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A mindset for success

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A wider role for STNs

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Controller: Hedy Ferreira
Secretary: Peter De Luca
Telephone: 1300 OSTOMY or
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Fax: (02) 9565 4317
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Kirrawee NSW 2232
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PO Box 1017
Hyde Park, Castletown 4812
Operating hours:
Monday 9.00am - 4.00pm
Thursday 9.00am - 3.00pm
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Secretary: Gwenda Williams
A/H (07) 4775 2303

QLD OSTOMY ASSN INC.

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PO Box 198 Moorooka 4105
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Admin (07) 3848 7178
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Web: www.qldostomy.org

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Settlement, 256 Stenner Street,
Toowoomba 4350
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Telephone: (07) 4636 9701
Fax: (07) 4636 9702
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Secretary: Bob Schull
Telephone: 0418 717 199
Email: bob.schull@bigpond.com

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Appliance Officer: Trina McRae
Email: wbostomy@bigpond.com

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1 Keele Place, Kidman Park 5025
Telephone: (08) 8235 2727
Fax: (08) 8355 1073
Email: colosa@colostomysa.org.au
Website: www.colostomysa.org.au
Distribution of supplies: Mon - Fri
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Secretary: Jeanette Aguilera

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Secretary: Donna Bengie
Telephone: (08) 8234 2678
Email: info@ileosa.org.au

TASMANIA

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Amenities Building,
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Sec/Treas: Sue Hoyle
Email: admin@ostomytas.com.au

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Suite 221, 98 Elizabeth St.,
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Administrator: Karen McKenzie

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Email: ileovic@onestream.com.au
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Email: poainc1@bigpond.com.au

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Coordinator: Mrs Lilian Damiani

WARRNAMBOOL & DISTRICT OSTOMY ASSN INC.

279 Koroit St, Warrnambool 3280
Telephone: (03) 5563 1446
Fax: (03) 5563 4353
Email:
warrnamboolostomy@sw.net.au
Operating hours:
Friday 12 noon - 4.00pm
Secretary: Heather Love



Editor: Peter Fuller

Foundation Editor: Barbara Callcott

Editorial Contributors: Margaret Allan,
Andrea Farrugia, Peter Fuller, Anne Kelly,
Kylie McGrory, Jodie Nelson, Geoff Rhodes,
Helen Searle, David Wright.

Correspondence/Contributions to:

The Editor, *Ostomy Australia*
PO Box 3378, Weston Creek, ACT 2611
Phone: (02) 8011 3535

Email: Journal@AustralianStoma.com.au

These contact details apply only to matters
directly associated with *Ostomy Australia*
Email, Word or PDF documents are preferred.

Published by:

Australian Council of Stoma Associations Inc.
Website: www.australianstoma.com.au
Email: feedback@australianstoma.com.au

Patron:

His Excellency General the Honourable
Sir Peter Cosgrove AK MC (Retd)
Governor-General of the Commonwealth
of Australia

Executive Members:

Geoff Rhodes — President
P.O. Box 152, Erindale, ACT 2903
Email: acsapres@australianstoma.com.au

David Munro — Vice President

PO Box 370, Chermide South, QLD 4032
Email: acsavp@australianstoma.com.au

Robert Barsing — Treasurer

PO Box 1254, Harvey Bay, QLD 4655
Email: acsatreas@australianstoma.com.au

Rosemary Quick — Secretary

PO Box 2427, Salisbury Downs, SA 5108
Email: acsasec@australianstoma.com.au

Printed by:

Graphic Print Group
Graphic House, 10-14 Kingston Avenue,
Richmond, SA 5033
Phone: (08) 8443 8011
Fax: (08) 8234 0226

Graphic design by:

Graphic Print Group

Illustrations on cover and pages 4, 19, 26, 28 —
Shutterstock

Advertising enquiries to: The Editor

Advertising & copy deadlines:

Issue	Copy and Advertising
April	1st February
August	1st June
December	1st October

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Volume 27
Number 1
April 2018

Print Post Approved
PP 100008088
ISSN 1329-959X



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PRESIDENT'S MESSAGE

I am pleased to report that the Stoma Appliance Scheme (SAS) continues to operate efficiently and effectively. The dedicated teams in our 22 associations continue to support their members by delivering the products available under the scheme whilst also providing personal support to new ostomates.

Adjusting to life with a stoma is a confronting and challenging journey into the unknown for new ostomates. Those of us who have had a stoma for a long time have generally made peace with our stomas and lead very normal lives. As an example, I play golf on Saturdays with the same extended group of about eight mates. In mid last year one of our group dropped out and I asked his closest friend where he was. I was told he had been diagnosed with bowel cancer and was about to undergo surgery that would result in a stoma. I told the close friend that I would be happy to have a chat with him, as I had a stoma. The close friend then said it was not necessary as he had also had a stoma and had been supporting our mate since he got his diagnosis. Our mate has since been reversed and we expect him back on the course in the near future.

This issue of the need to support new ostomates was also brought home to me at around the same time when a close family member was diagnosed with a condition that has resulted in a permanent stoma. He too has received excellent clinical support from the stomal therapists and doctors involved. I was thankful that I was in a position to provide support from both a practical and personal level and to help him on the journey of acceptance and adjustment to life with a stoma.

The reason I raise these issues is that I have been involved in the stoma movement since 1960. When I first joined an association the Stoma Appliance Scheme did not exist and associations existed purely to provide mutual support and advice to fellow ostomates.

The establishment of the scheme in 1975 saw the distribution of supplies added to the role of associations. In the period since 1975 the SAS has expanded to include more than 3500 items and support around 45,000 members through 22 associations.

The amount of effort required in associations to distribute product has increased enormously in recent years. One of the challenges for associations, particularly the larger ones, is to continue to deliver product to members and also provide the mutual support that was the basis for initially establishing associations back in the 1950s and '60s. In our technological age, social media has become a powerful vehicle to reach out to ostomates without being limited by geographic restrictions. Social media is being used

to great effect by several associations and may be a way for other associations to engage with their members.

From recent personal experience, one of the best ways to support new ostomates is to engage in personal conversations that allow them to express their concerns and discuss the challenges with someone who has been there. Perhaps it is time to take a leaf out of the

Lifeline organisation and establish a Stomaline for those new ostomates who can't get to an association or support group to initiate that personal contact.

I would welcome feedback from new ostomates on their views on whether easier access to one-on-one discussions with more experienced ostomates would ease their journey.

Geoff Rhodes PRESIDENT



Time for a Stomaline?



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Ostomates continually tell us how much pleasure—and how much useful information—they get from the journal. But we rely on your contributions.

When you send a contribution, we ask you to follow a few simple guidelines:

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- please don't identify medical professionals unless they have agreed to their name being used;
- try to avoid identifying companies or their products;
- give us your full name and address, and your contact details. We use full names whenever possible.
- photographs should be JPGs and at least 1MB in size. If there are people in the picture, let us know that they agree to publication.

Send your contribution to:
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PO Box 3378, Weston Creek, ACT 2611.

Your say – Letters to the editor

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

Dear Editor,

I've had a stoma a while now but would like to suggest that, every now and again, a visit to your stoma nurse is essential. I was struggling because I had problems with a sticking baseplate. I was using extenders but they were not quite right, as I required too many. A stoma nurse showed me a different brand and—wow! They were much better. I've decided not to be brand loyal and currently am using three different brands for different purposes—all providing what is best protection.

I would actually be interested in the cost of all items as I'd like to use the least-cost items for my needs. Every person has different needs and challenges and I'd never deny someone a product, but maybe the list of prices could be published so that people could make informed decisions about costs.

Bronwyn Kelleher, VIC

Dear Editor,

I have been contacted by a man who has an elderly father who is almost blind. His father, in his mid-nineties, has recently had a colostomy and also has arthritis in his fingers. In an effort to keep his father as independent as possible, the son, Ben, has designed a device for assisting the placement of a two-piece pouch on to its baseplate.

The son is asking how many visually impaired ostomates have the same difficulty and whether this device, if manufactured and made available, would be useful for our aging population in which macular degeneration is an issue.

I have no idea how many people are affected by poor eyesight in Australia, but I recognise that there are likely to be a significant number. The device might also assist sighted ostomates who have other issues in correctly placing their pouch.

To date the son has not carried out any market research to determine likely requirements before deciding to go ahead

Continued page 6

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to patent or manufacture his device, but is very keen to be contacted by STNs or ostomates to discuss the idea. He has contacted two suppliers of ostomy products in Australia and at the time of writing was awaiting their response. People needing further information can contact benphome@iinet.net.au.

Lorrie Gray, WA

.....

Dear Editor,

We all know it can be difficult to find comfortable pants when you have a stoma. After trying countless pairs of pants, many of which seemed perfect for at least a couple of hours, I have found some that work for me. I wear these to work every day, and often on the weekend as well. These Stretch Twill Pull-on pants can be ordered on-line.

Anne Kelly, NSW

.....

Dear Editor,

As a dual ostomate, I have long had issues with disposal of so many bags and pads. Thanks to a gift-giving grandmother, I learned of a product that is perfect for disposal, not of nappies as intended, but for all those smelly used bags. I have ‘discovered’ a Timmee Tippee Sengen bin. In a word, it is brilliant. A neat and efficient disposal system so no more smelly bathroom; I just had to share this discovery. Google it and I believe you will be as surprised and pleased as I have been.

Elizabeth Mosely, QLD

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Dear Editor,

I have been a ileostomate since June 2016 and attend the local monthly ostomy meetings which are most informative, both from the group leader and other ostomate friends who share their hands-on tips.

My confidence grew over the months after surgery and I decided to have a holiday in Japan, armed with instructions to photograph special toilets. What a revelation!

Apart from being a beautiful country with the friendliest people, they also have ostomy toilets just for us.

Around 90 per cent of all public amenity blocks have this facility, which is installed at a height to enable us to stand and empty our pouches without having to half undress. The photographs on this page show one of the facilities and the identifying logo.

Val Padley, QLD



Top: A well-equipped ostomy toilet in Japan and, below, a sign indicating an ostomy toilet.

Dear Editor,

A urostomy patient, I have recently returned from a week’s holiday in the Eurobodalla region, about 850km from home. About halfway through my stay I discovered I had not packed enough bags to go with the bases for the two-part system I use.

What a stupid omission on my part, I thought; I must get more from the chemist. A large one I called at did not have any but offered to phone around to try to locate some, which I was expecting to gladly pay for. But they had no success. By this time panic was setting in, being on the last bag, and I decided to visit hospitals in the area.

They seem to only know about the one-piece bags but I was grateful for anything at this stage. One had only one and would not part with it to a non-admitted patient.

I struck gold at the second with a lovely nurse discovering she had a few in the store. She gave me enough to see me through as she said that, even worse, she had once gone overseas leaving vital requirements at home.

This is a lesson to us ostomates to take care in packing sufficient supplies, as you may have Buckley’s chance of getting any when travelling, other than from your regular supplier under the scheme. I am eternally grateful for not having to cut my stay short and bolt for home. I wonder why large chemists do not stock a few for emergencies?

Clive Edmead, VIC

.....

Editor’s note: Travellers who need emergency supplies may be able to get something suitable from a hospital. They will also find that the nearest local stoma association may be able to help, and supplier companies are also able to provide supplies in case of urgent need. Contact details are published in this journal.



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Col and Uri – My Best New Friends

By David Wright

After three years of battling bowel cancer I have become bosom buddies with two new friends. Their names are Col and Uri. I truly treasure their friendship and do everything in my power to maintain an excellent and positive relationship.

But to go back a few years. After a tumour was discovered on the outside of my rectum there was a rapid process to get me into a surgical theatre to get the 'thing' out. That surgery left me with a shortened large bowel and a temporary friend named Ili. The relationship with Ili was short-lived but in the time that we were friends I learnt to respect his opinion on all things related to food. Ili didn't like spicy things, broccoli, cabbage, baked beans and fruit with tough skins. He always let me know when I sneaked one of the 'banned substances'.

Ili was very vocal when he felt like making a statement. In fact he could be quite embarrassing when he voiced an opinion in crowded places.

After 14 weeks or so Ili and I parted company as friends and I have to say I wasn't too worried about the separation. However, ending that friendship started a two-year period of constantly battling issues with what was left of my lower bowel. In fact at times I felt sorry that Ili and I were no longer buddies.

Almost two years to the day of my bowel surgery my surgeon ordered a CT scan of the pelvic area to make sure all was good on the cancer front. Alas, it was not a good result, with very obvious signs that I had a recurrence of the cancer on my tailbone.

The speed of the surgeon's staff was mind-boggling. In the space of three days I had an MRI,

saw a radiation oncologist and had a biopsy taken of the cancer. This all arranged just a few days before Christmas.

I was referred to a specialist colorectal surgeon who operated on complicated cancers. I also asked to have my radiation and medical oncology appointments at Nowra. Next I underwent six weeks of radiation and oral chemotherapy. The radiation was a nightmare but the oral chemo, even though it was a heavy dose, caused very few problems.

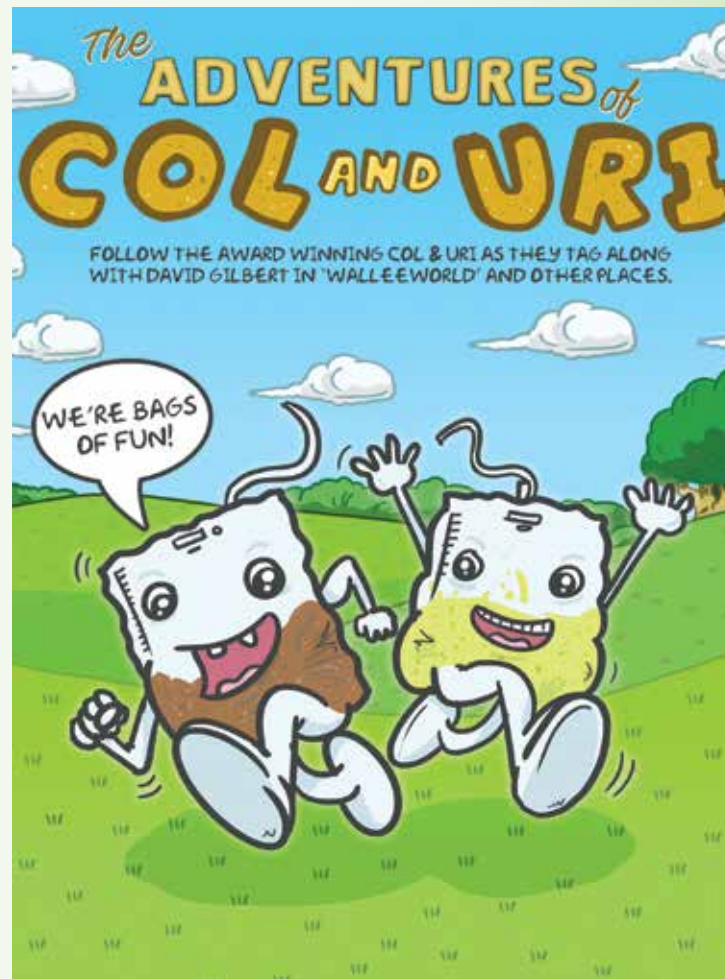
So with the radiation and chemo completed I was given three months for my body to recover before undergoing radical surgery at Royal Prince Alfred hospital. Recovery from the radiation was uncomfortable because of the short-term damage that the treatment had caused. Virtually no bowel control at all, resulting in the need to wear Depends for a couple of months.

On the 31 July I entered hospital to have a pelvic exenteration procedure: 14 hours in surgery with a team of many surgeons got the job done. What followed was a three-week stay at RPA that can be best described

as painful. Not painful from a body point of view but rather the chaos that was all around, day and night, in a very busy inner-city public hospital.

After 20 days of incarceration I was discharged. After overnighing at my daughter's I was on my way home. It took almost three weeks before my appetite returned and in that time my weight dropped to 77kg, down from 86kg when I went into hospital.

That's all well and good, but what about Col and Uri?



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With my bowel and bladder removed there was a need to replace the function these organs performed. That's where I found my new friends, Col and Uri. These two guys are helping me get through each day by conducting essential voiding activities. Col has the dirty job while Uri is the busy boy day and night.

So, let me introduce the boys one at a time.

Firstly, meet Col. Col is an extrovert. He is a very vocal person who always has an opinion on the right things for me to eat and drink. He is not averse to interrupting other conversations with his opinion. He can either comment loudly or be quite softly spoken. Col can be quite embarrassing when lecturing at length in public places. I definitely value Col's input as it generally can lead to an outpouring of politician speeches (you know what I mean). Col's biggest shortcoming is his love of all things ballooning. He plays with balloons whenever he likes. Unfortunately, he seems to save his playtime for when I'm trying to sleep.

Uri, on the other hand, is the introvert. He doesn't make his presence felt in the same way as Col. That said, Uri is very active and goes about his business with a constant, and sometimes annoying, efficiency. Uri's main issue is his almost insatiable thirst. He likes his host to consume at least two litres of liquids a day. Unfortunately beer and wine don't count (bugger). Col and Uri get on well except for their host's love of soft drinks. While Uri agrees with the fizzy drink intake Col often takes exception and voices his displeasure.

Col and Uri are definitely related, as they share a common bond of intestinal fortitude.

Col and Uri both have outer wear that helps them to do what they do. As both are collectors, they need to have methods of getting rid of the junk they accumulate. Uri's is the most efficient,

with the emptying process being somewhat like pouring a wine from a cask valve. Uri's storage area is nowhere near the capacity of a fully functioning bladder, hence a requirement of many emptyings over the day. As Uri's work never finishes, he needs assistance overnight. Enter a two-litre night drainage bag. I often wonder about the designers of this bag as my overnight output is usually in excess of two litres, which makes for a pit stop sometime during the night.



Col, on the other hand, is a little more labour-intensive when it comes to the process of pushing the waste out. Then a sectioned fold-up valve closes the exit via a Velcro tab. Gas is a constant problem for Col due to inappropriate food or drink intake. His clothing has a gas release functionality which is very slow-working. His host's gas production is exceptional, so Col

has an ongoing requirement for the manual release of pent-up gases.

Col and Uri both have a clean-up and clothing change every two days. Showering is done with appliances on (they are waterproof) as both the boys are unpredictable and unclothed voiding is not appreciated. Cleaning Uri is always first, as he is the most prone to sickness (infection). Removing, cleaning and reclothing takes about 10 minutes. Col's removal, clean-up and reclothing takes a little less than that of Uri.

Col and Uri both have formal wear, courtesy of my daughter.

The boys definitely are sensitive and a positive attitude to their needs goes a long way in keeping them happy. I have found that including them in conversations with my family and friends helps everyone around me appreciate the boys as much as I do. Don't be ashamed or negative about them, be proud of the work they do for you. ●

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Ceramide

The new ‘buzzword’ in stoma skin care



STN Paris Purnell explores the new trend in ostomy care- the addition of Ceramide to ostomy barriers, and what it means for your skin

We are lucky in Australia to be blessed with a wide variety of stoma products, but sometimes the choice can be confusing and navigating new products a little daunting- even for Stomal Therapy Nurses! However, keeping abreast of new developments is important, as improvements in skin barriers and pouches may mean discovering products that better support healthy skin around the stoma, achieve a better fit, or are easier to use than those of the past.

You may have heard of the new buzzword ingredient ‘ceramide’ in ostomy products - but what exactly is it?

Found in the skin’s vulnerable outer layer, ceramides are naturally occurring, waxy lipid molecules that help skin to retain its vital hydration and structure. A major component of healthy skin, ceramides lock skin cells together to form an impenetrable protective barrier from the rigours of everyday life. Time and environmental exposure depletes the natural ceramide levels in skin – compromising the protective barrier and making it more susceptible to factors

which leave skin feeling dry, itchy, irritated, and sensitive.

Whilst about half of those living with a stoma will report peristomal skin issues at some point in their lives, skin problems don’t have to be a normal part of living with a stoma. Maintaining skin integrity from the start is the key to maintaining both healthy peristomal skin and comfort, and avoiding the damage that can lead to a breakdown in skin integrity, pain, and infection.

Hollister Incorporated is the manufacturer that has brought ceramide-infused skin barriers to Australia, under the brand CeraPlus. A recently published clinical trial showed that peristomal skin complications were significantly more likely to resolve with the use of CeraPlus (treatment 53% vs. control 29%) .

Further, significantly more CeraPlus users were very satisfied with the barrier’s overall performance, prevention of leakage, and prevention of itching (75% vs. 55.2%)¹.

If you have been suffering from peristomal skin issues, or simply want to prevent them from occurring and support healthy skin with every barrier change, ceramide infused products may be worth looking into. With robust clinical evidence to support its use in ostomy, ceramide may be much more than a buzzword after all!

Reference:
1. Colwell, J., Pittman, J., Raizman, R. & Salvadalena, G., 2018. A Randomized Controlled Trial Determining Variances in Ostomy Skin Conditions and the Economic Impact (ADVOCATE). J Wound Ostomy Continence Nurs, 45(1), pp. 37-42.

“Ceramide infused products help lock moisture in the skin, keep irritants out, and strengthen the skin's natural barrier to keep it healthy”



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Clinical review, an expanding role for STNs

By Andrea Farrugia



Andrea Farrugia in her OAM office

Andrea Farrugia is the Clinical Nurse Consultant, Stomal Therapy, at Ostomy Association of Melbourne. This article is based on a presentation at the ACSA Conference in Melbourne in October 2017.

Stomal therapy has been my dream job, but it's safe to say that it is a specialty that you have to have a genuine interest in and be passionate about.

I have been fortunate to work exclusively in stomal therapy for the past 27 years both in public and private hospitals, and also at the Colostomy Association of Victoria for 13 years and then the Ostomy Association of Melbourne for the past nine years.

Stomal therapy and treatment has changed greatly over the years—nowadays it seems that refined surgical techniques, improved treatment options offering better outcomes, more sophisticated stoma appliances and wound care products become available every year. Wise choices are needed to select the most suitable products for comfort,

security and discretion, and to reduce waste and costs.

But how does the person with a stoma, the end user, choose from the many products available? STNs are there to help you to decide. Beyond guidance with initial decisions, ongoing reviews can help to maintain health and a sense of wellbeing.

As a new ostomate's condition improves after surgery, they start to understand what they are dealing with. They might then be ready to make decisions about managing their stoma and selecting products they want to try. For me, an STN working at an ostomy association, this is an exciting time to guide and help the person with a stoma make choices that will lead to them becoming more confident and taking charge of their life.

With so many products available, good decisions are not always easy. Many colleagues and ostomates are concerned that choice can be confusing. People can order inappropriate products, leading to further cost and distress.

Ostomates can be given ample information and have an opportunity to look at care strategies in discussion with their STN. People

should not be told which products to use, but should be active participants, decision-makers in their ongoing stoma management. Regular review with a STN can prevent difficulties and increase comfort and confidence in daily life. Reviews can equip a person with a stoma with the skills to manage their condition successfully.

Ideally, someone with a stoma should see their hospital-based STN for ongoing review after discharge, building on the rapport and trust established with the therapeutic relationship, but this might not be possible, for various reasons—distance and accessibility, cost or limitations on outpatient reviews.

A limited number of visits from a community STN through district nursing may be available after discharge, but not always. Then what? Where do people go if they cannot return to their hospital STN?

This shows the need for STN clinics to be established in stoma associations.

In the April 2016 issue of Ostomy Australia, ACSA president Geoff Rhodes called on ACSA, the Australian Association of Stomal Therapy Nurses (AASTN) and the Commonwealth Department of Health to explore setting up a co-ordinated, comprehensive support system for ostomates. He has repeated the call subsequently.

Ostomy associations across Australia recognised many years ago that their members needed reliable access to STN review. Some have employed or contracted STNs to provide a clinic to meet this need, or may have an agreement with their local hospital.

But the task is large. At September 2017 the AASTN had more than 470 qualified members, plus 21 student members, to serve some 46,000 ostomates around

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Australia—yet only 13 were working with ostomy associations in five states. That averaged 48 hours a week across Australia. We need to do better.

Victorian associations have been running STN clinics for years. The Colostomy Association of Victoria clinic started in the early 1990s and has run continuously for more than 24 years. The Peninsula association has run its STN clinic for at least 20 years, and Ostomy Association of Melbourne, where I work, has been operating for nearly nine years. Demand last year led OAM to increase the STN clinic schedule from nine to 10 appointments a day, two days a week.

So why is it so important for people to have easy access to stomal therapy nurses in the community?

For someone coming to terms with managing a stoma, a clinic provides education and support. For those having difficulty coping with the change, it can offer realistic expectations for recovery, discuss strategies, put setbacks into perspective, and encourage the person to look forward optimistically. Clinical review can help to keep people on track, avoid stoma management difficulties and maintain independence.

People often suffer in silence. I suspect people sometimes think that some discomfort is a normal consequence of having a stoma. Often people believe they should try to solve problems and manage difficulties themselves—it goes to our basic desire to be self-caring and continent.

I see it time and again: people who feel embarrassed because of a skin problem, or leakage issues that have become unmanageable. They feel nothing can be done. This becomes their new normal. They are stoic and put up with the discomfort they believe is expected. Others believe the nurse is so busy

that they don't want to bother her or anyone else with their small worries; or they may fret it is a complication of their initial disease and become fatalistic.

So the benefits of a stomal therapy clinic are many: to alleviate suffering, to build confidence and self-care, to increase independence, and to contain costs by reducing product use and waste.

We need to ensure that people with stomas feel comfortable to come for check-ups each year, or more often if they are having difficulties. Increased awareness, education, and the availability of stomal therapy clinic services will hopefully encourage more people to access these services rather than suffer in silence.

Having a stoma should not mean a life of sore skin and discomfort

We can see that people with stomas need access to regular reviews—but what of members in nursing homes? Unless they can be accompanied and are mobile enough to be brought to a clinic, they have little to no hope of accessing stomal therapy review.

Ostomates in nursing homes can be the most vulnerable in our community. They often rely on personal carers who have limited experience or training in stoma care. How do we tackle the frequent requests to STNs and ostomy associations from nursing homes for education and patient review?

I recently asked STN colleagues for their thoughts on handling these

situations. Though there are no easy answers, some suggested a visiting STN service to provide clinical review in nursing homes. It would include ordering of products and staff education.

But the idea raises important questions. Who would administer and pay for this service? How would it be co-ordinated with the nursing homes, assuming their administrations and ostomates' families consented? If staff education was offered, what form would it take? Would the staff require onsite education specific to their residents' needs, supported with written and or web-based programs and resources?

The challenge is to find a solution. It is in our best interests to come up with ideas and develop strategies as a priority.

One advance that would benefit ostomates and STNs alike is the availability of universal patient records. A standardised computer program available to all STNs working at associations could record patient histories, upload clinical photos and collect statistics and data. Records could be held in a professional format while ensuring privacy and security.

It could help STNs to keep track of members accessing the clinic service, record particular difficulties and conditions, and include a format to enable professional letters for referrals or information for colleagues and medical staff.

Having a stoma should not mean a life of sore skin and discomfort. People with stomas should not put up with leakage, skin problems or loss of confidence. Regular review with a stomal therapy nurse or at the first sign of trouble can nip problems in the bud. All people with stomas, across all parts of our Australian community, should have access to stomal therapy advice and review to reduce suffering and improve quality of life. ●

Two decades of getting together

How does a support group thrive for two decades? It's important to give people who attend the kind of information they want and the activities they enjoy, but so too does a certain informality. 'We don't call it a meeting,' says Marj Noy. 'We call it a get-together.'

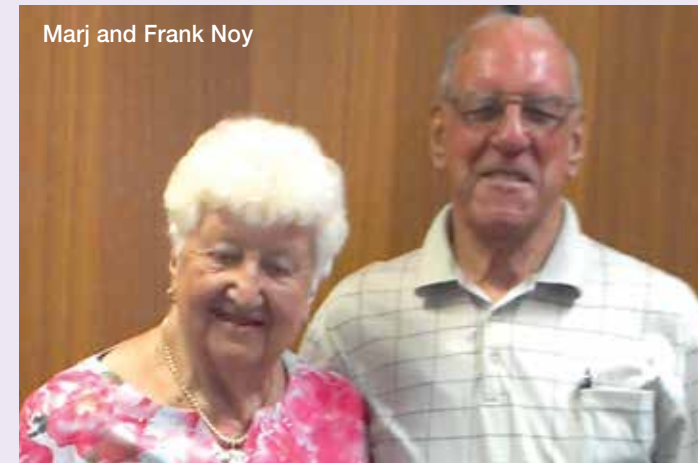
Marj and her husband, Frank, have been co-ordinating the activities of the Rockhampton Ostomy Support Group since April 1998, when 32 people from the city and the surrounding region on Queensland's central coast met for the first time at the Community Health Centre.

The group grew out of an open day for local ostomates when then national president Gerry Barry talked about the national stoma scheme and mentioned that in southern Queensland, support groups had been set up to provide forums where ostomates could meet, share experiences and hear about new products and techniques.

To Marj and Frank, that seemed like a good idea. How do we get started? she asked. All you need is to get a co-ordinator, Gerry replied. 'All the people that were at the open day said—you work out a time, advertise it, and we'll all come,' Marj recalls. The Noys did, and have been co-ordinating ever since.

The group has no office-bearers or committee, though there have been plenty of helpers over the years. STN Enid Vaughan was a foundation member and still attends, though now retired. So too does Shirley Hewerdine, the current stomal therapist at Rockhampton Base Hospital. Sometimes company representatives make the trip to Rocky, sometimes there's a video, and there's always a raffle to raise enough cash to cover the makings for afternoon tea. Everyone brings a plate. The health centre comes free of charge.

Marj and Frank Noy



'We all like to have a bit of a natter over tea on a Saturday afternoon,' Marj says. 'We have lovely afternoons, with lots of laughs.'

Numbers have fluctuated over the years, and attendance is now around 25. But, Marj says, at nearly every get-together someone new comes along. 'Frank and I have had a lot of pleasure being co-ordinators for all this time, and met many wonderful people. It's been an eye-opener to me, and we've made many friends.'

Still, at 84 and 86 years of age, Marj concedes that co-ordinating is 'starting to get a bit much for us'. It might be time for someone else to step up—though, Marj says, she and Frank would still lend a hand.

The Rockhampton group meets at 1.20pm on the third Saturday in February, May, August and November, and there's a Christmas get-together as well. The next get-together is on 19 May. ●

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Creating a mindset for success is a new feature by Jodie Nelson, 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. Jodie is a proud long-term ostomate who volunteers with the Queensland Stoma Association support group and is passionate about helping ostomates and their families to accept and embrace their 'new normal'.

LET ME begin my story in the late '80s, when bad hairdos, bad attitudes and bad fashion were at their peak. Bikinis were high-cut and definitely not for the faint-hearted; jeans were high-waisted to show off your tiny, tiny, waist. Women didn't fart, so men thought ... they passed wind in private because that's how a Lady was expected to behave. Ah, the '80s ... talk about pressure!

In 1989 I left school, started my dream job as an apprentice hairdresser and was going out with the most popular guy in our area. Not only was I living the dream but I was also a top sports woman ... that was, until two weeks after my 18th birthday.

Suddenly I was losing weight without trying, which wasn't a bad thing in my eyes as I was able to wear those 'barely there' bikinis. Before I knew it I had lost 14kgs in three weeks. 'Wow,' I'm thinking, 'Who needs Jenny Craig? I look amazing!' All my friends and family were commenting on how well I looked and commended me for losing weight. In fact I was underweight, as I was only 162cm tall and weighed just 43kg, but everyone kept telling me how great I looked, so I didn't mention all the unpleasant things going on inside my little body. Remember ... a Lady didn't fart in public, so after each meal at home I had to race outside, jump into my car and take off to the public toilets at the beachfront, just so I wouldn't be teased for the offensive smell that would be left in the toilet at home. Yes, I'm sorry to say but I was a closet farter and pooer. Nobody would be at the public toilets at night because there wasn't any power! This was my safe zone!

Fast-forward another two weeks and my sports coach took me aside to ask if I had an eating disorder. No, I



responded, what's the problem? The problem was he had to drop me from the team because physically I didn't have the strength or endurance to keep up with the rest. He was afraid for my health and I wasn't welcome back to training until I sorted out whatever was going on.

At this point the penny dropped. Maybe I should go to a doctor? So I booked myself into a doctor I had never met. His very first question was—how long have you been purging your food? Before I could answer his shocking question, he commented that a lot of young girls chose to have an eating disorder. What? Since when does anyone choose to have any disease, you moron, I screamed? Obviously, I wasn't welcome back there, so it was time to talk to my Mum. Mums fix everything, right?

On 5 August, 1989, I walked into my doctor's office and he immediately called an ambulance to take me to hospital. Three days later, after drinking copious amounts of salty water, I had a colonoscopy and was diagnosed with Crohn's disease. I was placed on prednisone, and this is when my life became really crazy. Suddenly I went from my dream life to living a teenager's worst nightmare. I went from partying with friends and ordering QFs to a world where FBC, CRP and ECR

I allowed my negative thinking to govern how I lived. I felt guilty and to some extent like a burden

were my new normal; where having a tube stuck up my bottom or down my throat was normal. Overnight I became a double agent, so to speak, as my friends had no idea what was going on and I had decided to fake it until I made it rather than talk to them about poo.

Prednisone made me anxious, put on weight, and gave me acne—and not the type you have on your face! OMG! I have to get off this immediately! Instead of complying with my doctor's request to ease off the medication gradually, I stopped immediately—and there is where I learnt my first valuable lesson in this new world I had unintentionally joined.

The next thing I knew I was back into hospital and on an even higher dose of prednisone. I stopped going out with my friends until I had lost enough weight and became 'normal' again. It was many years before I realised how detrimental this mindset would be to my health. When you are chronically ill you do everything in your power to be 'normal'.

I had to give up hairdressing and took a job in an office at a transport company. Nightmare number two! Oh, congratulations Jodie, we are going to offer you a position as long as you pass our medical. Are you kidding me? Off I go to the doctor, and I have to be honest and tell him I have IBD. Thankfully I passed my medical and then I was on my way! That was, until a couple of months later, when I collapsed at work and was hospitalised. Oh great, I was thinking, now I have to tell my employer about my disease and discuss poo. How embarrassing! I was scared he would fire me on the spot. He didn't but, again, due to my mindset, I decided I had to work longer and harder than everyone else to make up for my disease, because who knew when I'd have to go back to hospital and have time off?

This was another poor decision for my health. I allowed my negative thinking to govern how I lived. I felt guilty and, to some extent, like a burden to my family. I just wanted to go back to the days of being normal. I was either flat out or flat on my back, and nothing in between.

This pattern would go on for the next few years, until my Crohn's was so out of control that I had no choice but surgery. For me, 1997 was a big year: I had surgery in April and was married in October. Fast-forward a couple of years, I'd separated from my husband and had my next

surgery, which was for a bag that apparently matched all shoes. You guessed it, a full colectomy resulting in an ileostomy.

Infection after infection, tears, anxiety and eventually acceptance, all without any community support. It was a lonely time. The internet had been invented but wasn't used in Australia at the time, so Dr Google and online support groups didn't exist. Everything an ostomate tried was through trial and error. Your only support was from stoma nurses and your local ostomy association. They were absolute legends, but you know what? They can't be with you every single day.

I often say if there was a perfect age to have the operation it would have been the age I was, 28. You are young enough to adapt but old enough to have gone through the awkward years.

Since 2001 I have had a few major surgeries, all with varying results. If I'm being honest, most difficulties after surgery were due to my poor mindset and my health before the surgery. I was generally in a state of shock and fearful of what lay ahead. Some of the questions occupying my mind were—how much pain was I going to be in when I woke up? How long would I be in hospital? Sometimes it was 'I can't do this again! Why can't it be someone else?' All the while friends and family were telling me how brave I was but ... was I

really? In my private space I was terrified.

All that changed last year with my latest surgery. After a year in and out of hospital with adhesions and bowel obstructions, it was time to operate. Initially I cried and thought the worst. My surgeon said he would operate the following day.

Later that night my surgeon returned and I asked him for some time. Time to get my head right, time for me to do some research and time for him to prepare. Thankfully, he agreed. For me, this was the first time I had taken control of my own health. This was also the first time I hadn't seen myself as a victim. This time I knew the outcome would be different. This time it was.

Jodie ●

Jodie Nelson provides personal counselling and can be contacted via her website, www.thechangingme.com.au; on Facebook – The Changing Me; or on 0407 868 588.



VIETNAM, A TRAVEL DREAM COME TRUE

Anne Kelly tells how she satisfied a long-held wish to travel in Indo-China

Vietnam—I'd dreamt of travelling to Vietnam for decades but never got there for a number of reasons, including children and finances. Last November I finally boarded the plane with my husband for 10 days of wonderful people, incredibly beautiful scenery, and fabulous food, shopping and accommodation.

Hanoi was fantastic and vibrant, Ha Long Bay so peaceful and Hoi An very beautiful. The weather was as varied as the scenery! The staff from the tour company who arranged all our transfers were professional and friendly. I would recommend Vietnam to anyone. We would love to go back for a longer holiday, including to Ho Chi Minh City, but then of course there are so many other places to visit.

I had colostomy surgery 16 years ago for stage 3 bowel cancer, and after a difficult 12 months of getting used to the colostomy bag, chemotherapy and radiation therapy, severe depression due to early menopause and a gradual return to work, I've been thoroughly enjoying life.

I use drainable bags for work and holidays as they can be emptied instead of changed, and consequently result in less rubbish to dispose of as well as saving time—I just use closed bags at night. I packed additional supplies in my carry-on luggage on our trip to Vietnam but didn't need them. I take an acidophilus capsule every night before dinner (good for reducing wind and important for office work!) and was able to find some capsules to take overseas that didn't need refrigeration.

Now that I'm a medium-term owner of a colostomy, I hope to do a lot more



Anne Kelly at a sewing shop in Hoi An during her travels in Vietnam.

travelling and stay as fit as possible. I love swimming, and have asked the personal trainer at my local gym for exercises that ensure my stomach muscles stay strong and reduce the risk of a hernia.

Editor's note: Ostomates who plan to travel may find it useful to seek advice from their doctor or stomal therapist. Readers who wish to contact contributors who are experienced travellers can write to Ostomy Australia, PO Box 3378, Weston Creek, ACT 2611, or email journal@australianstoma.com.au.



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The rise of ostomy associations

In the November 2017 issue of Ostomy Australia, ACSA Administration Officer Kylie McGrory looked at the evolution of the Stoma Appliance Scheme. In this, the second of three articles, she shows how the scheme has influenced the development of stoma associations.

The first article in this series covered the origins of the Australian Stoma Appliance Scheme (SAS) and touched on the crucial role that advocacy by our pioneers in Australian stoma associations played in helping to secure Commonwealth Government support for what is today recognised as one of the most effective ostomy appliance schemes in the world.

But how did those associations come into being, and how has the growth of the scheme since 1975 influenced their evolution from volunteer support groups to the professional support organisations we have today?

Seventy years ago, the post-surgical experience of many ostomates was vastly different from what it is today. While

improved surgical procedures in the early 20th century had seen ostomy surgery become routine, post-surgical care for ostomates was almost non-existent. Stomal therapy nursing had not yet evolved and there was a general lack of knowledge among health care professionals about the common problems experienced by people with a stoma. Consequently, the quality of life for many ostomates was adversely affected by stoma-related problems.

The concept of ostomy peer support groups emerged in the mid-20th century. During the early 1950s, ostomates recognised the importance of sharing their experiences with new ostomates and so began to form peer support groups. The first officially recognised ostomy support group was formed at Mt Sinai Hospital in New York, USA, and named the 'QT Alumni' after the Q (men's) and T (women's) wards which housed patients after ostomy surgery at the hospital. This was followed by the formation of the Ileostomy Association of Great Britain and Ireland in 1955.

Australia was not too far behind. Early in 1957, Dr Edward



Continued page 24

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Sensor you swallow a potential game-changer

A swallowable sensor developed by researchers at RMIT University in Melbourne could introduce far-reaching changes to the way that gastrointestinal disorders are detected and diagnosed.

In trials the sensor capsule has already revealed bodily mechanisms that had not been seen before, including a potentially new immune system, RMIT University said when announcing the development of the sensor in January.

The sensor has been developed by a research team led by Professor Kourosh Kalantar-zadeh. It is about the size of a vitamin tablet and detects and measures gases in the gut in real time as it passes through the digestive tract and transmits the data to an external receiver, including mobile phones.

Because the sensor capsule is easily swallowed and passes naturally through the digestive system, it holds out the prospect of reducing the need for invasive procedures like colonoscopies. The first human trials were carried out in collaboration with researchers from Monash University.

Professor Kalantar-zadeh said the trials had shown that the human stomach uses oxidising chemicals to break down and fight foreign compounds that were staying in the stomach longer than usual. 'This could represent a gastric protection system against foreign bodies,' he said. 'Such an immune mechanism has never been reported before.'

Trials had also shown that the colon may contain oxygen. The trials showed

high concentrations of oxygen under rich high-fibre diets, Professor Kalantar-zadeh said. 'This contradicts the old belief that the colon is always oxygen-free. This new information could help us better understand how debilitating diseases like colon cancer occur.'

Those taking part in the trials were on low and high-fibre diets. The capsule accurately recorded the beginning of food fermentation, showing its potential to clinically monitor digestion and gut health. The sensor is now being prepared for further trials and commercialisation.

The researchers say the sensors are a potential diagnostic tool for many disorders, from nutrient malabsorption to colon cancer.

Continued from page 22

Stuart Reginald Hughes, a well-known and highly respected surgeon, learned that support groups had been formed in the USA and UK and, recognising the intrinsic benefit that a peer support group would offer to his patients, facilitated the inaugural meeting of the first Australian ostomy support group, QT Australia (Victoria Division), on 18 May 1957. It is now the Ileostomy Association of Victoria.

Other states quickly followed and divisions of QT Australia formed in New South Wales (1958), South Australia (1959) and Queensland (1960). Within a few years QT groups could also be found in Tasmania (1963), Western Australia (1966), the ACT (1971) and the Northern Territory (1984). Together these voluntary groups played an important role in helping the recovery and rehabilitation of people with a stoma. They were often called upon to provide visiting services to hospitals and communities and, in some instances, to give advice to student doctors, student nurses and outpatient clinics about stoma care and appliances.

One role that the support groups—or associations as we now know them—assumed in the early years was to act as 'buying groups' for ostomy equipment for members. Few appliances were available in the early days and were limited to items such as rubber bags, rubber flanges, surgical cement, karaya powder, deodorising agents and a small number of other pharmaceutical preparations. Until 1962, members had to purchase all ostomy-related preparations and appliances. However, changes to the National Health Act in June 1962 enabled the Minister for Health, Senator Harrie Wade, to make special arrangements to provide an adequate pharmaceutical service to certain classes of people. Stoma associations were then given authority to provide

members with a small range of subsidised pharmaceutical items for 'the treatment of conditions associated with colostomy or ileostomy operations and the management of a stoma'.

In November 1971 the Commonwealth Government announced that it would negotiate a fixed wholesale price with manufacturers for stoma-related products supplied to associations, and reimburse associations to the value of the supplies. These changes effectively established the relationship that still exists today between the Australian Council of Stoma Associations Inc (ACSA), Australian stoma associations, stoma product manufacturers and the Commonwealth Government.

On 17 September 1974 the then Federal Treasurer, Frank Crean, announced in his budget speech that '... it is intended to introduce legislation in 1974-75 to authorise the supply, without charge, of stoma appliances to all persons in the community who need them'. Although, under the existing arrangement, the Commonwealth supplied associations with subsidised pharmaceutical items for members, they did not automatically qualify as distribution points under the new scheme. Instead they were invited to participate in the scheme by application. The Stoma Appliance Scheme finally began on 1 October, 1975, with 11 Australian associations approved as distribution centres for government-subsidised ostomy appliances and pharmaceutical preparations in return for a 2.5 per cent handling fee that had been negotiated by the Australian and New Zealand Council of Stoma Associations Inc.

In the August issue: the growth of professionalism.



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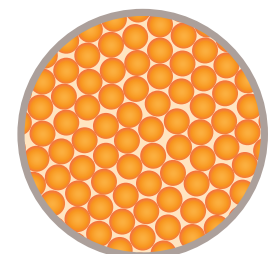
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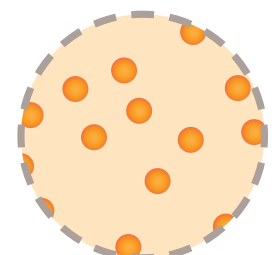
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Are you consuming enough Vitamin C?

As temperatures fall, nutritionist Margaret Allan looks at the importance of ostomates maintaining their vitamin C intake.



As winter approaches, the chance of developing sniffles or catching a cold or the 'flu increases. As a nutritionist, my thoughts turn to the nutrients that can defend against infection and help the body to stay healthy. Vitamin C, also known as ascorbic acid, is one of the first that comes to mind. It plays a major role in

protecting the body against illness and mobilises the immune system against viruses and bacteria.

However, vitamin C is a tricky nutrient for many ostomates to consume in sufficient quantities for optimal health. Humans cannot make vitamin C, so it must be supplied by diet. This is where the challenge for many ostomates begins. Many foods that are considered good sources of vitamin C can be difficult for ileostomates or colostomates to eat in sufficient quantities to ensure maximum wellbeing.

Vitamin C is water-soluble, which means it is not stored in the body for any length of time and is easily and regularly excreted. Therefore it needs to be consumed regularly and adequately to avoid deficiency developing. For ostomates, the possibility of developing a nutrient deficiency is quite high. However, these are not the only challenges.

Vitamin C in food

Vitamin C is found in a range of fruits and vegetables, the highest concentrations being in blackcurrant juice, orange juice, red and green chillies, red and green capsicum, Brussel sprouts and broccoli. It is found to a moderate extent in cabbage, cauliflower, grapefruit and grapefruit juice, pawpaw, oranges, strawberries, lemons and cantaloupe. Most meats, legumes, breads and milk products are poor sources of vitamin C.

General dietary guidelines recommend five to six serves of vegetables and two serves of fruit per day, sufficient to meet most healthy people's vitamin C needs. It is hard to meet vitamin C requirements without this quantity of these foods in the diet. Vegetables may be a more useful source because they are more often available throughout the year. However, many foods containing vitamin C are not suitable for ostomates to eat frequently or abundantly due to increased output or the risk of blockage. A limited ability to consume foods containing vitamin C will therefore affect someone's vitamin C status.

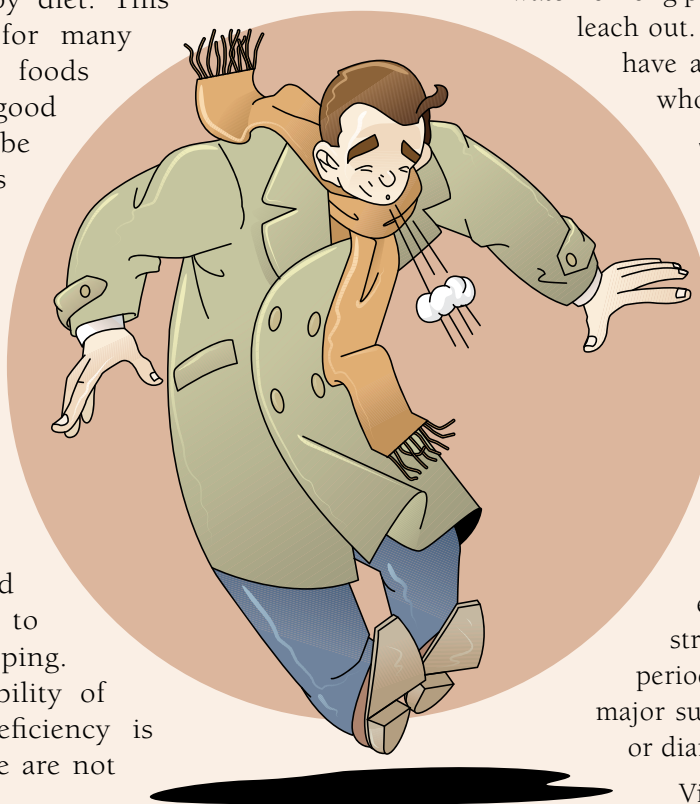
Vitamin C content is also strongly influenced by such factors as time of year, mode of transportation, storage time and conditions, and cooking techniques. Vitamin C is sensitive to light and heat, and methods of storing and cooking can harm nutrient content. Storing or cooking food for extended periods can reduce vitamin C status, with up to 90 per cent of vitamin C being lost during these processes. Cooking at a high temperature or in water is also detrimental. Steaming vegetables for shorter periods is better for retaining vitamin C content than boiling in water for long periods, as less of the vitamin will leach out. Food that is cut or bruised will have a lower vitamin C content than whole, fresh food.

Vitamin C requirements

Some people need more vitamin C daily than standard dietary guidelines recommend. Higher consumption is suggested for people experiencing both acute and chronic inflammatory conditions (such as Inflammatory Bowel Disease, diverticulitis, and arthritis); people under extreme physical and/or mental stress, especially over a long period of time; those who have had major surgery, or who have an infection or diarrhoea; and smokers.

Vitamin C deficiency is also more likely to occur in people who frequently experience low appetite, are restricted or limited in their diet, or have a condition that interferes with the vitamin's absorption. Deficiency is also likely when someone is taking certain medications, has a malignancy or chronic disease such as diabetes, or is advanced in age.

Many ostomates meet more than one of the above criteria, which can complicate vitamin C status beyond issues related to food. For example, when low intake



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Key points:

- Vitamin C is an essential nutrient that defends the body against illness and infection.
- Vitamin C must be supplied by the diet.
- It is difficult for many ostomates to consume enough dietary vitamin C to meet their health needs.
- The potential for ostomates to develop a vitamin C deficiency is quite high.
- Supplemental vitamin C is beneficial but care is required in selection.

of vitamin C-rich foods and extended storing or cooking processes are combined with illness, poor absorption and ageing, the likelihood of deficiency is much higher. Deficiency is more common in the elderly, especially those in nursing homes, as well as among people with poor diets and diseases such as diabetes mellitus and cancer that increase the use and turnover of the nutrient. Vitamin C deficiency can lead to death if left untreated.

Indications of vitamin C deficiency

Screening for vitamin C deficiency is not part of routine blood tests, so clinical signs and symptoms are used more often. Subclinical vitamin C deficiency is much more common than is generally recognised, especially because the first symptom of deficiency is fatigue—a nonspecific and common complaint. Deficiency can develop quickly and easily, and early signs include weakness, fatigue and listlessness, muscular weakness, easy bruising, swollen gums, poor wound healing and the breakdown of previously healed wounds, poor appetite, weight loss, irritability, depression, and vague muscle and bone aches.

More severe deficiency is indicated by fever, dry skin and mucous membranes, increased susceptibility to infections,

bleeding gums, loosening of teeth, swelling of the lower limbs, joint swelling and tenderness, anaemia, and frequent urination.

I frequently see many of these indicators of vitamin C deficiency amongst my ostomate clients.

Although vitamin C is important to defend ostomates against infection and illness during colder weather, its benefits are not just confined to winter. It has many other purposes and performs numerous other beneficial functions. I will discuss these in the August issue of Ostomy Australia.

Wishing you good health and happy days,

Margaret ●

Margaret Allan 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.

In our August issue: The importance of vitamin C for ostomates.

Crohn's, Colitis seeking new CEO

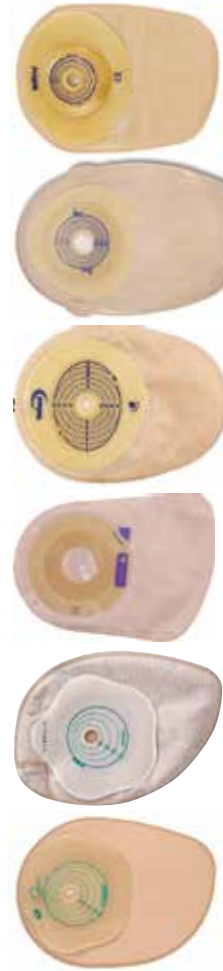
Crohn's and Colitis Australia has embarked on a search for a new chief executive officer, following the resignation of long-serving CEO Francesca Manglaviti. Beata Koropatwa, the chair of CCA, paid tribute in a statement to Manglaviti's 'critical role in the development and success of the organisation', the peak body that represents more than 85,000 Australians with Crohn's disease or ulcerative colitis. She had provided

'inspiring leadership' since taking up the leadership role in 2006. She finished formal duties with CCA at the end of April. Koropatwa said CCA's priority now was to find the best individual to fill the CEO role while maintaining a stable and effective organisation. It was seeking an appointee who would shape the next growth phase of CCA's work. The board recognised that Manglaviti had been 'transformative' for the organisation, she

said, 'taking it from a paper newsletter and support line to the professional, respected, collaborative and engaged peak representative body it is today, and the sought-out voice of not just patients but also health professionals, industry and government'. 'Francesca has helped educate, lead and inspire staff, members and board directors and at all times engaged them on the journey of CCA's growth,' Koropatwa said. ●

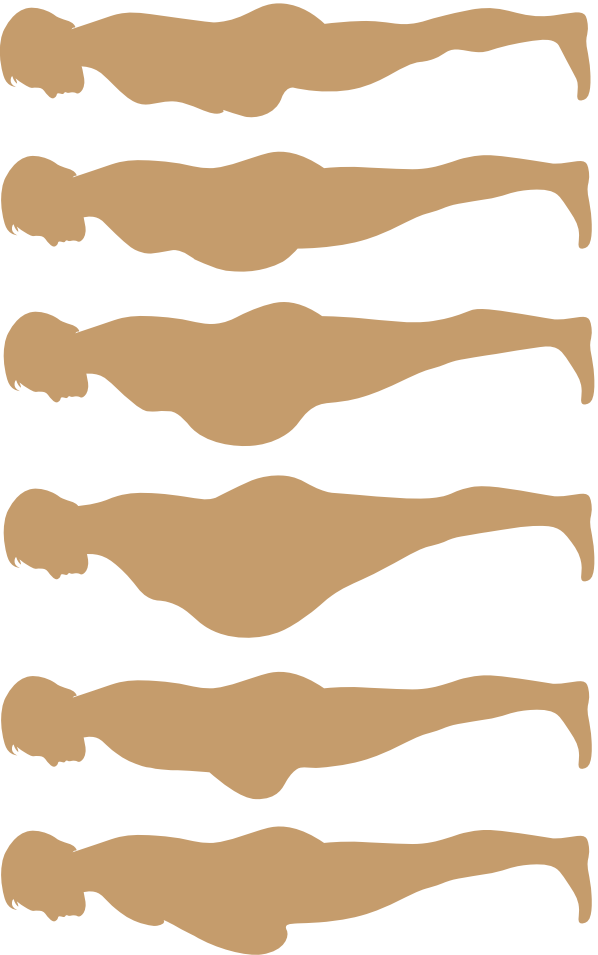
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An unexpected change for the better

A little over a year ago **Helen Searle** chose to become an ostomate—a decision, she writes, which has improved her quality of life.

My path to becoming an ostomate began in 2003 when I opted to have an operation to fix bladder and bowel incontinence I had suffered since giving birth naturally to my sons in the early 1980s. They were 4.28kg and 4.38kg, the second being breach. They were big boys and they came two weeks early.

I had not realised how inconvenient the condition was until I started getting up early to walk with my neighbour to lose weight. We live on a country road with very little traffic at 5.30-6.00am, but I was having to excuse myself to find a clump of trees or scrub to squat behind, as I could not hold on until I returned home. Sometimes this was not possible and found myself having accidents and trying not to let on. It was very embarrassing.

I didn't want this to control my life, and my GP arranged for tests and a referral to a specialist in Sydney. This involved several flights to Sydney for appointments before surgery and a 10-day stay in hospital after surgery. The specialists worked together to repair the bladder incontinence at the same time as the sphincter tear, which involved cutting out the torn muscles and stitching the good anal muscles back together. I was only home for two days when an infection meant another flight to Sydney for emergency surgery—but the infection had done so much damage that the wound had to be left open and dressed daily to heal from the inside out. After I returned home the district nurses visited me for weeks. They were great, though it was not a pleasant experience for either of us. The wound



Helen Searle

eventually healed but I was left with a horseshoe-shaped anal passage that would not allow the muscles to close sufficiently to stop leakage. I felt I was worse off than before.

I took medication to firm up my bowel movements and gain more control, and watched what I ate—but this did not always help, and again found myself not leaving the house until I had been to the toilet a couple of times in the morning. When I had to leave early I got up hours earlier than normal, hoping to use my bowels before leaving. Yes, accidents happened and I always wore a pad. My life was being controlled by my bowels.

My biggest fear was being a little old lady in a nursing home messing herself and people not understanding that it was out of my control, so I decided to investigate again what could be done. I was told I could have

another operation and hope it was successful, because if there were further complications I could end up with a 'bag'—which was not what I wanted. I was told about a new device that would stimulate the muscles to close the anal passage but I could not see this helping, so I decided to live with what I had been dealt.

Then in 2010, after I found lumps under my right arm, I was diagnosed with Hodgkin's lymphoma. I underwent six months of chemotherapy and radiotherapy without abnormal side effects. Life returned to normal, apart from the incontinence. In 2014 I was diagnosed with uterine cancer, requiring a complete hysterectomy and radiotherapy. Surgery went well and life returned to normal again, though incontinence was still a problem.

In June 2015 my husband and

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I decided to take a river cruise from Budapest to Amsterdam with friends, leaving Australia late July 2016 and returning mid August. We were all excited, as it was to be a major trip for all of us. We had never done anything like it before.

Then in April 2016 I felt a lump on the top of my left breast. I was diagnosed with breast cancer that had moved into the lymph nodes. My heart sank. Why me? I thought—three different types of cancer in six years. The trip had been planned for 12 months and I said to the doctors, 'I don't care what happens, but I am going to Europe'.

In May 2016 the lump and lymph nodes were removed and recovery from surgery went well. Knowing I was determined to make the trip, the doctors let me have radiotherapy first and chemotherapy after I returned. Radiotherapy finished on a Friday and we flew out the following Wednesday. We had a fantastic cruise. We flew back into Australia on 9 August and I started the first of four rounds of chemotherapy the next day. I was not concerned, as I had breezed through chemo treatment six years earlier.

But about five days after the first chemo treatment I started to suffer with diarrhoea. The medication I had taken previously didn't seem to help. On day seven I had to go to Macksville hospital to have a PICC catheter line flushed and told them about the diarrhoea. It was a concern, given my history of incontinence. I was put on a fluid drip to stop dehydration and stayed overnight.

Three weeks later, after the second round of treatment, the situation recurred, although the diarrhoea was worse. My temperature was high and my white blood cell was nil due to the chemo, so I was sent to Coffs Harbour hospital where I stayed for four days.

Hence I was not looking forward to the third round of chemo, and sure enough by day five I again had side effects, but worse than before. I was sick of being sick. On day seven, a Wednesday, I went into Macksville hospital, this time prepared for a stay at Coffs Harbour. My temperature and diarrhoea were real concerns. I was diagnosed with *Clostridium difficile* (C diff), an infection that severely inflames the bowel. By Friday I began having bad abdominal pain as well as diarrhoea.

On Saturday morning a CT scan found that I had a perforated bowel and needed emergency surgery. If

The goal now was to recover and have the stoma reversed as soon as possible

you don't have surgery you will die, I was told, and that I would need a stoma bag to allow the bowel to recover. If all went well it could be reversed after six months. I was devastated, but with love and support from family, friends, and a great medical team I left hospital after four weeks.

The goal now was to recover and have the stoma reversed as soon as possible. I had been told some stomas were reversed after three months and thought this might be possible, for I had recovered quickly and felt good. I was nearing five months before my first appointment with the surgeon, only to be told that the reversal would not be done before six months. The surgeon went through the procedure, recovery time and

possible complications. The bowel muscle would have to learn to work again, and diarrhoea afterwards was possible. I wanted to get rid of the bag and get back to work and normal life, so we set a date for reversal that could be postponed if I had doubts.

It was not as simple as I had thought, and my previous incontinence problems made me think twice about reversal. I had found the stoma bag convenient—I could get up in the morning and leave the house without worrying about getting to a toilet in time. I could go on a road trip without getting up hours before leaving.

I discussed my doubts with my GP who, knowing what I had been through, understood why I was considering not being reversed. I also consulted the stoma nurse to talk about any long-term problems involved in having a stoma. After listening to my story she reassured me that I was making a good decision, and reminded me that a reversal was possible if I changed my mind.

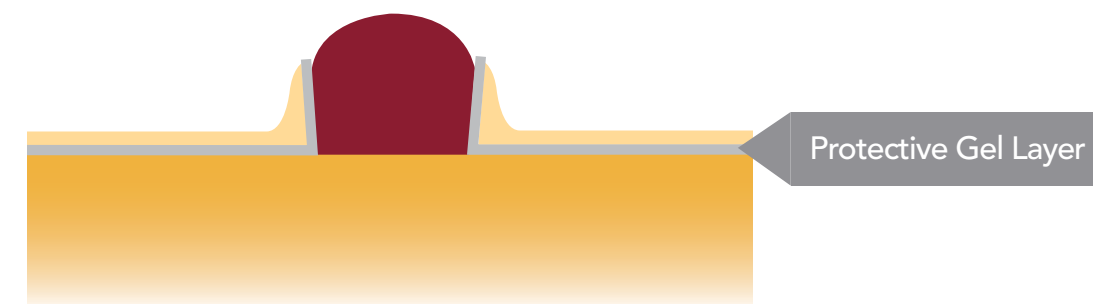
I got mixed responses when I talked to family and friends about my doubts on the reversal I had previously longed for, but at the end they said: 'It is your body, you have to live with what your final decision is'.

I cancelled the operation. The surgeon said he fully understood my decision, and that maybe this could be another avenue that patients with incontinence might consider.

I have returned to office work three days a week and babysit my granddaughter, born in August 2016, on one day, or more if needed. I still have to remember I am not the person I was years ago, especially when I go to lift heavy things, or stretch or bend for long periods of time. But a stoma has improved my quality of life, due to the freedom of not worrying about where the toilet is. ●

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While there was still no cure for inflammatory bowel disease (IBD), newly available drugs and new approaches to treatment have made it easier to manage the condition, Dr Emily Wright, a senior specialist in gastroenterology at St Vincent's Public Hospital, Melbourne, told the Young Ostomates United seminar in February.

Inflammatory bowel disease (IBD) includes the conditions Crohn's disease and ulcerative colitis, disabling inflammatory conditions that affect the gastrointestinal tract. IBD is associated with increased rates of hospitalisation, surgery and a reduced quality of life, Dr Wright said.

However, the recent Pharmaceutical Benefits Scheme (PBS) approval of two new biological drugs (Vedolizumab and Ustekinumab), in addition to established biological drug therapies (Infliximab and Adalimumab), reserved for the treatment of moderate to severe IBD, had broadened the therapeutic options available to gastroenterologists and patients, leading to more treatment options and an increased change of response to therapy over time.

Anti-TNF drugs, the first biological drugs available in Australia, have been in use for more than 10 years and had revolutionised the management of IBD, Dr Wright said. Most patients responded to these drugs initially, although some would lose response over time, she said. This remained a problem. Infliximab was now listed on the PBS for the treatment of acute severe ulcerative colitis and had reduced the risk of colectomy in the short term. Although some risks were involved in using anti-TNF agents, including an increased risk of infections, these were low, Dr Wright said.

Of the other biologic drugs, Ustekinumab was listed on the PBS in 2017 for treating Crohn's disease. The drug works by reducing inflammation in the body, and has been used for Psoriasis for many years. It appeared to be well tolerated and safe, Dr Wright said.

Vedolizumab reduces inflammation only in the bowel and therefore, unlike other biologic drugs, offers selective immunosuppression. Dr Wright said it was well tolerated and did not seem to be associated with an increased risk of infection.

Several novel treatments might also help people with IBD, Dr Wright said. They included microbial manipulation, which includes prebiotics, probiotics and faecal microbial transplantation, or FMT. Such therapies have attracted increasing interest based on the knowledge that people with IBD have different gut bacteria from healthy people.

Prebiotics have not been found to offer any symptomatic benefit to IBD patients, and the use of probiotics remains controversial with the probable exception of pouchitis—that is, inflammation of the surgically created ileal pouch. FMT involves the transplantation of stool from a healthy donor into the bowel of a person with IBD via gastroscopy, colonoscopy or enema.



Dr Emily Wright

Dr Wright said there had been four recent trials worldwide in the use of FMT for ulcerative colitis, each involving fewer than 100 patients. Two trials in Australia in recent years had had positive short-term results, demonstrating that FMT was superior to placebo for inducing remission in patients with ulcerative colitis. This was a promising therapy, but more extensive, longer-term trials and assessments were needed to establish the potential for FMT in future treatment. No randomised clinical trials were underway looking at the efficacy of FMT to treat Crohn's disease, so it could not currently be recommended outside of a clinical trial, Dr Wright said.

The audience heard that the use of stem cells in perianal Crohn's disease was also being examined in research centres overseas. Stem cells provide new cells for the body as it grows and replace specialised cells that are damaged or lost. In small studies, stem cell therapy for perianal fistulas in Crohn's disease was promising, but larger trials were needed. The therapy is not yet available in Australia.

Dr Wright reminded her audience that symptoms did not reflect the extent of IBD inflammation, so regular medical appointments and monitoring with blood tests, stool tests and colonoscopies was important.

Frequent assessment and timely escalation of medical treatment was essential if IBD was active, she said. Diet, bone health, vaccinations, skin care, screening for malignancy and management of psychological health were critical. Faecal calprotectin was a useful and readily available test which could identify patients with gastrointestinal symptoms who might have IBD. The test should be performed by GPs who were concerned about the possibility of IBD in patients with gastrointestinal symptoms. ●

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

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.

SUNRAYSIA / 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 Bvd. 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

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

Enquiries:

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

TOOWOOMBA

Insideout Toowoomba Stoma
Support Group.
Contact Margaret Brabrook,
emby1936@gmail.com,
(07) 4635 1697, or Leanne Wilshire,
leanne.wilshire@bigpond.com
or (07) 4630 0629

WIDE BAY

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

TASMANIA

"SEMI COLONS" - a support
group for men and women affected
by colorectal cancer with or without
ostomies. Meets in Hobart on the
third Thursday of every month,
from 2pm to 4pm.

Enquiries: Cynthia Taafe, Senior
Officer Support Services, Cancer
Council Tasmania, on (03) 6169 1915

NORTH & NORTH-WEST

North: Meets 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 Lavery:
(08) 8944 1800

YOUTH GROUP

Doris Steyer,
Telephone: (02) 4296 5354

YOUNG OSTOMATES UNITED (YOU)

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

BOWEL GROUP FOR KIDS INC

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

PARENTERAL NUTRITION DOWN UNDER

Secretary on (02) 9987 1978
Email: contactpndu@gmail.com
Web:
www.parenteral-nutrition-down-under.webs.com

MITROFANOFF SUPPORT AUSTRALIA

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

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