised their attendance are encouraged to sign up soon and take advantage of exceptional accommodation rates being made available. ●

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# A new beginning as Ileostomy Victoria closes

By Terry Carver



Sadly, I have to inform ostomates that the Ileostomy Association of Victoria (IAV) closed its doors on Thursday, 28 June 2018, after 61 years.

The association has amalgamated with the Colostomy Association of Victoria (CAV), which is a tenant in the same building, The Block, 98-100 Elizabeth Street, Melbourne. CAV occupies the rooms directly under those occupied by IAV and it was deemed a good reason to amalgamate the two associations, as IAV members who visited the rooms were familiar with the location. As well, the two associations have a shared past: they were one until an upheaval caused the split to two bodies in late 1959.

Amalgamation was made much simpler by the decision not to change the name of the Colostomy Association of Victoria. The only other option open to the IAV committee was to go to Consumer Affairs Victoria and report that we could no longer operate. This meant that Consumer Affairs would have appointed people to wind up the association, with the name Ileostomy Association of Victoria disappearing anyway.

What led IAV to this decision? Many factors were involved but two main ones stand out.

First was a shortage of volunteers with the skills to run the association's day-to-day tasks. Three years ago the association had six volunteers with the skills to manage the daily running of the association, but since then one has shifted interstate, one retired after many years as a volunteer, two became primary carers for their partner—leaving two to shoulder the load. This meant that for the

past year these two have found it difficult to find time for other activities outside the association.

Second was declining referrals in recent times. In the past three years the association's membership had fallen from a high of 1100 to 660 at the closure. In 2017 the association had a total of 21 new referrals for the 12 months. It has been disappointing to see this at a time when the membership of many other associations across Australia has grown.

I can assure all IAV members who have been transferred to the amalgamated CAV association that they will find there are only minor differences in the way CAV operates, as the two associations have had a very good relationship in recent years, helping out each other when needed.

Both associations are well represented on the new, appointed committee of the amalgamated association, and I envisage that there will be a term of learning by members from both associations. I have been appointed president.

While long-term ostomates will be familiar with IAV's history, I would like to relate the story for those ostomates who might not know it.

IAV came into existence through the interest of a colorectal surgeon, E. S. R. (later Sir Edward) Hughes, who had spent several years studying overseas, where he had seen the benefits when ostomates were brought together to talk about how they were managing the day-to-day problems associated with living with a stoma. Stoma output devices for collecting the waste were very basic, unlike today.

After he returned to Australia, he invited a small group of ostomates



Jim Cummins and Joan Williams, two long-serving members of Ileostomy Victoria.

to attend a meeting on 18 April 1957 at the Federal Hotel in Collins Street, Melbourne. In all, 28 people attended the meeting and formed the first Australian stoma association, known as the QT Association (Victoria Division), 'QT' referring to the two wards at Mount Sinai hospital in New York, one for female patients and one for males. Other associations across Australia also used QT in their original names.

Of the original IAV members, Mr R. Young is still a member of the Peninsular association, having transferred when it was formed as it was closer to home. Another founding member, H. (Bert) Feben, passed away in February 2018. He had been president, treasurer and auditor of IAV for many years.

Australian ostomates owe a great deal to the pioneers who worked tirelessly for decades to improve conditions of ostomates and helped create the Stoma Appliance Scheme from which we all benefit.

On behalf of the last IAV committee, I would like to thank all the volunteers and committee members, past and present, for the time they have given over 61 years. I look forward to a having wonderful working relationship with our companions at the 'new CAV'. ●

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**Dear Editor,**

I have recently received the latest copy of *Ostomy Australia* and would like to support the idea of a Stomaline. As a newbie there have been several times when I have had questions that I just did not know who to turn to, to get answers. I ended up calling the company selling products for many answers.

I also liked the article on toilets in Japan. I had a nasty experience visiting a shopping centre in Brisbane. I came out of a disabled toilet only to be verbally abused by a carer. That was bad enough, but a few minutes later there was a shout of 'There she is'—the man had reported me to the service desk! I walked over and said that a disabled toilet was suitable for, but not for the exclusive use, of somebody in a wheelchair.

It did upset me, though I think I should be proud that I look 'normal'. Maybe I need to put an ostomy label on when I use a disabled toilet (though he probably would not know what that was).

**Maggie Parker, QLD**

**Dear Editor,**

After reading Geoff Rhodes' suggestion for a 'stomaline' in the April *Ostomy Australia*, I would definitely encourage some form of support before and after for new ostomates. I know after my operation 14 months ago, my wife and I were very confused about some matters, with no one to ask or help.

**Bob Scott, QLD**

**Dear Editor,**

I always read with interest the introductory *Ostomy Australia* articles by Geoff Rhodes—unpatronising, informative and always offering interesting facts about the association's history and how it works.

As a relatively new (five-year) ostomate, I am still discovering ways of adjusting to the new lifestyle, always on the lookout to improving appliance procedures, clothing and the myriad of things that could benefit me and other ostomates.

The April magazine article outlines the value of personal and social media groups. This is an area where I feel that I could contribute with a personal look at the efficacy of

advice across various media platforms—and specifically, the value of the 'old fashioned' blogs.

Having looked at several ostomy support groups on Facebook, I found their value as a source of information to be limited, often quite poor. This is largely due to the nature of social media, being mainly a platform for personal views and opinions and sadly lacking clear advice and information, where a question posed by an ostomate is invariably swamped by superfluous and unrelated commentary. Of course, this is not specific to ostomy support groups, rather it is in the nature of social media's form, always lacking a structured discussion. In addition, there is the issue of collection and misuse of personal data, inherent in all social media platforms.

How to make it better then?

This is simple—a forum. A blog hosted by *Ostomy Australia* or individual associations would provide a more effective means of discussing multiple related topics, all clearly separated by the subject matter. The focus of each topic discourages gratuitous commentary and can be further enhanced by a qualified moderator. There is value here for ostomy appliance manufacturers too, as they may note trends emerging out of postings on individual experience with products, whether it be their limitations, perceived defects or suggestions for improvement. In short, I am proposing the introduction of a blog hosted by *Ostomy Australia*, accessible by members and service providers and moderated by qualified or passionate members—just like Geoff Rhodes.

**Alec Umansky, VIC**

**Dear Editor,**

I related to David Wright's article (Col and Uri, April 2018) very well. I also have two friends—or, as my daughter refers to them, the 'twins'. It all began in August 2015, when I was diagnosed with a very aggressive anal cancer.

I must admit that it blew my mind, and I took in very little of what the specialist outlined. In fact I was set against an operation. Then a very patient and helpful doctor in the Calvary Mater Hospital in Newcastle explained, with excellent sketches of the bowel, what would happen if I refused the operation. What transpired was a very hectic three months of chemo and radiation therapy, which had little effect, although it did shrink the cancer and slow it down a bit. In October I was given the option to have the operation or have a minimum of three months' life

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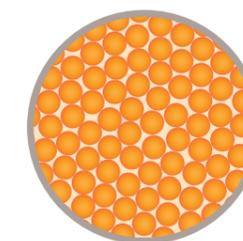
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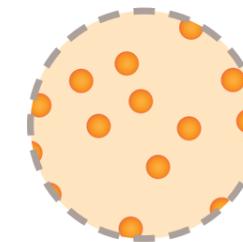
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expectancy, or 12 months at the most. Not a great prospect.

After much soul-searching I decided to agree to the operation. On the 14 January 2016 I was admitted to the John Hunter Hospital and the operation was carried on the 15th—hence the birth of my twins. Like David, I have named them and I think the names are self explanatory—Pee Wee and Pugsley. They have become my close friends, as they perform all the necessary functions for my wellbeing. The twins are changed twice a day and so we have a very close relationship. Both enjoy their warm water bath and can quite vocal at times, especially if something has caused an upset. Of the two, Pugsley is the most vocal—which at times is at the most inappropriate moment.

I agree with David that the twins are ‘sensitive and a positive attitude to their needs goes a long way to keeping them happy’. I have conversations with them at change times and this seems to be of benefit, although my daughters do get a laugh out of what is said.

My own attitude to cancer and stomas has had a huge effect on my life and how I live. The best thing is that because Pee Wee and Pugsley were born, I have a life that would have been cut short without them. Thanks to the twins I have a life to live.

Thank you for your journal, as I find the information it contains to be most helpful.

Lord bless,  
**Kevin Cooper, NSW**

Dear Editor,

First, can we say we loved the Col and Uri story in the April 2018 edition—what a great story! Thank you to the author, David Wright. Husband Lex has had his stoma since March 2014 and we call him Boris. Sometimes Boris makes his opinion heard if he is not happy with what he has had for dinner.

We love the products that are offered to try out through the newsletters. It is good to see that companies are trying help all recipients with great products, and we are glad to give any feedback that will assist, which we have done.

With regards to clothing, you do have to shop around for the most comfortable. Lex has tried lots of trousers and finds that the best for him are elastic waist types because they have pockets in the leg where you can discretely have a spare bag and a wipe and no one notices. So when we go shopping or visiting they are there just in case.

Thank you to those who share their tips—they are a great help. We wish everyone good health.

**Lex and Carol Wilson, TAS**

Dear Editor,

Greetings from Papua New Guinea. Firstly, I'd like to thank you and the contributors who write and provide helpful information related to ostomy as well as sharing stories from other ostomates. This wonderful journal keeps me informed and educated in our particular field and helps me generate a lot of ideas in my own work.

I would like to take this opportunity to thank everyone from the associations who have contributed towards our cause to better the livelihood of ostomates in Papua New Guinea. I am grateful to you all for your support financially as well as the precious gift of ostomy supplies. You are the ones making a difference in our lives. When you help me, an individual, you are helping many. Your help goes beyond the financial or material, it gives back a smile that was lost, it regains peace from turmoil, gives comfort where there was none, restores self-worth where it was lacking. Your help gives back belief to those who stopped believing that anyone cared, it gives the self-belief to face each day as it comes.

I thank the patron, the president, the management and the staff of Gold Coast Ostomy Association for their continuous support in this project, which they took under their wings. It was the first of its kind for them. I am indebted to two people who were my first contacts, Amanda and the late Norman Kelly, who made it possible for PNG Stoma Association to be where is today.

Not least, I would like to thank Jon MacPhail. My deep appreciation goes to this special woman who tirelessly gives her time and energy packing all the ostomy supplies to be donated to PNG Stoma Association. Her dedication makes my job easier, for at my end I continue to work alone.

Recently I got a few ostomates together and asked them to join me in moving PNGSA forward by managing the association ourselves, giving back volunteering time for the benefits they receive, but since then I haven't received any positive response. They don't seem to understand where I am coming from, as I have recently been diagnosed with more health issues and it is getting harder to run the association by myself. I wish they had the chance to see the commitment exemplified by ostomates running their own associations as volunteers in Australia and other developed countries. That is my current goal—to see ostomates here running our association.

I don't know what the future holds for me or what tomorrow brings, so I thought of writing this appreciation note to you all, the association members of ACSA. Thank you all from the bottom of my heart.

**Janet Yaki, PNG**

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## Stoma associations: the growth in professionalism

*In the April 2018 issue of Ostomy Australia, ACSA Administration Officer Kylie McGrory looked at how the Stoma Appliance Scheme has influenced the development of stoma associations. In this, the final of three articles, she shows how the development of stoma care has pressed associations to become more professional in their operations.*



many associations had little choice but to consider engaging appropriately skilled personnel to complement their volunteer workforces.

Fast forward to 2018. The SAS now supports about 45,000 persons living with a stoma by providing about \$100 million worth of subsidised ostomy appliances each year. There are now about 3,500 individually listed items contained within the SAS Schedule, representing 610 unique SAS codes.

Most of the 22 Australian associations are no longer 'voluntary organisations' but are 'persons carrying on a business or undertaking', reliant on a combination of paid and voluntary workers. They have a responsibility to their membership base to be professionally managed, with a focus on excellent customer service and support. Depending on their corporate structure, they must fully comply with the requirements of either the Corporations Act or the Associations Incorporation Act—and all, regardless of their structure, are required to comply with the Work Health and Safety Act, anti-discrimination legislation and the Privacy Act.

Further, they must be conversant with and meet the requirements of fair work legislation, National Employment Principles, taxation legislation, superannuation guarantee rules, Australian Charities and Not for Profit Governance Standards and the Stoma Appliance Scheme Operational Guidelines. Association administrators are expected to possess high-level skills in financial management, risk management, human resource management, conflict resolution, stock control and logistics. Associations' governing bodies, tasked with the fiduciary duty of making decisions within the best interests of the association and its objectives in mind, must be fair and transparent. Individual executive or board members risk being held personally liable if they aren't.

Since 1975 the scheme has changed, and so too have associations. As the scheme has grown, most stoma associations have had little option but to respond by evolving from what were essentially small groups of incredibly dedicated volunteers committed to improving the wellbeing of other ostomates to become professionally managed organisations—albeit still with the same objectives and still largely reliant on teams of very capable and dedicated voluntary workers to assist with day-to-day operations.

As the Stoma Appliance Scheme continues to evolve, associations will be faced with more and more challenges—the most immediate now being how we manage the foreseeable problem of meeting the rising costs of delivering expected levels of service in an environment where our ability to recoup costs is limited. Some interesting times ahead, to be sure!

When the Stoma Appliance Scheme (SAS) began on 1 October, 1975, the 11 existing stoma associations were approved as distribution centres for government-subsidised ostomy appliances and pharmaceutical preparations. In return, they received a 2.5 per cent handling fee.

The scheme rapidly proved to be successful. During its first full year, 1976-77, the voluntary associations distributed \$687,000 worth of SAS-funded appliances to members. By 1980 expenditure had increased to \$1.77 million, and by its tenth anniversary in 1985, it had reached almost \$5.2 million. By the time the scheme reached its twentieth anniversary in 1995, there were 22 approved stoma associations distributing ostomy appliances valued at \$20 million per year to more than 20,000 eligible people! The range of listed products also grew exponentially. While the first SAS Schedule had been released on 1 October 1975 with only 20 or so appliances and preparations listed, by July 2000 the number of subsidised products available to registrants had increased to around 380 unique SAS codes across 70 product groups and subgroups.

As the scheme continued to grow, so did administrative demands on the associations. In the 1990-91 Budget, the Commonwealth Government announced that all claims for the reimbursement of PBS items would have to be submitted in electronic format. Although welfare associations such as stoma associations were exempt, the Health Insurance Commission 'highly recommended' that associations move to computerised claiming. Suddenly a whole new set of skills had to be learned!

Then, by February 1992, the Commonwealth expected that all association administrators would have the 'ability to operate a small business organisation with particular reference to financial skills in the area of accounting, including ability to manage and operate an accounting system and to manage a stock management system'. These demands, coupled with the ever-increasing legislative obligations imposed upon contemporary businesses, including not-for-profit associations and charities, meant that



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## The importance of vitamin C for ostomates

In the April edition of *Ostomy Australia*, with winter coming on, Margaret Allan discussed the value of vitamin C in our diets, and looked at ways for ostomates to avoid suffering a deficiency of this critical vitamin. But, as she explains in her second article, vitamin C is important for other aspects of ostomates' general health.



**Vitamin C is an important nutrient to defend ostomates against infection and illness during colder weather, but its benefits are not just confined to winter months.** Vitamin C has many other purposes and performs numerous other functions which can also benefit ostomates.

Vitamin C is important for synthesising the protein collagen, which is found in skin, bones, tendons and cartilage. The normal development and maintenance of these tissues therefore depends on an adequate supply of vitamin C. Many signs and symptoms of vitamin C deficiency—such as frequent bruising, poor wound healing, loose teeth and easy fractures—are the result of a lack of collagen production. Scar tissue involved in wound healing requires vitamin C for its development and maintenance, so wounds that do not heal after stomal surgery may be related to vitamin C deficiency.

Many ostomates are of an advancing age, a stage of life in which bones can become thinner and more brittle and osteoporosis may develop. The risk of bone fractures increases significantly. Vitamin C is important for bone health because the collagen that helps to keep bones strong requires vitamin C for its production. Studies have shown a positive association between higher vitamin C intake and greater bone mineral density, which indicates stronger bones and reduced fracture risk.

Many ostomates commonly experience fatigue and low mood after stomal surgery, and vitamin C can be helpful in this regard. Vitamin C is required to produce energy in the body, and is essential in producing chemicals that support a happier mood. Adequate vitamin C status can therefore improve energy levels and lift mood, which can enhance one's overall sense of wellbeing.

Vitamin C can also benefit ostomates who have concerns about heart health. Low vitamin C status has been found to be related to an increased total blood cholesterol concentration, which may increase the risk of heart disease, whereas a high concentration

### Key points:

- Vitamin C is an essential nutrient that defends the body against illness and infection.
- Vitamin C cannot be produced by humans, it must be supplied via the diet.
- It is difficult for many ostomates to consume enough dietary vitamin C to meet their health needs.
- The potential for developing a vitamin C deficiency is quite high amongst the ostomate population.
- Supplemental vitamin C is beneficial but care is required in selection.

of vitamin C in the blood has been associated with lower blood pressure and higher levels of high-density lipoproteins (HDLs), which are the good form of cholesterol. Vitamin C is a nutrient that can therefore protect against heart disease if status is adequately maintained.

People with a urostomy can be more at risk of urinary tract infections (UTIs) as a result of intestinal tissue containing bacteria being implanted in the sterile urinary tract to form a conduit. Vitamin C can help to acidify the urine, creating an unfriendly environment for bacteria to grow. This nutrient can therefore protect people against UTIs, although very high doses are required and supplementation may be necessary.

Chronic stress is a very nutrient-depleting situation, and unfortunately vitamin C is one of its major victims. Stress depletes vitamin C very quickly, and even low-grade stress has an impact over the longer term. Anyone experiencing stress of any kind will therefore reduce their vitamin C status, which can have a flow-on effect to other functions in the body and affect wellbeing. Make sure you are scheduling some fun into your days to preserve your vitamin C!

### Maintaining vitamin C status

Maintaining vitamin C status can be difficult for people with an ileostomy or colostomy because of the reduced range and quantity of fruits and vegetables that can be safely and comfortably consumed. Eating the vitamin C-rich foods that are tolerated as often as possible and cooking them in ways that retain nutrient content will help to maintain vitamin C status. People with a urostomy should be able to meet the dietary guidelines and consume sufficient quantities of vitamin C-rich foods to meet general requirements. However, a much larger amount of vitamin C may be required to combat UTIs in particular.

In all these cases, it may be necessary to source an appropriate vitamin C supplement to compensate for insufficient dietary intake of vitamin C-rich foods. Care needs to be taken when choosing a vitamin C supplement, as many of them can cause looser output or stools. If you would like assistance to appropriately increase your dietary or supplemental intake of vitamin C to ensure it is sufficient to meet your needs and attain your greatest level of health, please contact me.

Wishing you good health and happy days,

**Margaret** ●

The first part of this article is in the April issue of *Ostomy Australia*, pages 26–28.

*Margaret Allan is a nutritionist who advises both ostomates and the public on diet and health-related matters. She is the director of the consultancy Nutrition For Ostomates. To contact her or read more nutrition articles supporting the health of ostomates, go to [www.nutritionforostomates.com.au](http://www.nutritionforostomates.com.au).*

### TO THE EDITOR

### How to ensure you have enough vitamin C

The article 'Are you consuming enough vitamin C?' in the April issue correctly commented that 'screening for vitamin C deficiency, is not part of routine blood tests', and also that 'subclinical vitamin C deficiency is much more common than is generally recognized ...'.

There is however a very simple way of finding out if your body has the best amount of vitamin C, also known as ascorbic acid.

All that's needed is for you to have your doctor request a vitamin C blood level test. The blood is best taken before breakfast or before another meal so as not to get a falsely high result from recent food or juice intake.

The tube with the blood needs to be kept in ice and under foil so as not to get a falsely low result from breakdown of the ascorbic acid by warmth or light.

If the level is only average or below average, then it's easy to improve the level into the upper half of the normal range by taking a daily supplement. One gram of vitamin C three times daily with food—that is, with breakfast and two other meals—is appropriate.

After a month or two a repeat blood test will tell you how much improvement you have achieved, and therefore whether another course of supplement is worthwhile. In this way the tissues of your stoma, and of your entire gastrointestinal tract will be strengthened, and your immune system will be supported.

**Associate Professor Ross Philpot, SA** ●

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Carmen has been a Stomal Therapy Nurse in many of Australia's largest hospitals for a number of years. She has also represented her profession internationally on many occasions.

# The power of a positive outlook

*Jodie Nelson is an Accredited Life Coach, mindset specialist, motivational speaker and executive leadership coach who specialises in chronic disease management and effective communication strategies for patients, medical professionals and supporters.*

‘Mindset for success’—many people use this tagline for just about everything, but what does it actually mean to you? How do you know if you have a ‘mindset for success’?

Success can be seen through many different lenses. For example, through the values and beliefs you were brought up with or the culture you were born into.

Success for some people is being wealthy, having a dream job or that perfect house with the white picket fence. To someone else it's having all of that and more. To others success isn't about money or status, but being happy with simpler personal things, like family and friends.

Success to me is having a perfect work-life balance, being financially free, being able to do what I want, when I want, with whom I want, and not having barriers in my way. For example, being healthy and active not unhealthy and inactive.

Sounds pretty sweet doesn't it? So why doesn't everyone achieve it in their lifetime?

I'm pretty sure most of you have guessed it, it's your mindset.

How does mindset affect someone who is about to undergo lifesaving, body-altering surgery? Think back to your own experiences. What was your mindset before and after surgery?

I would like to share my story about my mindset before all my major surgeries.

Surgery number one. Mindset terrified, physically tired, sick, in constant pain and exhausted. Outcome—pain could not be controlled for 36 hours, paralysed intestine, major infection. Long recovery. Mood level, down and anxious.

Surgery number two. Mindset terrified, physically tired, sick, in constant pain and exhausted. Outcome—pain could not be controlled for 24 hours, nauseous and unable to eat for five days, mentally and physically depressed. Longer recovery.

**I felt that my concerns were not only heard but validated**

Surgery number three—same as above. Outcome—same as above

Surgery number four. Mindset, initially in shock and terrified, but this time I took the scary step of taking control of the situation rather than just going along with whatever was being discussed around me by a team of doctors.

**mind** over matter



I now believe that because I had the courage to ask questions and dared to slow down the process so that I could understand the medical teams' way of thinking, I felt that my concerns were not only heard but validated.

I asked a couple of questions that were directed to my doctor. The first was: 'If I'm going to be operated on after dinner, how long will you and all the team have been working that day?'

Now I must say my surgeon is awesome and so is his team. They are dedicated, informed and have a beautiful bedside manner. But sometimes I think they push themselves to exhaustion.

I immediately thought—how is this going to affect their concentration? Will they have the energy to take things really slowly or will they be rushing because they have already been working for twelve hours?

The surgery was delayed for a number of reasons. The two most important were, first, I needed time to get my mindset under control. I knew I needed to see my life coach to clear all the negative thoughts about my impending surgery; and second, after seeing my anxiety and

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hearing my concerns, my surgeon decided to clear his schedule in order to make me the priority. How awesome was that?

After this discussion I felt in control. A level of certainty and the wish for a positive outcome were in the forefront of my mind. I had also decided to set some small goals starting from the minute I returned to my room.

The morning of the surgery arrived and, rather than being nervous, I was ready. I was in high spirits and so was the team around me. My intention was to be happy and positive. Everyone I spoke to that day, from the orderly through to the surgical team, was in a great mood. Then I realised they were only responding to the way I was treating them.

The outcome this time was very different. For the first time I woke up and remembered the recovery area. Wow! I didn't realise how many patients were in there at any one time. Amazing.

I returned to my room that afternoon and was up out of bed and walking around the ward that night. Goal number one attained—Tick!

Three days later I was released from hospital. Again—absolutely amazing!

This positive experience it got me thinking: what would it be like for everyone to have an opportunity to alleviate all the shock, anxiety and fear before surgery? How many more people would be up and out of hospital in record time?

Think back to your own surgeries. Did you have all the information you needed to understand what you were about to embark on?

Admittedly my first two surgeries were before 'Dr Google' and little information was available. What was available was through Chinese whispers and went something like this:

*You know Gloria down the road? Well, her mother had a bag and that was the end of her life! She couldn't go out, she couldn't hold down a job, she couldn't go to bowls and she really used to smell so nobody visited her.*



I thought—what am I in for? Shock, anxiety and fear hit me then and there, like a sledgehammer. My life was going to be over at the age of 28. Fantastic!

The reality couldn't have been further from the truth, but I had to overcome quite a few mental hurdles to understand I had actually been given a life, not a life sentence.

I was resigned to having a bag but when the words were actually spoken, and everything started to move, I felt like I was mouse on a spinning wheel and couldn't get off.

The difference with a positive mindset was that everyone I came in contact with fed off my positive

energy and therefore my body was relaxed before going under. I woke up the same way—relaxed. My body was able to function and metabolise the drugs appropriately to provide the pain relief I needed to be comfortable.

When you fear for your life, adrenaline will pump fiercely through your bloodstream. It gives you the strength to survive in a fight or flight situation. Is it any different if you have exactly that same feeling before surgery? It's not really a mindset for success, is it? It's not really setting you up for an optimum recovery, is it?

Fear is there when we think about what is to come. It grows the more we think about the challenge ahead. What we get is what we focus on! Courage comes when we act, and is magnified the more we confront the challenge.

Then it stops being a challenge, and we are ready for the next level of growth.

For people who fly through their recovery, the difference is their ability to have courage and be resilient.

So how do you know if you have resilience?

The quick answer is— we all have it. Different levels of resilience explain why one person is able to adapt and bounce back to normal life more quickly than another person.

If you are able to deal with shock and fear before surgery and focus instead on your courage, you are already setting up your mind for success. Congratulations! It's that easy. You are now set to move ahead.

**Jodie** ●



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Reference: 1. McGrogan G, Haughey S, McDowell K. An absorbent, enzyme-inhibiting seal reduces peristomal skin complications. *Gastrointestinal Nursing* 2018; 16(1):42-49.





## A RICH AND FULFILLING LIFE

Lutheran Youth Society, Apex Club, local show society and then the Lions Club. In 1981 I joined the local Masonic Lodge and in 1983 I joined the Order of the Eastern Star. My wife and I enjoyed this organisation very much, with me being installed as Worthy Grand Patron of Queensland in 2003. I also joined the Manchester Unity Order of Oddfellows, where I achieved the position of District Grand Master.

I loved dancing and was often asked to partner young ladies when they made their debut. This love of dancing led me to meet my wife, a young widow with a small child at the time we met.

When told about my problem, she asked how it would affect her. I told her she would have to wash binders and make new ones when required. Her response was that that would not be a problem. We married in 1964 and this year celebrate 54 years of happy marriage.

Until 1988 I still used cotton wool pads and binders which my wife used to boil in a copper in the back yard. For a considerable time I had been suffering from bladder infections and just before Easter 1988 my doctor referred me to a stoma therapist. The therapist was astounded at the size of my stoma, which was as big as the top of a teacup. The dead end of the loop colostomy had eaten a hole into my bladder, thus causing the infection. After seven weeks, five operations and losing 19 kilos, I was able to go home. Since this time I have been a member of ostomy associations—first with Moorooka and then, when Wide Bay Ostomates was formed, with that branch. It has been my privilege to provide information to other ostomates as well as telling my story at meetings.

I have had to have further operations for skin breakdown and hernias but fortunately nothing since 2001. Over the years I have travelled by caravan in Australia, visited many overseas countries and embarked on more than 30 cruises.

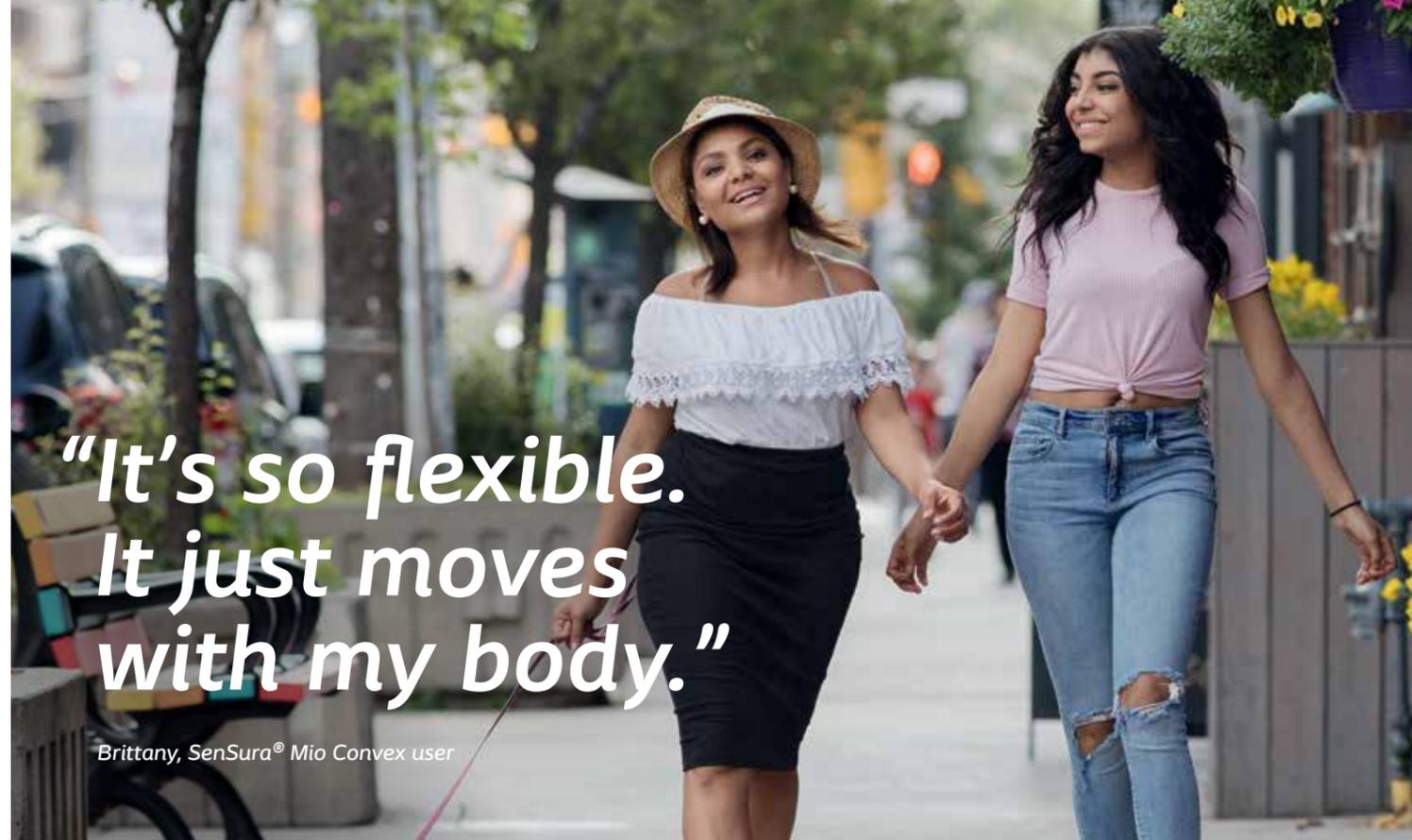
The only thing I have not been able to do is play contact sport. To me my life has been fulfilling, with the love and support of my wonderful wife.

My name is Eric Pape and on 13 January 2018 my colostomy was 82 years old. Because of an abnormality at birth I was given a loop colostomy when I was three days old. I was born in a small country town in rural Queensland. My mother gave birth in what was known as the Dutch Nursing Home. It was very fortunate that the local GP, Dr Dimwoody, was astute enough to perform the needed operation. My mother had no idea of what appliances could be available so for most of my life a pad of cotton wool, held in place by homemade binder, was the way in which my colostomy was managed.

Because of this primitive method I did not attend school until I was seven-and-a-half and had to walk home a mile at lunchtime to change. This was often traumatic as my path led through a cane field and snakes were prevalent.

When I was 13 my father died and, being the eldest, I had to leave school and start running the farm. I started cutting cane by hand and did this for the next 20 years. My wife would often get distressed when I would come home from a day in the field and my colostomy would be bleeding because of the severe perspiration and constant bending. On the farm I drove tractors, trucks and harvesters, and ran a bulldozing business. There was nothing that I could not do.

I became involved in the local community, being a member of Rural Youth, the Young Country Party,



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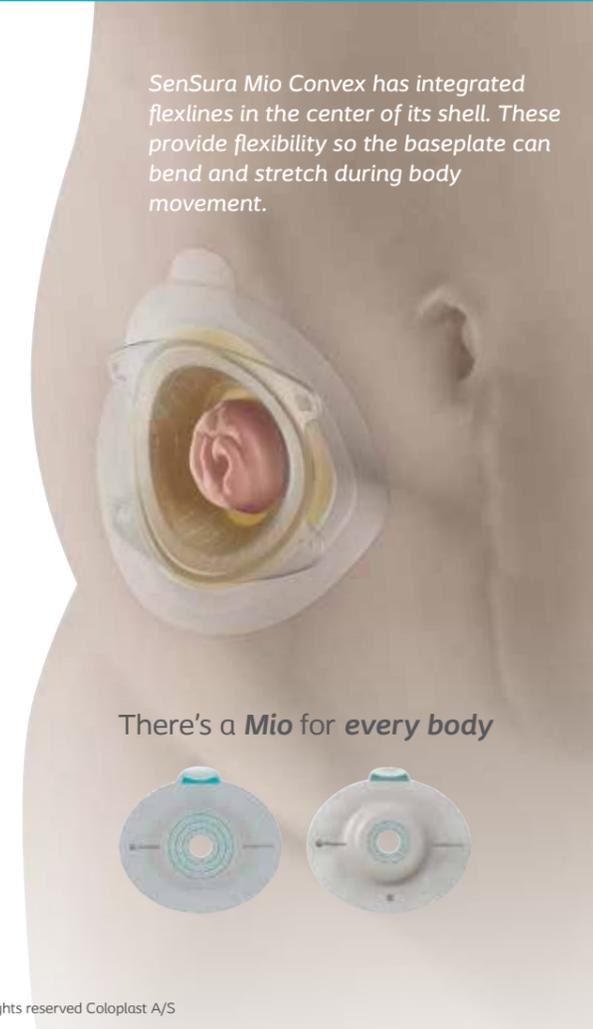
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1. Reduces leakage compared to Standard of Care. Walker et al. Raising the bar: New flexible convex ostomy appliance – a randomised controlled trial. WCET supplement 2016

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Tony Costa 'always enjoyed playing the piano' and set himself the challenge of playing 60 songs over five hours as a fundraiser.

I've been really inspired by some of the great 'people' stories I've read in *Ostomy Australia*, and after lots of thought I decided to put fingers to keyboard. I am 53 and live in Geelong (Go Cats!) in Victoria.

For me, 1983 was an interesting year. It was my first year of university, having enrolled in a commerce degree. I didn't know what I wanted to do career-wise, and fell into this course. About a month into the studies I began losing weight and seemed to be going to the toilet more often. I'm a light guy anyway, so nobody really noticed the weight loss and I put the whole thing down to first year university nerves. The 'nerves' didn't go away and at midyear, in spectacular fashion, I managed to fail everything.

It was time to get these 'nerves' sorted out. I could no longer ignore the possibility that something might be wrong. The first GP consultation was a disaster. I was told to go home and eat properly! So I saw another GP, who agreed that something was wrong. I was put on all sorts of medication and sent for lots of tests, X-rays and eventually a colonoscopy. Sometime in September the Crohn's disease diagnosis came and surgery for resection in the large bowel was required. But first I had to be fed by TPN—total parenteral nutrition—and 'fattened up'

before surgery. The operation happened the following month, in October. It was very scary. I didn't know what Crohn's disease was and no one I knew had heard of it. Home computers didn't exist so of course there was no internet, Google or social media. If support groups existed I certainly didn't know about them.

The following year I was allowed back to uni on compassionate grounds to start again. I kept reasonably healthy for the next couple of years but slowly became worse again in 1986. Once again my studies were affected. This time I endured a hospital stay of 9.5 weeks and was again on TPN. Ileostomy surgery was spoken about at length and looked the most likely outcome. Eventually I was referred to a gastroenterologist to pursue non-surgical options.

Through sheer determination I finally got through that commerce degree and graduated. I still wasn't sure what I wanted to do career-wise, and still wasn't in the best of health. A couple of years' unemployment wasn't exactly helping the situation. Realistically, I probably wasn't well enough to be working.

Come 1991 and now I am studying in a Graduate Diploma of Education with a view to secondary teaching.



250 brushstrokes applied

1 sunset captured

0 irritation around his stoma

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It was also my first experience of living away from home. It should have been an exciting time but once again Crohn's disease tried to ruin my studies. Somehow I got through all the assignments and teaching rounds with reasonable marks. This was despite having no energy, running to the toilet around 30 times a day, and losing lots of weight. If there was a day when I only went to the toilet 25 times I actually thought I was getting better! Once back in Geelong I was referred to another gastroenterologist. Another colonoscopy confirmed that I needed life-saving ileostomy surgery.

The date 20 December 1991 was a big occasion for a couple of Aussies. Paul Keating became prime minister of Australia and I had surgery for removal of the large bowel and the formation of a permanent ileostomy (proctocolectomy).

After recovering from the surgery and getting used to the bag, I could not believe how well I was. My life was literally given back to me and once again I could enjoy food, going out, and living life without rushing to the toilet. And this time there was a support group. I joined Young Ostomates United (YOU). This was a great avenue for meeting other ostomates and other people with IBD. I was secretary of YOU for a while and enjoyed many fun interstate journeys with the group. I recall an amusing moment going to the toilet during one of these trips.

At the Adelaide Oval (I think it was during an ACSA conference), when I went to the men's room, all the urinals were vacant but all 10 cubicles were occupied. This could only happen at a function for ostomates!

Not long after the ostomy surgery I finally ventured into the workforce, taking an administrative job at a fisheries research institute in Queenscliff. I was just happy to be well enough to work. When this job finished up it was back to study again, this time in a Graduate Diploma of Education (Integration/Special Education). This was the first time I had been able to study while in good health. The difference was amazing, and it showed in my results. Halfway through the course I was encouraged to upgrade the qualification to a Masters by coursework. I was proud to complete the Masters—I felt it was a great achievement for me. I eventually settled into work with a local disability service provider, teaching basic literacy and numeracy to adults who have intellectual disabilities. Now approaching 23 years later, I am still in this job.

I am forever grateful for my stoma but it hasn't been all plain sailing since the ileostomy surgery. There have

been more medical issues and challenges. In 1999 it was a bowel obstruction that led to significant renal failure. There was more surgery in 2003 with a laparotomy and resection of the small bowel due to active Crohn's disease. And then bacterial meningitis came my way in 2008. All of these were life-threatening, but all faced with a determination to not be beaten.

I'm happy to say that I've kept in reasonable health since 2008. There were some minor medical concerns last year and I made the decision to drop to working four days a week, with a rest on Wednesdays. This is working well.

In recent years I've become involved in online Facebook support groups for IBD sufferers and ostomates. These groups have been useful and supportive and I have formed some great friendships through them. There have been many catch-ups, wonderful times and IBD fundraising events. One group was responsible for naming my stoma via an informal naming competition. 'Alice' won the day due to my liking a certain song where 'Alice' leaves after 24 years. Fortunately, my 'Alice' is still with me, even though it has been more than 24 years!

Last year I ran my own IBD fundraising event with the support of Bottoms Up Inc. I've always enjoyed playing the piano so I set myself the challenge of playing 60 songs over five hours as a fundraiser. This also meant overcoming a fear of playing piano in public—and, of course, getting through 60 songs. The event was held at a local café associated with my work. I'm still astounded by how well the whole thing went. People were giving me money before the event, a GoFundMe page was set up and of course tins were rattled on the day. I wasn't nervous and lots of people supported me when the big day came. And I did it. I got through the songs and along the way raised just short of \$3000. Bottoms Up Inc. ensured the money went directly to the Walter & Eliza Hall Institute of Medical Research for IBD research.

Well, that's my story so far. I'm proud of what I've achieved with my studies, happy that I'm well enough to work, grateful that 'Alice' is keeping me alive, and amazed that I raised so much money for IBD research. I've also had amazing support from family and friends all the way through this journey.

**My life was literally given back to me and once again I could enjoy food and going out.**

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1. Gary et al. 2005. A review of 16,470 patients on the American Ostomy Association Registry. 2. et al. 6675OMN

## Support and acceptance get you through adversity

 by Mike Gray

In June 2014, when my story begins, I was enjoying retired life and looking forward to my 70th birthday on 26 July.

Apart from migraines, I had been healthy all my life. The oldest of five children, I had never had the dreaded measles, mumps, or any of the other childhood diseases that my younger brothers and sisters suffered. I had my first migraine at 14 and since then they have occurred throughout my life.

But in June 2014 I began to feel a pain in my right arm, around the elbow. My wife, Wilma, and I thought it was simply tennis elbow, which I had experienced a few years before. I tried the usual pain relief, even wearing a bandage especially made for tennis elbow, but as the pain grew more intense over about eight weeks, I took myself off to Burnie Hospital in northern Tasmania.

After several X-rays and scans the doctor said I had nerve problems in my neck that were affecting my arm. I was discharged from hospital in late July 2014 with instructions to make an appointment with a neurosurgeon to examine my neck.

Then all of a sudden life was travelling too fast. I had an appointment five days later at Royal Hobart Hospital for a PET scan. Was it cancer?

Next day I was in the Holman Clinic, where I met Dr David Byram. He went through the scan with Wilma and me. Scary stuff! I had prostatic cancer that was eating away three vertebrae in my neck. There were spots on both hips, on the ribs on both sides, and on the spine. I was fitted for a face mask in preparation for radiotherapy, which

began on 31 July and continued every weekday until 28 August.

When Wilma was driving me home, I suddenly had a terrible pain in my abdomen. The pain increased over the next hour or so, so we called into my doctor, who saw me immediately and, thinking I might have some serious problems, called to tell Burnie Hospital that we were on our way.

After X-rays and scans I was wheeled into the operating theatre, still not knowing what was happening to my body. I awoke next morning to find that my colon had burst from diverticulitis, and that I had a colostomy bag attached to my stomach.

**I was wheeled into the operating theatre, still not knowing what was happening to my body.**

The next few days were spent learning how to cope with this new apparatus and how to change and clean when necessary. With the help of the stoma nurses I managed OK and was discharged on 3 September with a belly full of staples.

But things don't always go to plan and a week or so later all the staples burst and I was left holding my insides in my hands. So back to hospital to be stitched up again. This time I had trouble with my waterworks and was discharged on 10 September with a catheter attached to my leg. Wilma and



Mike Gray: attitude is the secret.

I had some good laughs while we were getting used to changing the colostomy bag—those who have been through it will know what I mean.

I had been telling the doctors and nurses that I was having great difficulty breathing. My breathing did not improve and an X-ray showed that I had a spot on the lung. After treatment I was discharged on 6 October to begin my rehabilitation. That was complicated when I was diagnosed with an underactive thyroid, which created a few problems within the body.

Wilma and I joined the North-West Ostomates Support Group which meets in Ulverstone, organized by Adrian Kok and his wife, Leah. Adrian also organizes the North ostomates support group in Launceston and the South ostomates to meet in Hobart.

We meet every three months and have a laugh and exchange stories about who are going through, or have gone through, the drama of ending up with a permanent stoma. Another great help is the ostomates delivery service. The help and advice these good people provide is outstanding.

Attitude is the secret to handling life's adversities. Accept life as it is: We cannot change what has been.

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# A celebration for the gift of life

NEW

Caroline Collins spent late July with her brother Simon in Paris, marking a special anniversary. It was two years since Caroline, a director of Omnigon, had flown to Britain from her home at Lennox Head on the NSW north coast to donate a kidney that saved her brother's life.

Two years on and a check-up confirmed that Simon Gooden is 'fighting fit'. The anniversary reunion with brother, sister and their spouses was, Caroline says, 'a wonderful few days and very precious for all of us.' But was she apprehensive when she made her decision to donate? 'I was a nurse when I was younger and knew what to expect, medically. It took me eight weeks to get back to full strength, physically. It was a more emotional experience than I expected but in a very positive way.'

Thus Caroline became one of that small number of Australians who have donated an organ to save the life of someone else. The need for transplantation continues to exceed the availability of organs and tissues in Australia, according to the federal government's Australian Organ and Tissue Authority. Again this year, from 29 July to 5 August, the OTA ran DonateLife Week to alert people to the life-saving potential of donations, and to encourage them to place their names on the Australian Organ Donor Register. During DonateLife Week last year, Caroline devoted a great deal of time to media work to prompt people to decide to donate, and to register.

Donations may come from living people or those who have died. On a trend line, the number of donors and recipients has increased steadily since a program began in 2009 to change the way that Australia approaches organ and tissue donation: the number of deceased donors has more than doubled since 2009, up by 106 per cent; the number of transplant recipients has increased by 75 per cent. In 2017, 1402 Australians had their lives transformed by 510 deceased donors. In the same period there were 273 living donors, comprising 271 kidney and two liver donors. But people in need can wait up to seven years for a transplant; three years is the average.

Getting people to register is a key area of activity for OTA. So too is talking the question through with family or loved ones, and letting them know when a prospective donor has made a decision. Australians strongly support the idea of donation: one in every three is on the register, with women (54 per cent) being substantially more numerous. A large majority—81 per cent—believe that it is important to register a donation decision.

Registration matters because family will always be asked to confirm a dead person's decision to donate before transplantation can go ahead. The OTA points out that registration also directly influences consent rates, with 90 per cent of families agreeing to donation going ahead when their deceased family member is registered. However, only 44 per cent agreed to donation when the potential donor had neither registered nor discussed their wishes. Thus for families, registration removes the stress of having to make a decision at a turbulent time—and, of course, it means that a potentially life-saving medical procedure can be quickly put in hand.

The situation is different where a living donor is involved. Simon's life had already been saved by deceased donors on the Australian registry, in 1976 when he was 16 and again in 1984. 'My brother would not have survived this long without the generous decision of the previous donors to register,' Caroline says.

But though the second transplant had lasted 30 years, by early 2016 it was clear that he needed another. 'They would only give him a third transplant if it was an exceptionally good match, due to the complexities of his particular case,' Caroline says. 'We have always been close and I think I just knew I would be a good match, so I contacted his renal team in the UK and while I was there on business had the tests to confirm the match.' The transplant was made at Portsmouth's Queen Alexandra Hospital in June 2016.

There are few impediments to becoming a donor—even for ostomates. While a potential donor's age and medical history will be taken into account, the OTA says people shouldn't assume that they are 'too old, too young or not healthy enough'. 'There's every chance that some of your organs and tissues will be suitable for donation. Only some medical conditions, such as transmissible diseases like HIV, may prevent someone from being a donor.'

How to take the first step? 'I always ask people to think about it like this,' Caroline says. 'If you would say yes to an organ donation for yourself or a loved one should they need one, then you should be on the organ donor registry. It is a lifesaving gift. I would ask people just to have a conversation with their family this month. It is a very personal choice. Not everyone can be a live donor and as fortunate as I am, to get to see how healthy and happy my brother is, but registering as an organ donor will potentially save lives and benefit many people when you no longer need your organs.'

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## Celebrating those who 'give a little' to make a difference

By Lindy McDonald

What is a volunteer? As one definition says, 'A volunteer is one who gives their time to help a 'not-for-profit' organisation. The impact on the community and the benefits of volunteering is what holds us together.'

At Ostomy Association of Melbourne, we celebrated National Volunteer Week, 21-27 May, with morning tea and lunch treats each day, with each volunteer being presented with a certificate of appreciation and a lapel pin.

Our volunteers mean the world to us, and without their presence, their contributions and exuberance, we wouldn't be where we are today. We have more than 40 volunteers who assist us during each week—some have a morning shift, some have an afternoon shift and a couple give us a full day's volunteering. They are always happy to come to 'work', being given tasks without a whimper or complaint. Tasks include picking and packing orders, filing and assisting with order pick-ups, among many other varied duties.

Our group of volunteers vary in age and come from a range of different career backgrounds—among them are engineers, managers, nurses, administrators, business people, IT specialists, bankers, housewives and retirees, just to name a few.

Some comments about their role from our volunteers—

- 'A pleasant way to spend a few hours being productive and meeting new people. It provides both friendship and a sense of purpose.'
- 'It has given me a chance to keep working after retirement and to help others in need.'
- 'Makes me very happy donating my time to an amazing organization.'
- 'Enjoying making a difference and enriching other's lives.'

Volunteer Week is our chance to thank our helpers for everything they do for us. The smiles, the joy and their will to work is contagious. It is a delight to see each and every one of them each day, each week.

The slogan for National Volunteer Week 2018 was 'Give a Little, Change a Lot'.

This is what our volunteers mean to us. From all at the Ostomy Association of Melbourne—we thank you. ●

## Petro's story

by Petro Zonnekus

*This is my story  
Just a word of warning—  
Some details may be quite gory  
And there is little glory.*

*Interstitial cystitis,  
An awful bladderitis,  
The faulty lining  
Had me pining  
For years.*

*The news came swift and sure:  
Nothing terminal  
But I was offered no cure,  
And it gave no inkling  
Of what I was about  
To endure,*

*The shivers and the shakes,  
Nearly tripped,  
And fell into a coma:  
Needless to say  
In the hospital I had to stay  
Quite a while.  
They had to wheedle  
For poking me  
With each and every needle.*

*This was but the start:  
Through it all  
Many new words,  
Medical bills  
Blood  
Leucocytes  
Proteins  
(and not those in meat, either)  
Mid-stream  
Monster (hahaha)  
Antibiotics  
And Finally  
Bag  
Stoma.*

*The saga continued  
Many, many years  
The parade  
All part of the charade,  
A lot blood  
And pain.  
All the tests I failed,  
Again and again.  
Finally the surgeon  
Had no more choice,  
Stepped in  
With his knife  
He saved my life,*

*Thus I lost  
Ten years plus—  
Gained a life.*

This is a personal account of my brush with this disease. It is not intended as an academic piece. Interstitial cystitis can easily be googled. I need to tell my story to gain perspective on an event that covered a significant period of my life. I also need to draw something positive from this experience to continue with the rest of my life. And perhaps I can inspire or encourage by sharing this story.

My story starts in 1989, the year I had my first fungal infection as a young woman. The only reason I remember this is because it was one of the few times in my childhood that I needed to consult a physician. As I grew older the occurrence and severity of infections increased dramatically. Medication after medication, procedure after procedure followed, but all failed to bring any kind of relief. In fact, some of the procedures were so painful that they had to be stopped. Eventually, on 30 September 2002, an ileostomy was performed. My then severely damaged bladder was removed and a stoma created.

Something I remember quite vividly is the constant pain. Only the severity of it varied. Sometimes it was so bad I could hardly walk upright. Then there was the stress of always trying to find toilets in public places. Right at the very end, the urine and blood simply flowed uncontrolled.

I have learnt a few valuable lessons:

- Do your research. The professionals do not always have all the answers. Just ensure that your research is factual and presents a balanced point of view.
- Educate your support system. Communicate to your loved ones about what you are going through. Sometimes you will have to be strong for your support system.
- Adapt your lifestyle. If something this dramatic is happening to you, you will also need physical strength to cope. ●

## Do you listen to your bag?

By 'Big P'\*

Technology has gone too far. Nothing is private anymore. A new gadget now hangs around my neck. It talks wifi, Bluetooth, and other frequencies with my hearing aids, which in turn talk to each other, and then it links in with my smart phone, which links in with my computer, iPad, door bell, key finder, smart TV and goodness knows what else. There must be thousands of gigabytes of high tech all clicking away that I, previously, was not concerned about. Anyhow it's got out of control. Everything talks to everything in my home—even my colostomy bags.

On my recent 80th birthday, I celebrated with a gin and tonic. Well, you know how things go. One wee sipple leads to another and so on. Anyhow I fell asleep with my hearing aids and the gadget still in and on. Then during the night I started getting these voices. It was my colostomy bags chatting away to one another.

'Hey guys this poop stuff isn't as bad as I thought it would be. Big P uses this deodorant. My inner linings love it. Great stuff,' says the pouch I am wearing.

'Oh that's good,' replied another bag from the toilet drawer. 'How did getting stuck on go?'

'Good,' replied my wearing bag. 'We're lucky Big P's skin didn't have any of the problems we were taught about. Had a shower just before, don't think there's any sticky or removers, skin soothers and such like. Oh! There could have been a little of that barrier stuff around.'

'That's all very good for you to talk about, but what about us?' said another bag in a quivering voice, this time from the storage cupboard. 'When you came out of the cupboard, what was the circumcision like?'

'Yep, I wasn't looking forward to that,' the drawer bag replied. 'We're not as lucky as the precuts. Whizz! Snip! Bang! Over and done before you can blink your peep-hole in the factory. Yes, Big P's got problems—not too bad, though. A wee bit shaky and his eyesight ain't much. Veers off the line now and then. Pretty slow. Takes a long time over the operation. Could have been worse.' Then: 'How are you guys getting on?'

'Oh, we're OK. But some new samples have just arrived. Different factory again. Say they've got something special. They carry on a bit upper-class or up themselves. Don't know how well we'll get on.'

'Quite well. You're technophobic, bag, retorted one of the new arrivals. 'You think you two brands have a monopoly here—well, just wait and see. We didn't come by chance, you know. Big P asked for us, so you ain't as perfect as you think.'

'Wait until he circumcises you!' responded another bag from the drawer. 'You're so far up yourselves you'll expect him to use pinking scissors on you.'

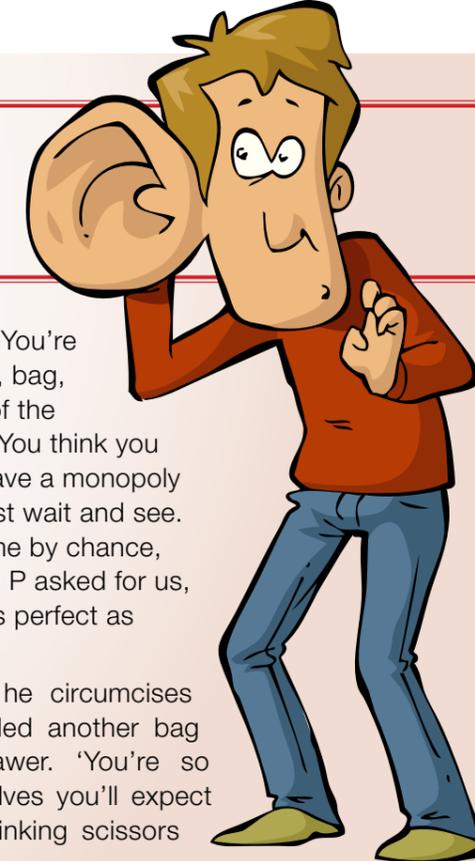
That sort of discussion and banter went on for most of the night. They discussed philosophy, the great hereafter; how all bags end up in a blue plastic bag and are taken to the almighty great tip. There bags that have been good will get to lie in peace for all time. Bad bags, which have sinned by leaking or tearing the skin, go to a terrible part of the tip where they have to live forever and ever with the nasties—they're plastic.

There were ribald stories of encounters with other bags from yet other factories who, with their Big Ps, met at the sun-bathing club. There egalitarianism was the rule and colostomy, ileostomy and urostomy bags were all equal. Drainable and undrainable—it made no difference. There was no longer bickering: they were all Stomamates or Pallypouches and respected each other. A sort of preparation for moving on into the big tip.

I thought of telling the bag who was critical of my surgically precise professional excisions that the comments made earlier on were quite incorrect, unprofessional and in bad taste. But then I realised—anybody hearing me, a retired medical man, ranting at a half-full colostomy pouch might form a misconception as to my sanity.

So I desisted. However, what worries me now with all these hi-tech gadgets is what other commodities, like those in my drinks cabinet, might have to say about me.

\*Big P—Patient, Person, Pooper, Piddler ●



# Going from strength to strength in Toowoomba!

by Margaret Brabrook

In February 2017 I had the privilege of leading the first meeting of Insideout Toowoomba Stoma Support Group. Unfortunately, in November that year, we decided to fold the group due to lack of numbers. Our five stalwarts were very disappointed—but there was a silver lining lurking under that cloud!

Our group had met once a month in a free meeting room provided by the council. At most meetings we had a speaker from a stoma product supply company to show us their products and answer questions. The volunteers at the local stoma office were very helpful—I made a poster that sat on the desk for people who picked up their supplies, and a flyer was included with mailed-out products. The hospital stoma nurses knew of us, too, as did a few doctors. Some people came just once or twice to gain information by talking to us or the stoma company rep, but others lived too far away or could not come on a weekday. The stalwarts were a great support to me, particularly when I had to miss two meetings when recovering from surgery.

After much deliberation we decided in October 2017 that enough was enough, and that we should disband. I thought that was the end of that, and felt that I'd failed in my aim to put stoma mates in touch with each other, particularly new stoma mates. But I was told, 'don't despair, you did your very best and at least now we know each other.' There were other messages of support and comfort, too.

Soon after our decision was made I had a phone call: 'I'm new to Toowoomba and want to book in to the support group.' Sadly, I had to tell the caller that we had disbanded.

One member emailed me: 'Let's meet for coffee anyway.' So in December we stalwarts gathered at a local café and you could not shut us up—we had a great time! And they said 'Let's do this again, that's all we need, just a get-together to chat.'

In December I had a phone call from a man who was about to face stoma surgery and was worried about the medication that he was taking for his illness. I knew nothing about that but I contacted one of our stalwarts, who was able to help him. I was stoked!

On the Facebook page of the Australia and New Zealand Ostomy Support Group I wrote that Insideout Toowoomba had folded. Then I got a message from Laurel in Toowoomba, who would have joined our group but she worked each weekday. And Rob from Rosewood emailed—she'd love to meet us! Leanne, another stalwart, told me that a lady had contacted her and would also like meet us. She called herself a 'bag lady'—love that!

January 2018, stalwart Margaret emailed me: 'Happy New Year, how are you?' and we emailed back and forth about—guess what!

Recently stalwart Shirley rang: 'Have you got any spare seals?' 'Yes,' I replied, so she came and sorted through my stash and took a few home. We had a chat about the new bag I'd been trying out and she took home the details as she

thought it might suit her daughter, who is also an ostomate.

It was then that I realised that we haven't folded, we're still here, we're just doing it in a different way—every cloud has a silver lining!

So now there are two groups, an afternoon group and a 'different times' group. The afternoon group meets at 2pm at the City Golf Club Toowoomba, South Street, on the third Wednesday of every second month—August, October, December, and so on. Come and join us if you're nearby or, if you'd just like a personal chat, you can ring me, Leanne Wilshire or Laurel Czynski. If you're homebound, perhaps you'd like one of us to visit you? Our details are in the support group info on the back page of this journal.

Laurel is the person who would have joined if we'd met out of work hours. She had an ileostomy due to acute, severe ulcerative colitis in October 2016.

Then she went back to hospital in February 2017 to have a total end colectomy and have everything made permanent. She says: 'It was the best decision I ever made—for me! It got me back to work and I haven't looked back.'

'It can be difficult when you work full-time, as most of the support groups seem set up for meetings during the working day. If there are ostomates in the Toowoomba-Darling/Southern Downs area who would be interested in meetings on a weekend, or just for dinner/coffee chats after work, I would love to hear from you.'

## 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. Flyers 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 9.00am to 11.30am  
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 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.  
Inquiries: Neil 0427 856 630 or Glennie (02) 6583 7060

## ILLAWARRA

Meets 10am to noon, April June, October and December (Christmas Party).  
Venue: 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 Lynda 0425 209 030 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.  
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).  
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

## SYDNEY - PENRITH AREA

Nepean Educational Support Group meets 2pm-3.30pm in April, June, August and November.  
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, 185 Fox Valley Rd. Wahroonga.  
Contact: San Cancer Support Centre (02) 9487 9061

## National Directory of Ostomy Support Groups

## TWEED-BYRON

Meets 3rd Tuesday of March, June, Sept., 2nd Tuesday in Dec., noon to 2pm.  
Venue: South Tweed Sports Club, 4 Minjungbal Dr., Tweed Heads South.  
Contact: Lisa Clare STN (07) 5506 7540.

## 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 2.00pm on the third Monday of each second month.  
Venues: Wangaratta: North-East Health, 4-12 Clarke St., Wangaratta, April, Aug., Dec. Benalla Community Health, 45 Coster St., Benalla, Feb, June, Oct. Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943.  
Email: mgpwang@gmail.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 0447 942 406 for more information.

### SUNRAYSLIA / RIVERLAND

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

### WARRNAMBOOL & DISTRICT

Meets at 10.30am 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, 9.30am to 11am on the first Friday every three months.  
For details, contact Terry (08) 9847 4701 or 0428 502 530

### PERTH (WAOA)

Venue: 15 Guildford Road, Mt Lawley.  
New members support orientation session: Second Saturday of every month, 12 noon-1pm.  
Weekend general support group: Second Saturday of every month, 1pm-3pm.

## QUEENSLAND

### BEENLEIGH

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

### BOWEN

Meets the first Wednesday of each month at Bowen Hospital, 10.30am.  
Contact: Natasha Leaver (07) 4786 8222 or Valerie McDonald 0407 691 160.

### BRISBANE

Brisbane Ostomate Support Visitors Service (BOSVS) is a new ostomate visitor service operating in the Greater Brisbane Area.  
Phone: (07) 3359 6500.  
Website: qldstoma.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 10.00am 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 Noy  
Phone: (07) 4921 0728

## SOUTH BURNETT

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

## SUNSHINE COAST

Sunshine Coast Stoma Support Group  
meets at Maroochy RSL Events Centre,  
Memorial Avenue (off First Avenue),  
Maroochydore, second Monday of every  
month, commencing 10am.  
Enquiries:  
Laurie Grimwade: (07) 5445 9008  
sid.and.laurie@gmail.com  
Janelle Robinson: 0409 762 457  
candjrobinson@bigpond.com  
Kathy Himstedt: (07) 5445 9270  
greg.kath1@bigpond.com

## TOOWOOMBA

Insideout Toowoomba Stoma Support  
Group Afternoon group: Meets the  
third Wednesday of every second  
month (Feb, April, June, Aug, Oct, Dec)  
2pm at City Golf Club, South Street,  
Toowoomba. Join us, ring for a chat,  
a home visit or email for info—  
Margaret Brabrook (07) 4635 1697,  
emby1936@gmail.com, Leanne  
Wilshire (07) 4630 0629,  
leanne.wilshire@bigpond.com.  
Different times group: Meets with  
Laurel Czynski, 04138 05809,  
laurel.a.469@gmail.com.

## 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'

Meets in Hobart on the third Friday  
of every month from 2pm to 4pm.  
Enquiries: Renata, Cancer Council  
Tasmania, (03) 6169 1900.

### NORTH & NORTH-WEST

**North:** Meets at Cancer Support  
Centre, Howick St., Launceston, on  
first Monday of March, June, Sept  
and Dec.

**North-West:** Meets Ulverstone Senior  
Citizens' Club, King Edward Street,  
Ulverstone, 10am-noon, on the second  
Wednesday of March, June, Sept  
and Dec. New and present members  
welcome.  
Contact: Adrian Kok  
on 0498 196 059

## SOUTHERN TASMANIA

Meet at Glenorchy RSL Club, Main  
Road, Glenorchy, 10am-noon on first  
Wednesday of March, June, Sept, Dec.  
New and existing members welcome.  
Further information:  
Adrian Kok: 0498 196 059

## 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: (08) 8234 2678

### FLEURIEU

Meet: 10.00am until 12 noon at the  
Flinders Rural School, Bay Road,  
Victor Harbour.  
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 Lavory:  
(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-  
down-under.webs.com

### MITROFANOFF SUPPORT AUSTRALIA

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

## Stoma Appliance Scheme Product Suppliers



### AinsCorp

PO Box 572, Niddrie, Victoria 3042  
Toll Free Number: 1300 784 737  
Email: service@ainscorp.com.au  
Website: www.ainscorp.com.au



### Dansac

PO Box 375, Box Hill, Victoria 3128  
Phone: 1800 331 766  
Email: customerservice@dansac.com.au  
Website: www.dansac.com.au



### Coloplast

PO Box 240 Mt Waverley Vic 3149  
Freecall: 1800 653 317  
Email: au.care@coloplast.com  
Website: www.coloplast.com.au



### ConvaTec

PO Box 63, Mulgrave, Victoria 3170  
Freecall: 1800 335 276  
Email: connection.au@convatec.com  
Website: www.convatec.com.au



### Sutherland Medical

PO Box 1194, Huntingdale, Victoria 3166  
Phone: 1300 664 027  
Fax: 1300 664 028  
Website: www.sutherlandmedical.com.au



### Future Environmental Services

PO Box 319, Blairgowrie, Victoria 3942  
Phone: +61 3 5985 2828  
Email: health@futenv.com.au  
Website: www.futenv.com.au



### Hollister

PO Box 375, Box Hill, Victoria 3128  
Freecall: 1800 335 911  
Email: customerservice@hollister.com.au  
Website: www.hollister.com/anz/



### Nice Pak Products

Free call: 1800 506 750  
Email: healthcare@nicepak.com.au  
Web: www.nicepak.com.au



### Omnigon Pty Ltd

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