

Ostomy

A U S T R A L I A

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2013 ACSA CONFERENCE HOBART

★ **Unity is Strength** ★

National Directory of Ostomy Associations

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

AUSTRALIAN CAPITAL TERRITORY

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Tues, Wed. 10.00am - 1.00pm
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Operating hours: Mon to Thurs
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Telephone: (02) 9542 1300
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Email: orders@ostomynsw.org.au
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Sandy Bay, Hobart with Wrest Point convention centre and casino in the foreground.
Photo courtesy of Tourism Tasmania & Southern Cross Television

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Please take this advice into account when responding to company promotions and competitions.

In this issue of the journal we sadly say farewell to Barbara Callcott, the founding Editor of our *Ostomy AUSTRALIA* journal and a former ACSA Secretary, who passed away in May this year. Barbara's most significant and lasting legacy within ACSA was her work in creating *Ostomy AUSTRALIA* as our national journal, first published in 1991 and with Barbara continuing as Editor until 1995. In her national role Barbara helped to develop the role of ACSA into a group which included all of Australia's Stoma Associations, and she was one of the driving forces in expanding ACSA's international role. Barbara was also well known to many Australians in her role as "Mrs Marsh", a teacher in the Colgate toothpaste advertisements who used chalk dipped in bright blue dye to explain how fluoride gets into teeth. What TV viewers did not know was that Barbara was an Ostomate who lived with her stoma most of her public life.

As demonstrated by Barbara and many people like her, courage and a positive approach to life are significant factors in the independence many Ostomates can gain after their operations. This is also a recurring theme in the many stories we receive from Ostomates in all parts of Australia.

In this issue, one such article is from Peta-Leigh Ross, who tells of the difficulties and successes with her baby son who was diagnosed with Hirschsprung's just days after his birth in "*Bouncing back. Hudson's story*".

Another article, "*Dancing up a storm. Charli's Story*" by Sue and Paul Baker, tells of their courageous daughter, Charli, who developed severe Ulcerative Colitis at the age of just two and a half. Charli, after a hard struggle and now with an Ileostomy, is an extremely active five-year-old living each day to the fullest.

In his article "*Why did I put off surgery for so long?*", Brendon Ryan describes his long battle with Crohn's, with symptoms that started when he was just nineteen years old. Now a forty-four-year-old Ostomate, he is once again enjoying life after his surgery.

Len Surtees, an Ostomate since 1987, describes how and why he decided to sail solo around Australia in a prototype nine-metre sailing catamaran which he designed and built, just to get out of his comfort zone. In the process he raised money for the Cancer Council and attempted to break a world-record by being the oldest sailor and in the smallest boat during his voyage.

Tania Place, after having a temporary stoma for three months explains how the brain needs to relearn toileting after a stoma reversal operation in her "*Trial and error again! This time without my bag.*" article. Similarly, Hans de Nys "*My roller coaster ride*" tells of the importance of the BowelScreen Australia® test-kits and a subsequent colonoscopy in the early detection and treatment of cancers. Irene Stewart also gives us a few invaluable tips on what to take when travelling in Asia in her "*Confidence and tissues!*" article.

This year's ACSA National Conference, with its theme of "*Unity is Strength*", is to be held at the Wrest Point Hotel Casino in beautiful Hobart on 18th and 19th October. This is a great opportunity to meet up with old friends, make some new ones and keep our Australian Council of Stoma Associations a strong and energetic group striving to do the best for Ostomates throughout Australia. All are welcome and registrations will be accepted until 30th August.

Thank you once again for all your letters, helpful hints and stories, as well as the articles from Ostomy Associations and support groups.

Take care and stay healthy.

Kim Lyell EDITOR

*Help one another;
there's no time like the present
and no present like the time.*

James Durst

Help!

Ostomy AUSTRALIA
needs your stories,
experiences, helpful
hints, etc

Please send your submissions via Email,
Word or PDF documents to:

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

**The Editor, *Ostomy AUSTRALIA*,
PO Box 195. Frenchs Forest. NSW 1640**

Please ensure that your contribution does not specifically name any doctors or nurses, unless they have agreed in writing to his/her name being published. Just refer to them as 'my surgeon' or 'my doctor'.

Similarly, try to avoid specific use of an appliance company's name when it may suggest advertising in articles and letters.

Remember, all contributions must include your name and address. However, if you do not wish your name published, please say so in your letter, and only your initials and State will be printed in the journal.

An electronic copy of this journal is also available to Ostomates and non-Ostomates via the ACSA and other internet websites.



Like to be on the front cover of this journal?

We are keen for the front-cover of our journal to better reflect the resilience, achievements and enthusiasm of Australian Ostomates – babies and children who are not only cute but brave and resilient; young adults who are coping with rigorous daily routines; older adults who are out there making the most of life.

Readers are invited to send in their digital photos along with a narrative relating to the photo subject.

Photographs must be high-resolution JPEG files and preferably in portrait aspect (i.e. vertical format).

We are unable to use hard-copy photos as scanning does not deliver images with sufficient clarity and sharpness for the front cover.

Written permission from all people shown in the photos should also be provided.



President's Message

In the last issue of *Ostomy AUSTRALIA* I touched on the topic of responsible consumption as our role in ensuring the long term viability of the Stoma Appliance Scheme. This topic has been developed further to the point that a "Charter of Responsible Use" has been developed by ACSA. I now take this opportunity to share it with you.

With the recommendations of the Stoma Appliance Scheme (SAS) Review almost fully implemented it is only appropriate that we, as users of the Scheme, take some responsibility for the efficiency and effectiveness of what is considered to be the best Scheme of its type in the world.

One of the review outcomes was a new pricing framework which led to substantial price reductions on some products. As the appliance companies are now playing their part towards a sustainable Scheme, it is now time that we as Ostomates, played our role in the Stoma Appliance Scheme's future.

In May 2013 the ACSA Executive met with officials from the Department of Health and Ageing and from the Department of Human Services in Canberra as part of the bi-annual Executive meeting.

Both Departments recognised the value of ACSA's input into the effective management of the Scheme and were committed to working with ACSA and other stakeholders in all Scheme related issues. It was also confirmed that there was no set plan to review the operational guidelines other than through the normal ongoing policy and guideline review process. The Executive were also assured that the Commonwealth was satisfied with, and recognised the efficiency of, the current program delivery framework and confirmed that there were no plans at this stage to introduce a formal agreement with ACSA and Associations.

The Annual Conference of the Australian Council of Stoma Associations will take place in Hobart at the Wrest Point Hotel on the 18th and 19th October, 2013. This year will see a reduced timeframe for the Conference from three to two days and with an extensive program in place, it will be an interesting meeting. The Annual Conference is an excellent opportunity to see the national organisation at work and for those interested in attending, more information can be found in this journal.

For now, keep involved.

Peter McQueen PRESIDENT



Australian Council of Stoma Associations Inc

Charter of Responsible Use

As a stakeholder in the Stoma Appliance Scheme, the Australian Council of Stoma Associations (ACSA) is committed to working towards the long term sustainability of the scheme for the benefit of current and future Australians who require Commonwealth Government subsidised stoma products to assist in the management of their stoma.

The objective of this Charter is to recognise the role that all Australian registrants of the Stoma Appliance Scheme play in the sustainability of the scheme and to define the principles of responsible use promoted by ACSA to all users of scheme listed products.

Principle 1: Only order those products which have been identified through careful review of personal use as being required and only order in quantities commensurate to individual use.

Rationale: Many of the monthly quantity allowances of scheme listed products are very generous and are in excess of a normal usage requirements. Placing an order each month for the maximum monthly quantity of every product used in stoma management could result in product excess and wastage as unused product reaches its "best before" date.

Principle 2: Keep an adequate but not excessive stock reserve on hand.

Rationale: 1 to 2 months of emergency reserve is an adequate supply to be kept on hand. A reserve supply equal to more than 2 month's standard supply is excessive (with the exception of holiday supply).

Principle 3: Only order ancillary items following referral by a qualified Stomal Therapy Nurse or registered Medical Practitioner.

Rationale: Not every product listed on the Stoma Appliance Scheme is suitable for use by all persons and some products may compromise the effectiveness of others. The advice of your Stomal Therapy Nurse or registered Medical Practitioner is essential before adding additional products to your stoma care regime.

Principle 4: Only use products for the purpose of managing and maintaining your stoma.

Rationale: Using products for a purpose other than that intended can result in product churn (eg: using a colostomy pouch to cover an ileostomy, using skin conditioning cream for a purpose other than stoma management).

Principle 5: Don't expect the taxpayer to fund personal choice.

Rationale: An "Application for Additional Stoma Supply" (Medicare 4050) request is to be used when a Stomal Therapy Nurse or registered Medical Practitioner has assessed (following review) that a genuine need exists for a quantity of supplies which exceed the standard allowance for that product. Additional supplies required for any other reason may be purchased through an association.

Letters to the Editor

Dear Editor

I have almost reached the first anniversary of my surgery, and am thankful to be getting back to a normal life.

Living in a rural area, I have never met another Ostomate and there are no support services nearby, so I just pick it up as I go along.

My lifeline in the early days after my operation was a volunteer from the Cancer Council of NSW - Kate, of Lismore NSW - who phoned me periodically to check on my progress. Kate gave me lots of useful tips and her help and moral support was invaluable to me. Kate, if you're out there, I can never repay you. Without you I would not have been able to get my life back on track.

Our *Ostomy AUSTRALIA* journal is full of helpful information and the contributions from other Ostomates are so interesting and informative. The journal is an ongoing resource, with every issue teaching me something new.

Thanks so much.

Rosemary Seam, NSW

Dear Editor

As I do not have to order appliances each month, I do not receive the *Ostomy AUSTRALIA* journal regularly. When I do receive a copy there seems to be someone who finds it inconvenient to order their supplies in writing, or wonders why they have to pay a fee to an Association.

Let me tell you how it used to be. I received my Ileostomy in July 1961. There were no Stomal Therapy Nurses, no free Appliance Scheme, and few people who knew much about handling a stoma or acquiring appliances.

We used a large rubber bag attached to a rubber flange (which stood out at least 1.5cm from your body). The flange was attached with a surgical cement and sticking plaster then the bag attached to this. This required lots of cleaning and took some time to attach to your body.

To get your supplies you had to go to a pharmaceutical company and buy them. The cost of this worked out at one pound a day or the equivalent of \$25 in today's money.

Ostomy associations are now largely run by volunteers and they first have to buy the ostomy appliances, issue them to members and then claim the money back from the Federal Government.

I am not familiar with today's full regulations, however I know that 30 wafers and 60 bags are available to me each month. I feel readers are not aware of the cost of their ostomy appliances. Some of the wafers cost \$20 a box and the bags \$22 a box. However there are some one-piece ostomy appliances which cost as much as \$180 for a box of 30.

So the next time anyone feels hard done by, just give a thought to our present and past volunteers, who balance the accounts, lobbied the Government for years and who issue the ostomy appliances to members so that we can all benefit from this wonderful Scheme.

Helen Miller, NSW

Dear Editor

Congratulations on a wonderful journal, which I really do read from front to back. Forget about Women's Weekly, New Idea, etc - our journal tops all of those.

I really enjoyed reading to my husband, Bob, the 'Oh, the Horror!' article in the April 2013 issue as his grandmother had a colectomy in Brisbane in 1958 when Bob was just nine years old. He still remembers the ancient appliances that his grandmother had used for twenty-eight years until her passing in 1986. We are so lucky to have what we have these days.

I had an Ileostomy two years ago and a colectomy nine months ago so I realise just how fortunate we are when you can see what they had back then, and still use in poorer countries.

I was also really inspired by 'Imogen's Story', written straight from the heart. Thank you Imogen for sharing your experience with us!

Keep up the great journal.

Nancye Turner, QLD

Dear Editor

I had an unpleasant experience around my Urostomy which was badly infected. The cause of it was unknown, even by the Stomal Therapy Nurses. The base plate had to be changed four times a day for weeks on end.

All sorts of creams were tried but did not help, and in desperation the Stomal Therapy Nurses called in a dermatologist who advised me to use Aluminium Acetate Solution APF diluted twenty to one. The infection cleared within two days. After applying it, I used a hairdryer to dry my skin.

I have been using this for the last six months and haven't had any more trouble.

Frank van Ryswyk, VIC

Dear Editor

I am wondering how other Ostomates deal with weight gain.

Over the six years I have had my stoma I have tried to keep my weight at a healthy level but am finding this increasingly difficult as I am restricted in what I can digest. I tend to eat more carbohydrates which has resulted in a weight level that I am not comfortable with. Not being able to eat high fibre foods, salads, nuts, etc (all the things recommended when trying to lose weight) is proving to be a constant battle. Consulting with dieticians has also not been successful. I would really like to hear from others how they deal with this problem.

Thank you for the interesting articles in the Journal.

Suzanne, VIC



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Vale, Barbara Callcott

Better known to generations of Australians as Colgate's Mrs Marsh

Submitted by **Gerry Barry**, ACSA Past President

Barbara Callcott, the founding Editor of the *Ostomy AUSTRALIA* journal and former ACSA Secretary lost her battle with cancer and passed away in the Noosa Hospital on the Sunshine Coast on 10th May 2013. Barbara was aged just sixty-six and was comforted by her husband Frank and many friends during her last few days.

Barbara was an icon to generations of Australians in her role as “Mrs Marsh”, the teacher in the Colgate toothpaste adverts who, by using chalk dipped in bright blue dye, explained to countless children how fluoride gets into teeth. She appeared in a total of twelve advertising segments over a period of fourteen years. For those who do not remember back that far, she did a short revival campaign last year in a new “Mrs Marsh” series for Colgate. What TV viewers did not know was that Barbara, the bright and bubbly personality on the screen, was an Ostomate who lived with her stoma most of her public life.

After becoming an Ostomate in the 1980's Barbara soon became involved in the administration of the then Ileostomy Association of NSW (now Ostomy NSW Ltd). She represented that association as a delegate to the ACSA National Conferences before being elected as National Secretary in 1990. In her national role Barbara was involved in helping develop the role of ACSA into a progressive and truly representative one which, for the first time in its history, included all Stoma Associations as members. Barbara was also one of the driving forces in expanding ACSA's international role culminating in the hosting of the World Congress of the International Ostomy Association (IOA) in Adelaide in 1994. She was also involved in the formation of the South Pacific Ostomy Association of IOA through which Australia and New Zealand were represented on the international body.

Barbara's most significant and lasting legacy within ACSA was her work in the creation of *Ostomy AUSTRALIA* as our national journal. Barbara had the foresight to see the benefit of a national journal as a means of informing all Ostomates in Australia of what was happening in ostomy circles at an association, national and world level. Under her guidance our journal was developed, essentially in its present form, when it was first published in 1991 with Barbara as founding Editor. Barbara continued as Editor until 1995.

Another innovation in which Barbara was the main driving force was the introductory DVD for new Ostomates entitled “A beginning ... not an end” which was, and still is, the only Australian produced short film which explains what an ostomy is and shows how Ostomates

can resume a normal life after surgery. Barbara, who was previously an actress of note in the theatre in England, narrated the film and was one of its producers. She also produced the associated booklet published under the same title, which provided new members with details on how they could cope with their new life. This booklet has been adapted over the years and is still given to new members by many of our Associations.

Barbara Callcott played a pivotal role in the history of ACSA in the early 1990s. She was an outstanding leader who contributed to the development of ostomy support, particularly at a national level, over many years. Her enthusiasm and dedication, together with the spirit and the energy with which she carried out her roles within ACSA will be remembered by those of us who worked with her in those early days.

I had the privilege of attending Barbara's funeral at Tewantin near Noosa on Queensland's Sunshine Coast and representing ACSA and the ostomy community. The funeral was a very moving service with tributes to her family life, her community involvement, her past involvement in the theatre and the Mrs Marsh advertising program. A series of DVD presentations depicted her theatre experiences and successes which extended to a number of high profile parts including that of understudy to June Bronhill in the stage production of *The Merry Widow*. Representatives of Colgate made a presentation of her Mrs Marsh advertisements and spoke of the contribution Barbara made to the dental health of earlier generations of Australians. Mention was also made of Barbara's involvement with ACSA.

The funeral service concluded with a release of a white dove by each of her grandchildren followed by a mass release of doves. The service was a reflection of Barbara's theatrical and somewhat flamboyant life and was a worthy tribute to her. It even extended to a voice-over from Barbara herself giving the instructions on how she wanted the service conducted!

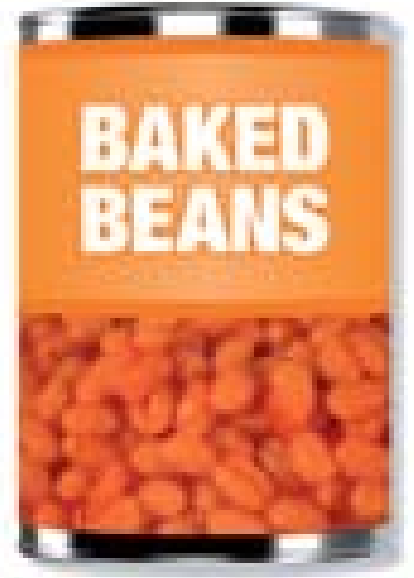
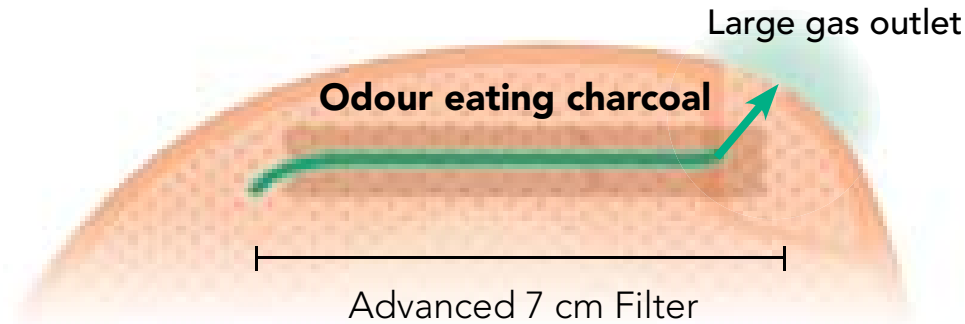
Barbara will be greatly missed particularly by the “old guard” in ACSA including myself. She was an inspiration to those who knew her both in her ostomy work and in her wider community life.



Barbara Callcott (front) with Yvonne Barry at the QSA 50th Anniversary Celebration in 2010

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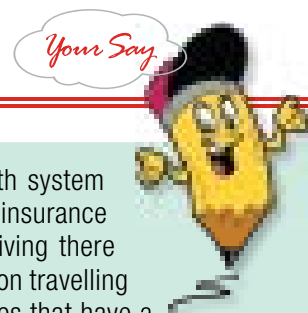


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A Nice Drop of Red

Submitted by **David Gardiner, WA**

I believe everyone, where possible, should donate blood.

Having had bowel cancer and subsequently a permanent ostomy, I was really looking forward to resuming giving blood. I was informed that I had to wait five years after my last treatment (chemotherapy) and was finally given the "all clear" after visiting my oncologist for the last time.

I'd made an appointment at the Red Cross Blood Bank many weeks before and was now all "primed" to give blood again. At my appointment, I filled in all the mandatory questionnaires, had my blood pressure taken, blood checked for suitability, etc and even sat on the lay-back couch with a cuff around my arm. Then the nurse read in the notes that I have a colostomy. She went to check with a doctor, who gave me the extremely disappointing news that they couldn't take my blood!

I was never told that having an ostomy and being over the age of sixty-five precluded me from giving blood. Apparently, people under sixty-five can give plasma under certain criteria.

I was upset that I couldn't fulfil my ambition to resume donating blood, so I pursued the matter further and was informed that having a colostomy increases the chances of blood infection. While the chance of blood infection is miniscule, the Australian Red Cross Blood Bank's guidelines meant that they were not prepared to take the risk. I'm now satisfied as I have a definitive explanation!

Only one in thirty-three adults in Australia currently give blood, yet most of us are only too willing to receive it.

Odour Control

Submitted by **C.L.**

Among the topics listed in the Stoma Think Tank leaflet which I received along with my last Journal was one that has very simply solved an ongoing problem for me - odour. Others have claimed not to notice, perhaps through kindness or embarrassment, but I certainly do.

I had major surgery for bowel cancer three years ago resulting in a permanent colostomy pouch. I have tried a couple of suppliers' products without great success.

Now when I change my pouch I dip a cotton-bud into tea tree oil and wipe it over the inside of the clean pouch, being very careful not to get the oil on any part of the appliance that will touch my skin. No more odours, not even in the toilet when I drain the pouch. It works a treat!!!

Problems Obtaining Travel Insurance Cover

Submitted by **Sarah Larcombe, SA**

In the April 2013 issue of *Ostomy AUSTRALIA*, M.Y. of QLD wrote that they could get travel insurance cover a couple of decades ago but now cannot. I'm only twenty years old and have Crohn's Disease plus a permanent Ileostomy. I wanted to go to the USA to

be a nanny but with the USA health system the way it is, I was denied any travel insurance cover and so decided not to risk living there for a year. I have now set my sights on travelling to the UK, or to a few other countries that have a reciprocal agreement with Australia's Medicare system which allows you to receive needed medical attention (if admitted to a public hospital) if you hold a valid Australian passport and Medicare card.

I get along with the people in the CRS Australia* office who are helping me get employment in the mean-time. During one interview with the manager I discovered that his wife also has Crohn's yet they still travel frequently. He told me about his "Platinum Credit Card" which provides free travel insurance with the card.

I was initially hesitant because I don't want a credit card at my age, but he said I just had to have the card but didn't have to use it. The only catch is you must buy something for your holiday on the credit card (such as plane tickets, luggage, power point adapters, clothes, accommodation, your holiday - basically anything that is needed for your holiday), and no minimum spend. Just spend as little as you please (and keep the receipts of course) and you are covered with travel insurance.

I thought it was too good to be true so he logged on and we read the fine print together. The only extra that must be paid is an "administration fee" of \$72 per year if you have any pre-existing conditions.

He and his wife had made insurance claims for problems during a trip to Europe and another to India. One of their claims was for medical treatment and one was for his lost camera (worth AUD \$1,000). He just called the number on the back of the card and they took care of the hospital charges. They did not have to pay any cash up-front and the company did it all for him.

I thought this may help people and if you want any more information just go into your local bank and ask for a pamphlet about their particular "Platinum Credit Card" offering.

Happy travels because we deserve as much peace of mind when travelling as anyone.

*Editor's Note: *CRS Australia, part of the Australian Government Department of Human Services, is a leading provider of disability employment and assessment services to people with a disability, injury or health condition.*

Please also note that travel insurance terms and conditions will differ between banks and their various credit card offerings. Please always read the fine-print and visit or call your bank to check what cover you may, or may not, have.

Overseas Reciprocal Health Care Arrangements

Submitted by **J.H., QLD**

In the April 2013 edition, M.Y. flagged problems obtaining travel insurance. In the past, I too had always been able to cover my pre-existing inflammatory bowel disease (IBD), with an extra fee. This year, I took out insurance to travel to North America, and found for the first time that I was declined cover



for my IBD. I then put in the same application details, but changed the destination and was granted cover for Europe and everywhere else, just not North America, presumably because of the enormous health care costs there.

A number of countries (United Kingdom, Belgium, Finland, Italy, Malta, Netherlands, New Zealand, Norway, Republic of Ireland, Slovenia and Sweden) have reciprocal health care arrangements with Australia for essential medical treatment, which gives some peace of mind when traveling without insurance for a pre-existing condition. Beware though, if you are deplaned en-route, you may not be covered in other countries.

Editor's Note: Reciprocal Health Care Agreements cover the cost of essential medical treatment for Australian residents travelling in some countries. Reciprocal Health Care Agreements aren't designed to replace private travel health insurance for overseas travel.

You will need to provide local authorities with:

- *your Australian passport, or another valid passport, which shows you are a permanent Australian resident.*
- *a valid Medicare card - if you do not have a valid Medicare card, or your card will expire while you are away, visit a DHS Service Centre before you travel overseas for a new card.*

For a list of the countries where reciprocal care is available as well as the detailed requirements please visit: -<http://www.humanservices.gov.au/customer/services/medicare/reciprocal-health-care-agreements>

To Sauna or Not To Sauna?

Submitted by Heather Hill (Retired STN), NSW

This is not a common question from people with stomas and the answer is not in the text books. A friend of mine has a Urostomy and really enjoys having a sauna. His question to me was:

- 1) Is it safe for me to have a sauna with a stoma?
- 2) Could any damage be done to the bowel mucosa?
- 3) What temperature can the sauna be?

In an attempt to ascertain that I was giving him the correct information I corresponded with Stomal Therapy colleagues around the world (including Carmen) and a professor of colorectal surgery. All my professional colleagues were confident that mucosal damage to the stoma would be unlikely unless the sauna was excessively hot. The surgeon also commented that a number of his patients use saunas regularly without any problems. The Israelis recommend that people with stomas change their appliance before and after bathing in the Dead Sea. On the USA west coast region there are many hot springs which can burn the skin, therefore the experts recommend testing the water by holding your hand in for two to three minutes before bathing - if the hand turns red then it is too hot!

According to United States regulations, saunas must not be operated at temperatures above 195 degrees Fahrenheit, and the Finnish Sauna Society suggests 176 to 194 degrees Fahrenheit. For those of you who prefer the new system this is approximately 80 to 90 degrees Celsius.

Everyone suggested that the amount of time spent in the sauna should initially be short and increased gradually as tolerated.

It was a unanimous concern that pouch adherence was a very real difficulty as the ostomy product's adhesive could be undermined or weakened by the heat and sweating whilst having a sauna. Advice was to use extra adhesive and/or a belt to hold the appliance in place.

The consensus was that the biggest problem would be dehydration, especially for those people with Ileostomies or Urostomies, as the body sweats excessively during sauna use and the body will therefore lose water and fluids more quickly. This quick loss of fluid can lead to another potential serious problem, hypovolemic shock. Hypovolemic shock is a fast drop in blood pressure which needs immediate medical treatment.

If you have any type of cardiac (heart) problem you should discuss with your doctor whether or not a sauna is a good idea.

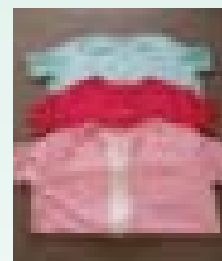
The Internet was researched in many different ways but most of the information was anecdotal. There is very good and reliable literature that saunas do not help with weight loss and can cause severe dehydration.

However, taking the foregoing into consideration, saunas do appear to be safe for people with stomas and will possibly help sore muscles, provide a feeling of relaxation and a beautiful feeling of wellbeing.

Managing after having Rotator Cuff Surgery

Submitted by Maxine Wade, NSW

A few years back I submitted an article on how to manage your ostomy after having rotator cuff surgery and/or with limited use of one hand. As I have now had a bigger operation on my left shoulder, I'd like to add the following which may be of use to some Ostomates.



I bought some large cotton night T-shirts (two sizes bigger than what I normally wear), then carefully measured and cut them down the front, turned in a small hem on each side and then sewed in an open ended contrasting zip. Or you can add wide ribbon to either side of the centre and then insert the open ended zip. Not only is this easier to manage at home, it also makes it simpler when in hospital for medical staff to examine you. These could also be worn by elderly/frail or less mobile people.

I also used the open-ended zip solution for blouses as buttons are difficult to manage with one hand. It is also easier to adhere to the surgeon's rule for putting on clothes after rotator cuff surgery, that is "bad arm - first on, last off". You don't need to be a fashion statement for the first few months after surgery, just comfortable! All my carers think they look terrific and such a good idea.

Another reminder regarding cooking. Always take your plate to the pot/stove (while no heavy carrying is permitted). Also cut your food on the kitchen bench, putting your plate/bowl on a non-slip mat, especially if you eat at a coffee table or with a tray on your lap. Much easier and safer!

BOUNCING BACK

Hudson's Story

Submitted by: *Peta-Leigh Ross, NSW*

My pregnancy was a dream. No morning sickness, no strange cravings, no high blood pressure – it was perfect. My twenty-week ultrasound showed a growing healthy baby boy and I was over the moon. I went into labour on my due date but after a slow progression and signs of the baby being in distress they decided that an emergency Caesarean section was the safest delivery option. Within the hour my beautiful little boy had arrived. Hudson was finally here – ten little fingers, ten little toes and weighing in at 3.9 kilograms. By all examinations he was healthy.

Over the next few days he progressed like any regular baby. He passed a small amount of meconium in the first twenty-four hours and was very interested in his feeds. On day two we were both given the okay and discharged.

However, soon after arriving home Hudson became irritated and started projectile vomiting. Even though a first time mum I knew this was not normal behaviour, so straight back to the ER we went. Hudson was again given the all clear but we were kept in hospital for a few days for observation. Over this time Hudson did not have another bowel movement and he eventually refused his food.

On day five we were transferred to the Neonatal Intensive Care Unit (NICU) where they immediately noticed his stomach was distended and after a quick ultrasound, Hudson and I were both being transported by ambulance to The Children's Hospital at Westmead.

The doctors and nurses of the Grace Intensive Care Ward jumped straight into action and started eliminating possible causes for Hudson's current state. This was a long process and although very hard to watch my five-day-old baby being hooked up to machines, I knew he was in the best place he could be. Once they managed to get Hudson's vomiting under control we all thought he was going to be okay from then on but unfortunately this was not the case.

After four weeks of living in the hospital with daily bowel washouts, two rectal biopsies and a trip to theatre, the surgeons finally settled on the diagnosis of **Hirschsprung's Disease**.

Hirschsprung's Disease is a congenital condition of the colon where much needed nerve cells (called Ganglion cells) never develop and therefore the bowel is unable to move food through, which then results in chronic constipation. In most cases only a section of the large intestine is affected and a pull-through

procedure is performed to remove the damaged part of the colon. However, during his six hour operation they discovered that Hudson's case was much worse with his entire large bowel being affected and therefore had to be removed. Hudson ended up having Ileostomy surgery, where they removed his large intestine and some of his small intestine and then pulled the end of the remaining small intestine through an opening in his stomach to create a stoma from where his waste is discharged into an ostomy bag.

Hudson bounced back very quickly from his operation and was discharged five days after surgery. Despite several admissions back to the hospital to be treated for gastro problems, Hudson's progress since surgery has been perfect.

Hudson is at high risk of dehydration and contracting a gastro bug would be serious for him. The surgical team at Westmead Children's Hospital have been amazing and I have formed a very close bond with the Stomal Therapy Nurse who has been a God-send whenever I have had a scare or concern. She has always been able to ease my fears.

The new routine of dealing with an ostomy bag at first is scary, overwhelming and nothing short of heartbreaking but Hudson is now almost six months old and I can honestly say that I now look at his beautiful pink stoma every day and I am in love with the medical miracle that saved my son.

Hopefully Hudson's Stoma is only temporary and one day in the near future they will be able to operate and give him a chance at a life without the bag.

I look forward to the day when Hudson is old enough that I can sit with him and tell him about the journey he had to take and all the wonderful people he met who helped him grow to be the magnificently strong, resilient and determined human being I know he will be. Especially Nanna Lea and Grandpa Tom, you have been there every day reminding us both that we were strong enough to tackle whatever came our way.

I know we still have a long road ahead of us but I am honoured to be the single mother of a Hirschsprung's baby – especially this baby! Hudson you're amazing, Mummy loves you.



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Dancing Up a Storm

Charli's Story

Submitted by **Sue and Paul Baker** (Charli's Mum and Dad)

This is the story of our beautiful, courageous five-year-old daughter, Charli.

Charli was born a happy, healthy baby in June 2008. However, at the age of two and a half our lives changed forever. Charli started having bloody stools after taking an antibiotic for a small infection on her finger. At first, the paediatrician thought a bacterial infection was responsible ... and so onto the roundabout we climbed ... countless emergency room visits, always ending with no definite diagnosis.

Charli was often in extreme pain. She was losing large amounts of blood and was thin, pale and sick. This went on for several months until we changed paediatricians, knowing we could not give up and give in to the "stomach bug" diagnosis we kept getting handed. My husband and I were confused, exhausted and frightened.

Our new paediatrician, I believe, saved Charli's life. He took one look at her and immediately sent her in for several tests, one of which brought up a red flag for **Ulcerative Colitis** (UC).

I had asked the previous doctor if she could possibly have UC as in all my months of late nights trawling the internet for answers, this seemed to match the most with her symptoms. But the "no, she's too young" answer was promptly given and round we went again.

Charli had now endured almost five months of pain and exhaustion but after a colonoscopy, it was confirmed. Charli had Ulcerative Colitis. We were upset because we had read about this horrific illness but also relieved to finally have a diagnosis.

Charli began Prednisone and then went on Sulfasalazine as a maintenance drug. All was fine and life went back to normal until

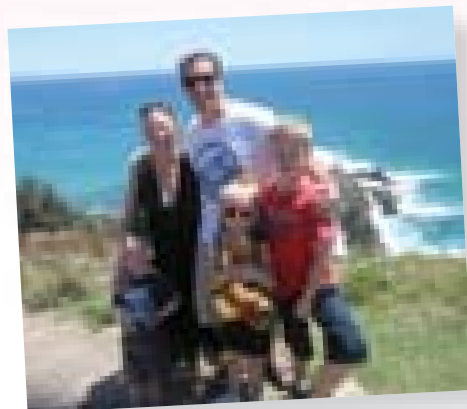


Charli was four-and-a-half. Charli's gastroenterologist and others were surprised that the Ulcerative Colitis had not returned as it is most often very severe in children, so we started having doubts. Could the diagnosis have been wrong after all and here she was taking drugs that could be affecting her small body, in particular her liver, for no reason at all? Her gastroenterology specialist agreed this could be possible, so we decided to try taking Charli off the drugs. The worst I believed could happen is that it would come back and we could start the drugs again. Unfortunately it did come back, less than two weeks after stopping her treatment, but this time Prednisone did not work to get her back into remission. We were devastated.

Charli started going downhill, slowly at first, but this is an insidious disease and within a few months she was quite unwell and we were at a crossroads. Do we try the more potent drug therapies such as Infliximab? Do we have any choice? What if it doesn't work and we have been putting this potent drug into her small body? I remember asking Charli's specialist what would give her the best childhood, trying

various drugs or an ileostomy? He point-blank told me the ileostomy would be best, and my husband and I agreed. We understood that the more potent drug therapies could have kept her UC at bay, but at such a young age, surgery was going to be inevitable one day due to the increased cancer risk. Also, although small, there was a very real risk of these drugs having catastrophic consequences to her health. We understand this was our personal, heart-wrenching decision to go down the road of surgery and other parents may choose a different route, but for us we do believe we did the best for our daughter. We actually did try one round of Infliximab at the urging of doctors, but Charli's symptoms got worse and we lost all faith. After many, many blood transfusions, and an illness that had almost broken us all, we knew it was time for surgery.

My husband and I packed a bag for Charli, took her to the emergency department and promised ourselves we would not leave the hospital before Charli was better. We waited two weeks in hospital, with Charli now going to the toilet fifteen to twenty times a night (no easy feat getting to the loo when she is attached to two poles, including a central line to give her the nutrients




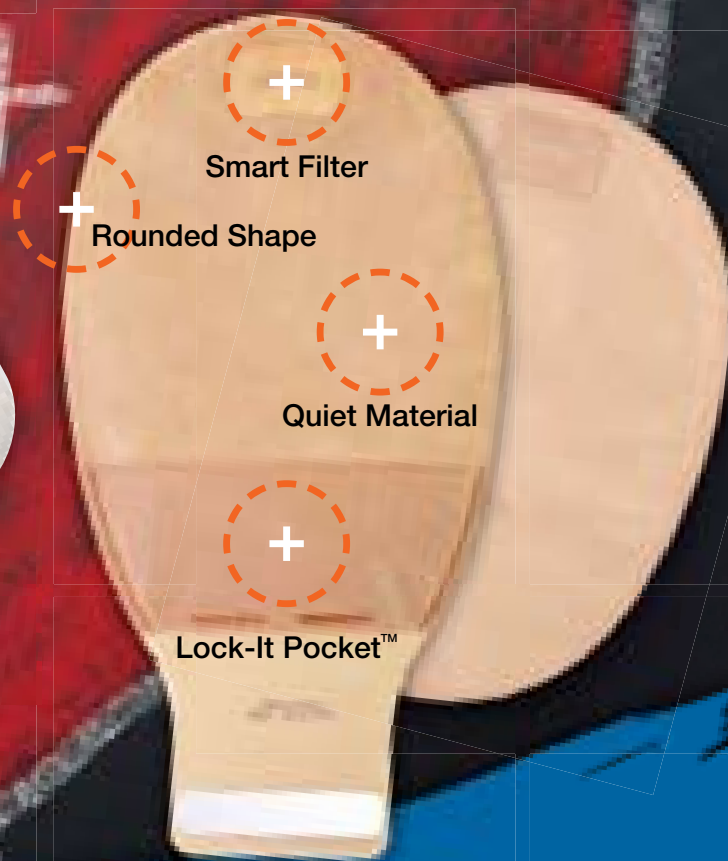
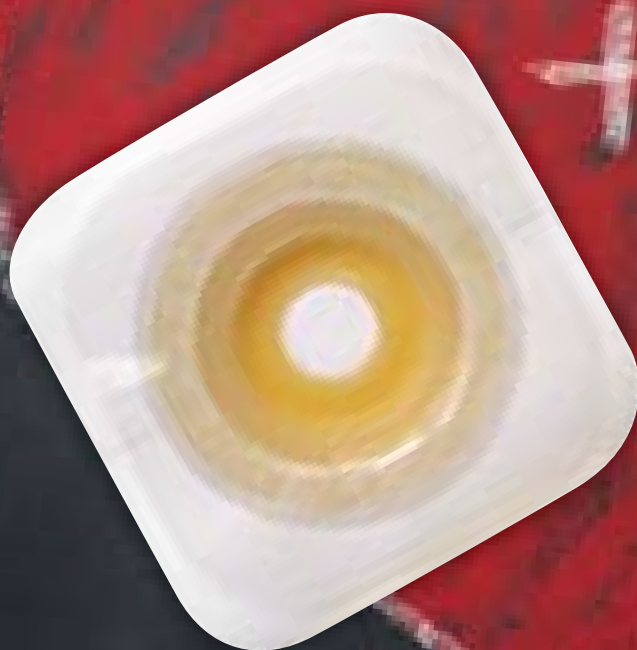
she so desperately needed) and getting a blood transfusion every few days.

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Finally, surgery day arrived and we were desperate. Most parents would not be happy to see their child losing part of their body but we were so relieved that our little girl would start to get better after surgery. We were ready and so was Charli.

The surgery appeared to go well, although the surgeon did tell us that it looked like she had **Indeterminate Colitis**, meaning it could be **Crohn's Disease**. This

was upsetting as it would mean she was not "cured" as such and could continue to have problems. A J-Pouch would not be possible if it turned out to be Crohn's Disease.

However, before I could ponder that thought too

much, in the early hours of the morning following surgery, Charli started having problems - severe stomach pain, high pulse rate and fever. After a few Code Reds were called, Charli was taken back into surgery. We knew something was

very wrong. We will never forget those few hours where we were not sure if we would get her back. As a mother I felt like I had failed my daughter in the worst possible way.

Finally Charli came out of surgery. She was in septic shock. The staple holding her rectal stump in place had failed as her rectum was so severely diseased and her body was turning septic. Charli was in intensive care for four days, but improving every day.

Unfortunately, when we got back onto the ward it was found Charli had a blockage so she could not eat and was vomiting masses of green fluid. After a week, the blockage fixed itself and she could finally start to eat real food. Charli was elated after four weeks of bits of juice and jelly only!

Just as we felt we were finally homeward bound, along came the final blow, her pulse rate had been gradually getting faster for a few days. The doctors were puzzled but after calling in the cardiologists (and another multitude of tests), it was found that Charli had a Pulmonary Embolism, probably brought on when her central line was removed.

This meant Charli would be on Warfarin for the next six months. I thought ahead and realised she would be starting school whilst taking Warfarin and the worry that would entail. At this stage though, as long as Charli was getting better and was home with us, we could deal with anything.

Charli was in hospital for six weeks in total. Obviously things did not all go to plan but as the doctors explained, she was so very sick that it complicated everything, in every way.

Charli has been home from hospital for seven months now and is doing fantastically well. She started kindergarten in February and although she now has an Ileostomy, she is no different to any other child at school. She is extremely active, swimming throughout summer, jumping on the trampoline and dancing up a storm. As for her parents? Well, we are still recovering!

We are hoping Crohn's Disease does not show up and she will get a J-Pouch in about five years. The only issue we have had with "Millie, the Illi" happened last week when her stoma prolapsed but things are okay again now.

Charli has a fantastic team comprising her Gastroenterology specialist, her surgeon, her Stomal Therapist and her fantastic school and teacher's aide, all of whom have made this journey a little easier through their compassion, understanding and professionalism. For that we thank them from the bottom of our hearts.

We are now filled with an abundance of hope for the future and an immense amount of pride in the strength and resilience of our amazing little girl who continues to show a bravery beyond belief and lives each day to the fullest, just as a five-year-old should! ♥



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Let's Not Take Things for Granted

Submitted by **Paul Martin**, Returns Officer, Queensland Colostomy Association Inc.
Australia Fund Co-Ordinator, Southern Brisbane Region.

Australian Ostomates do very well with support when compared to Ostomates in many other countries. Here in Australia we have a support network of twenty-two associations manned by volunteers dotted throughout the nation. Each association dispatches a quota of supplies to each of their members, generally monthly and based upon what a member orders. The Federal Government allows we Ostomates to receive those goods free of charge by way of the Pharmaceutical Benefits Scheme (PBS) with a 100% (plus 2.6%) subsidy given to each association. That subsidy, met solely by the Federal Government, costed in the region of \$80 million during the last financial year, and that figure is steadily climbing higher each year. All we Ostomates are asked to pay is a yearly membership fee to our chosen ostomy association, a mere \$45.00 or \$35.00 (if you are on a concession). Yet as we Ostomates just try to go about living our normal lives, some don't give a thought of just how much the goods we receive actually costs.

In an effort to educate our members, the Queensland Colostomy Association sends out an invoice as part of the ordering form for the following month with their ordered supplies. The invoice clearly shows each member just how much the goods supplied would have cost them should the government not have subsidised these goods.

The Australian population currently stands at around twenty-three million people and we are repeatedly told that we are an ageing population. Approximately 40,000 Ostomates in Australia accessed the Stoma Appliance Scheme (SAS) last year and it is inevitable that the number of Ostomates across the nation will increase for one reason or another as the years progress. We Ostomates should therefore take a good look at how we can better manage the monthly ordering of our ostomy products. In simple terms, each new Ostomate means an increase in costs to the Pharmaceutical Benefits Scheme, putting more pressure on the government to find extra funding. Only in March of this year there were media reports of the Federal Government's concern that in the year 2012-2013, waste of up to \$3.5 billion had been found in certain areas of the national PBS. All ostomy associations receive their subsidy from the Federal Government only after they have supplied goods free of charge to a member and then claiming through the PBS (under the SAS umbrella).

It is for all our benefit that each of us knows just how many items, pouches, wafers etc. that we use between monthly orders. Why? Because each box of flanges or pouches not ordered means less of a financial burden on the Federal Government, which in turn means the level of support we currently receive can continue into the future.

One of my roles at the Queensland Colostomy Association is that of Returns Officer and I do see an abundance of stock

being returned to QCA, which had been stockpiled by some members. While we appreciate returned and unwanted items, not all of the returned stock can be sent onto less fortunate countries. Returned goods also cannot be given out a second time to association members in their monthly orders because we have already received the government payment after it was initially ordered and sent to a member. The goods may also have passed the expiry date nominated on each box, plus the adhesive backing on some goods can break down over time and won't adhere to the body as well as a new item would.

Each member is allotted a monthly quota of goods by the government and a great many members order their full quota regardless of whether or not they will actually use that amount of goods between orders. If we wish to maintain the subsidy level that we currently receive from the Federal Government then there is an important question every Ostomate should ask of himself or herself when ordering their ostomy goods.

Do I need another box of flanges or pouches when I have unused supplies from the previous month's order still sitting idle in my cupboard at home?

How many of us actually calculate just how many pouches and flanges on average we each use in a month?

Just take a minute to think about this, keeping in mind that it may not happen but we can't afford to say "Never, ever". What if the Federal Government, seeing the ballooning cost of PBS goods ordered by Ostomates, says "enough"? It may change the Scheme from what it is today by putting some of the cost back onto association members. Given the high cost of ostomy goods and the limited income of many members we must all do our bit so that such a thing won't happen.

So please, let's not take things for granted and instead order our supplies responsibly.

Before placing your next monthly order please think what unused appliances you may still have on-hand from your previous orders, and then **order only what you actually need, not what you are entitled to**. Remember by simply reducing your appliance order to what you actually need, pressure is lessened on government funding of our great Scheme, which in turn means that we Ostomates can continue to enjoy the benefits of getting our supplies free of charge via the Pharmaceutical Benefits Scheme, now and on into the future. ●

Before you place your next order, just take a moment to check what ostomy supplies you still have on hand.

If you have an over-supply of items then don't order just for the sake of ordering.

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2013 ACSA CONFERENCE HOBART

The Management Committee of Ostomy Tasmania Incorporated is pleased to invite Association delegates and observers (and anyone else who may be interested!) to Hobart to attend the 13th Annual General Meeting and the 44th National Conference of the Australian Council of Stoma Associations.

This year the Conference has been reduced to a two day format, and we hope this will encourage and enable all Associations to send attendees. This is our chance to meet up with old friends, make some new ones and keep our Australian Council of Stoma Associations a strong, vibrant group of like-minded people, striving to do the best we can for Ostomates throughout Australia.

We have again chosen **Wrest Point Hotel Casino** for this Conference, to enjoy the spectacular riverside location in the suburb of Sandy Bay, about four kilometres or ten minutes' drive from the city centre. There is a choice of accommodation from 4½-Star in the Tower, 4-Star Water Edge

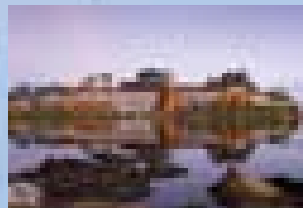
and 3½-Star Mountain Side. Wrest Point offers a full range of services – 24 hour room service, a variety of restaurants, gaming, entertainment, sporting and recreational facilities.

Since Tasmania lies between 40°S and 43.5°S and is an island with no place more than 115 kilometres from the sea, its climate is classified as temperate maritime. During October the daily average temperatures range between a maximum of 17°C and a minimum of 7°C. About half the days in the month can be expected to have some showers (but hopefully not between 17th to 20th October). Being Spring, the weather can be glorious but is often unsettled and October can be very windy and blustery. We recommend you bring warm clothing, particularly for the evenings.

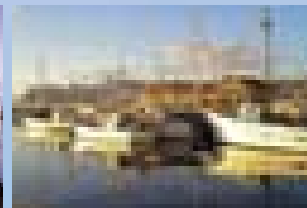
Don't forget your brolly and a warm, waterproof jacket on the day tour just for insurance!

A Welcome Reception for Conference attendees will be held at Wrest Point on the Thursday evening, following on from Delegate's Registration. This will be a two hour function with drinks and canapés, and will be free to full registrants.

The Conference will be opened on Friday morning by the **Lord Mayor of Hobart, Alderman Damon Thomas**, and we will celebrate ACSA's 50th anniversary at morning tea. Business will continue for all of Friday and Saturday and appliance company displays will be available in an adjoining room. Our guest speaker on Saturday will be **Dr Jane Tolman**, Director of Aged Services at the Royal Hobart Hospital since 2006. Dr Tolman is a committed advocate for the rights of older people to live independently wherever possible. Her current goal is to develop a state-wide plan for the management of dementia around Tasmania, to support those with dementia, their families and carers, and the providers of their health care.



Museum of Old and New Art (MONA), Hobart



Hobart Waterfront, Tourism Tasmania and Kathryn Leahy



Japanese Garden, Royal Tasmanian Botanical Gardens, Hobart
Tourism Tasmania and Liz and Chris Graham

Friday night will be a free night. Our Conference Dinner Dance will be held on Saturday night when we can enjoy some of Tasmania's fabulous food and a great dance band.

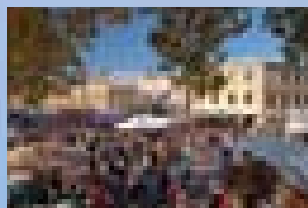
On Sunday, we will be taking a river cruise from Wrest Point to the **Museum of Old and New Art (MONA)** to spend a couple of hours wandering around this spectacular Hobart attraction. MONA is located within the Moorilla Winery on the Berriedale Peninsula and is the largest privately funded art museum in Australia. The museum presents antiquities as well as modern and contemporary art in a unique architectural setting. The featured exhibition for this period will be "The Red Queen". We will then travel to the **Royal Tasmanian Botanic Gardens** for lunch in the restaurant which boasts sweeping views over the landscaped grounds. The Gardens will have a glorious display of tulips and other spring bulbs; there is a Subantarctic Plant House and a Japanese Garden among the attractions.

Once we leave the Gardens, participants can either return to Wrest Point or perhaps disembark at the waterfront area to visit Salamanca Place or the stunningly redeveloped **Tasmanian Museum and Art Gallery (TMAG)**. TMAG's collection embraces the diverse treasures of art, history and science and provides the starting point for the exploration of many fascinating stories about Tasmania's rich and complex history.

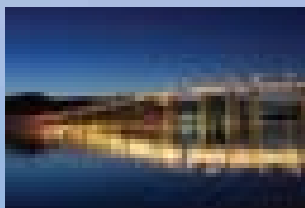
Ostomy Tasmania would like to thank our Sponsors for this conference – Convatec and Liberty Medical (Gold), Coloplast (Silver), and Ainscorp and Omnigon (Bronze). Their assistance is much appreciated.

Late registrations will be accepted until 30th August. Registration Forms can be found on our website: www.ostomytas.com.au.

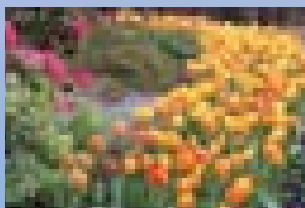
We look forward to welcoming you all in Hobart.



Salamanca Market,
Hobart Tourism Tasmania and
Hobart City Council



Tasman Bridge,
Tourism Tasmania and
Brian Dullaghan



Royal Tasmanian Botanical Gardens
(Queens Domain, Hobart)
Tourism Tasmania and
Andrew Ross

Programme

Thursday 17 October

Delegates arrive

- 5.30 pm** Registration desk opens
- 6.00 pm** Welcome Reception (drinks & canapés)

Friday 18 October

- 8.00 am** Registration desk opens
- 8.30 am** Welcome by the President
- 9.00 am** AGM commences
- 9.30 am** Official opening by The Lord Mayor
- 12.30 pm** Lunch
- 1.30 pm** Committee meetings
- 5.00 pm** Close of business

Saturday 19 October

- 8.30 am** General Meeting
- 10.00 am** Guest Speaker **Dr Jane Tolman**
- 4.00 pm** Close of meeting
- 7.00 pm** Pre-dinner drinks
- 7.30 pm** Conference Dinner at Wrest Point

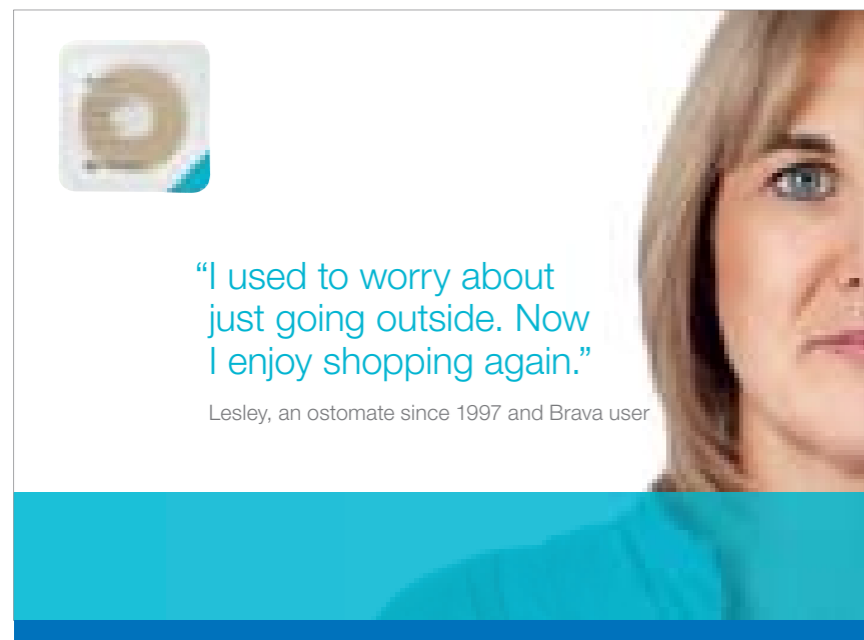
Sunday 20 October – Day Trip

- 9.00 am** River cruise to MONA (Museum of Old and New Art) with lunch at the Royal Tasmanian Botanic Gardens
- 4.00 pm** Return to Wrest Point (approx)



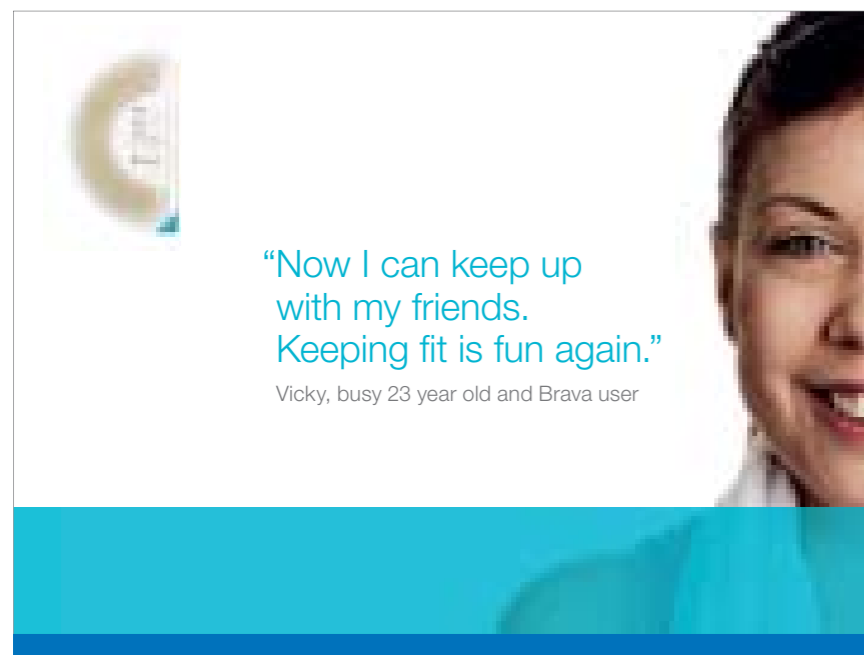
Constitution Dock, Tasmanian Museum & Art Gallery, Hobart - Sarah Brabazon

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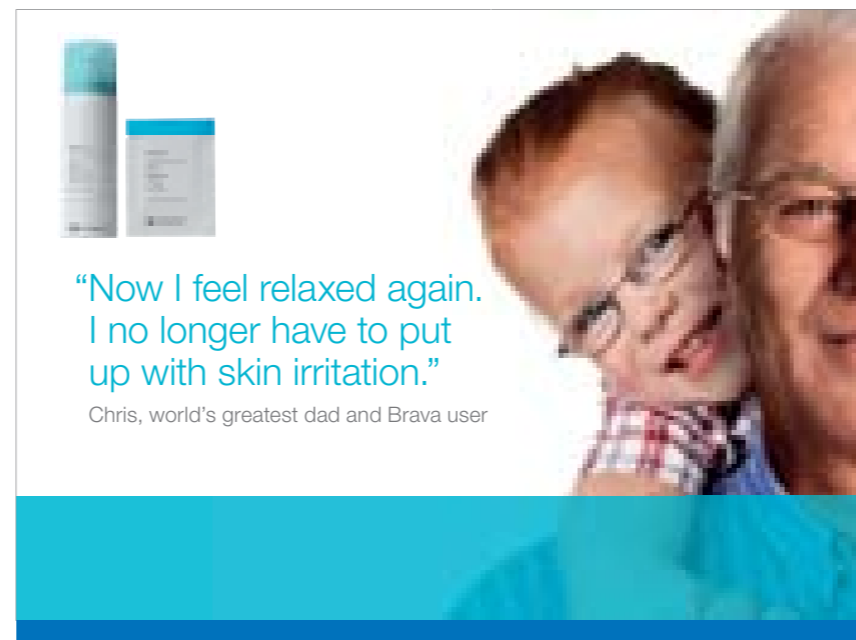
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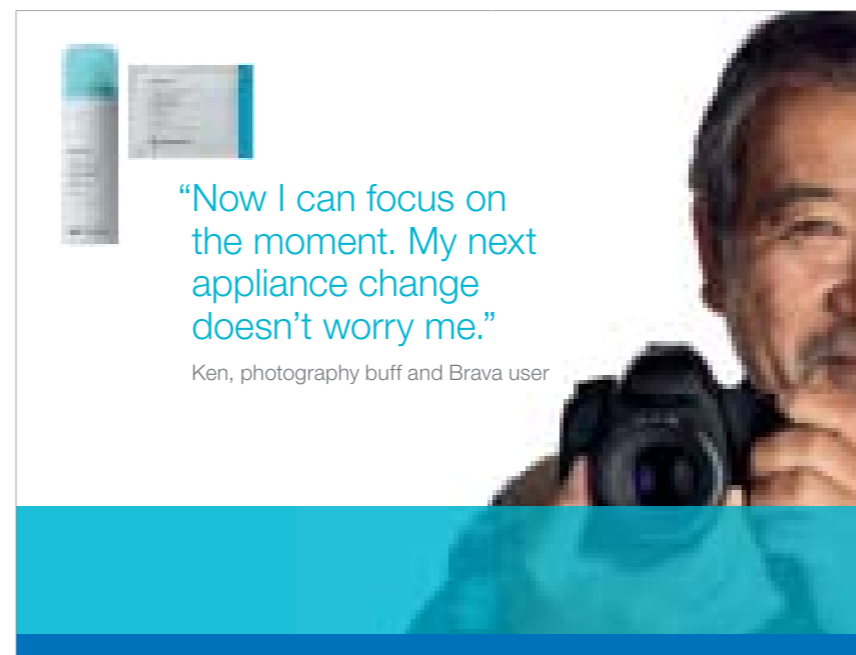
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Every time I receive the *Ostomy AUSTRALIA* journal I read stories of how people have managed, from being extremely sick through to feeling well after having their ostomy surgery. Whilst reading the experiences of my fellow Ostomates, I also reflect on my own journey and become emotional for the people who have written about their life-changing operations.

For a couple of years after my own surgery I said I would write about my own journey from being a fit and active young man, through years of pain and interruptions to my day-to-day life, to now, as a healthy and happy person. So here's my journey.

I have Crohn's, with the symptoms starting (or when I actually took notice) when I was nineteen years old. I am now a forty-four-year-old Ostomate. My symptoms initially were an itchy anus from the discharge, then increasing and regular loss of blood when I went to the toilet. After ignoring them for at least two years (I am a male and it takes a bit for some of us to admit something is wrong and to visit your doctor), it became such a worry that I finally visited a physician who performed one of those lovely examinations in his room (where they pump air into you). As a twenty-two-year-old he nearly scared the life out of me when he said "My God, what have you been doing? You have scar tissue throughout your entire rectum". It left me wondering what was wrong with me.

He believed I had Ulcerative Colitis, then sent me for a colonoscopy and put me on Prednisolone and Salazopyrin, which I took for the next few years. My symptoms initially eased but then returned much worse. I was sent to a colorectal surgeon who advised that he could fix me with surgery but I said that I wanted to fight on and avoid going down the surgery track, to which he politely said "Good luck" and that "surgery was inevitable".

As some of you will also have experienced, the diagnostic process is prolonged with multiple invasive tests. After visiting another physician and at twenty-four years of age I was eventually diagnosed with Crohn's. Every day for the next six years I battled with abdominal pain, dry-retching and vomiting, and loss of blood whilst trying to go to the toilet. All of this time I was increasingly lethargic and suffered from joint pain and low iron levels. The constant blood tests showed I was anaemic. Added to this, I gradually lost my appetite and progressively became thinner. By this stage I was at my wits-end. A second opinion from another physician suggested I should return to the colorectal surgeon

and all the lovely invasive tests started again. The results showed that my large bowel was riddled with Crohn's, along with signs of it in my small intestine and rectum. The news which I didn't want to hear but had half expected, was that surgery was the only option to get me healthy again.

I was still in denial and put off surgery for another year. However, by then I weighed just sixty-five kilograms at best and was enduring extreme pain and nausea due to blockages (at times my large bowel was extremely narrowed) requiring frequent visits to the hospital. Essentially, my failing health made the decision for me and I had surgery in September 2001.

The operation went well, to the point that he was able to re-connect what was left of my large bowel and I escaped having an Ileostomy. My surgeon told my wife (Kim) after the surgery that he couldn't believe how diseased my bowel was and questioned why I had put surgery off for so long. Much to her relief he also told her he had fixed me. All along I was lucky to have such a rock of support in my beautiful wife for without her I certainly would have lost it. She was so caring throughout and was such an important factor before and after my surgery. Kim was so strong, seeing me in constant pain whilst also looking after a business, me

and our two children (who at this stage were just five and seven years old).

I got six or seven great years out of that surgery until a job change, which was highly stressful, coincided with the dreaded Crohn's symptoms returning and gradually becoming worse.

Another two years of battling the now crippling disease under another physician, who tried all the medication options available to me at the time. I remember one (Imuran), which I had tried previously and had such a violent effect on me within thirty minutes of taking it, was one of the worst experiences I had been through. Infliximab via transfusion was his last effort but unfortunately didn't turn things around. All this time I was on high dosages of Prednisolone tablets again to keep the disease under some sort of control. I had emotional moments by myself, asking myself "why me?", "what have I done to deserve this?", before brushing myself down and battling on in front of my loved ones. They said they knew by the look on my face!

Then while all that was going on, I also had chest pains after work and my wife insisted I go to Emergency. Well that was the start of another hideous three months, starting

Why did I put off surgery for so long?

BRENDAN'S STORY

Submitted by: **Brendan Ryan**, NSW



with one week in the cardiology ward because I had had a mild heart-attack. All the tests performed indicated that I didn't have any of the obvious heart-attack triggers (great cholesterol levels, no indication of narrowing of the arteries, etc). The cardiologists and my physician had, let's say, "a constructive conversation" about the medications I had been on in the past. Their eventual diagnosis was Myopericarditis (inflammation of the heart wall and muscle) and I had a further two short hospital visits via Emergency over the next three weeks with the same symptoms and outcomes.

My physician basically told me later that all medication options had been exhausted and he could no longer do anything for me. He suggested that I return to my surgeon as this would again be my only fix! At this time my Crohn's symptoms were at their worst. In particular I needed to visit the toilet approximately eighteen times a day and every one to two hours during the night. I became very bitter with myself and again asked many questions of myself. After reviewing my health, the surgeon said that surgery was again inevitable, but this time I was looking at a proctocolectomy (removal of the entire colon plus my rectum which was severely diseased). Due to the extent and severity of the disease, he said we should start planning surgery to either remove both my colon and rectum at once (which he said would be extremely difficult) or as separate operations. He organised for myself and my wife to visit a Stomal Therapy Nurse to discuss the proposed surgery but after the visit I said to Kim there was no way I would have that surgery.

Every day I continued my losing battle, but one day I decided to pursue another option after my daughter said to Kim that I was always grumpy in the morning. I had heard of a Professor in Sydney who had helped someone I knew indirectly. So I made an appointment. As he went over my files during my first visit he said "Gee, you have had long battle with this, haven't you! Your files are extremely big. I have a product called Humira that I want to try". Unfortunately Humira wasn't on the PBS at the time but he jumped through hoops to get me on it. The only downside was that I was required to take Methotrexate with it. I didn't have any immediate side-effects but within three months I started to get clots in my lower legs to a point where I was injecting myself every day with Clexane on top of my fortnightly injections of Humira. As someone who hates needles I learnt very quickly as I had no choice.

The Professor weened me off the Methotrexate because of this plus I was actually feeling fine, which I now put down to the amount of Prednisolone I was on. The Professor then suggested we also decrease the Prednisolone dosage and see how I handled it. Well, the Crohn's symptoms increased again as I decreased the dosage.

That was November 2009. My wife and daughter (Lilly) had planned to travel to Thailand that Christmas, but Kim said she wouldn't go because she knew I wasn't well. However, I said that I was fine and insisted they go, leaving my son (Sam) and I to play over Christmas. Just the two of us boys and I was eager to do lots with him. For obvious reasons I struggled but he was good with that. I am sure he knew

something was wrong because ever since the girls left I wasn't myself and it was starting to get worse. I was eating alright (those Prednisolone tablets do give you the munchies), but very little was passing through. I still had the urge to go to the toilet but nothing was happening down there. This obviously got worse over the ensuing days and the breaking point occurred a day before the girls returned. Sam and I went for a surf, but the pain of lying on my stomach while paddling was so intense that I broke down in the surf in front of him.

The girls arrived home to see me in excruciating pain, which came in waves every ten minutes. My wife insisted on taking me to Emergency, but I didn't want to go because I knew I wouldn't be coming home for a while. After eventually giving in, I was admitted to hospital when abdomen x-rays clearly showed a severe blockage. I was in an Emergency Ward bed for two days with my stomach being sucked clear via a tube down my nose, before being transferred to a private hospital.

I had surgery to remove the remainder of my large bowel and a Loop Ileostomy was in place when I awoke. My anus wasn't removed as they hoped it would settle down after the operation. After the first few days of recovery I felt a huge relief within myself as the pain had gone, but I wasn't happy with my new attachment. I hated it with a passion and it was extremely embarrassing for me.

I was allowed to go home after four weeks in hospital but they organised a home nurse service to assist in my wound cleansing and re-dressing. Perhaps, they had known what might happen, as my wound opened leaving a massive hole in my abdomen (5cm deep, 12cm long and 7cm wide). I had home nurse visits for six weeks to re-dress the wound and help with my appliance changing. I went back to work after fifteen weeks away.

The nursing staff at Lake Macquarie Private Hospital were incredible both times I had surgery and my Stomal Therapy Nurse in particular was extremely helpful, knowledgeable and caring. They are all very special people.

In telling this I can't (and won't) look back, let alone remember, how bad those times were with Crohn's. After surgery and recovering I am now so healthy and happy that I'll say again, "why did I put off surgery for so long?". My good days now outweigh the bad days ten-fold. I still have bad and dark days where I hate myself and my stoma but I snap myself out of it when I think that there are people a lot worse off than I am.

I am still on Humira and inject myself every fortnight as maintenance to control any Crohn's relapses, in my rectum in particular as this would need to be removed if it flares up too much.

I keep saying to my wife and children that I will soon stop celebrating as I am enjoying my food and feeling so well, as well as having a few beers here and there. I have regained my weight (maybe even a few too many extra kilos), but I have certainly enjoyed myself since surgery, plus I am becoming more comfortable with my new "friend". ●

AASTN President's Report

Submitted by **Kirsti Dixon** - AASTN National President [Australian Association of Stomal Therapy Nurses]

Hello from the beautiful Snowy Mountains and welcome to winter, one of my favourite times of the year. A time to cosy up next to the fire with a good book and enjoy some down-time or to go skiing!

The *Australian Association of Stomal Therapy Nurses* however, have been busy. We recently held our bi-annual conference in Tasmania. What a fabulous conference it was and the committee are to be congratulated on an informative, scientific conference.

Apart from enjoying the culinary delights of Tasmania, It was also a time to connect with colleagues from all over Australia, to attend sessions on what's new, learn what others have been achieving and how we can improve on our care of Ostomates.

At this time we also held our annual AGM at which I was elected the next President. I'd like to take this opportunity to thank retiring President, Elaine Lambie, and the executive members for their dedication over the last two years.

The AGM also elected some new committee members for the next two years. I'd like to welcome Bronwyn Overall of South Australia (Secretary), Lisa Wilson of Victoria (Editor) and Tanya Webber of South Australia (Committee Member).

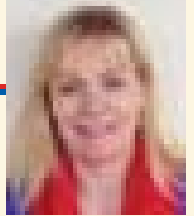
Also welcomed back to the committee for the next twelve months are Susan Vaughan of Victoria (Vice President), Sharon Gibbins of New South Wales (Treasurer), Sue Delanty of Tasmania and Louise Walker of Queensland (both as Committee Members).

As you may have worked out I live in the beautiful Snowy Mountains. Winter is a magical time of the year, but it also brings about many challenges for our environment and our health. It's an important time to look after ourselves, keep healthy and fit. I encourage you all to take time out for yourself. My time-out in winter is to enjoy a ski day with my family.

The AASTN recently finished working on a number of projects. We have updated our Standards and developed Clinical Guidelines for Stomal Therapy Nursing Practice, which will ensure best practices and continuity of care across the spectrum.

I look forward to the challenges that being President will bring, and will to the best of my ability keep you up-to-date and informed.

Your comments, ideas and feedback are always appreciated, so please do not hesitate to contact me. My details are available on the AASTN website.



Bulletin Board

Ostomy Association Changes

COLOSTOMY ASSOCIATION OF SOUTH AUSTRALIA New Website

We are pleased to advise that CASA recently established our new Website - www.ColostomySA.org.au

COLOSTOMY ASSOCIATION OF NSW INC. New Phone Number - 1300 OSTOMY

A new 1300 telephone number has been installed to provide our Members with the convenience of low-cost untimed calls from almost any fixed phone in NSW. The cost of a call made to this new 1300 number is similar to a local call (more for mobiles), regardless of where you are calling from within Australia. Members who live outside of Sydney will no longer have to pay STD rates when they call this association via the new 1300 service.

CA of NSW have selected a 1300 number which can be translated into an easily remembered phoneword. Our new **1300 OSTOMY** phoneword is the same as dialling **1300 678 669**

Ostomy Support Group Changes

YOUNG OSTOMATES UNITED INC. Now on FACEBOOK

We extend an invitation to all Ostomates plus their carers and family to join Young Ostomates United on Facebook, so we can help YOU share the load.

A new page now allows you to discuss your concerns and experiences, or you can sign-in to a 'closed' page and discuss or ask questions in private.

A great, easy way to stay in touch with other Ostomates.

GOLD COAST SUPPORTING OSTOMATES NEEDS GROUP Now on FACEBOOK

We extend an invitation to all Ostomates plus their carers and family to join Gold Coast S.O.N.G. on Facebook. Please add our Facebook page

www.facebook.com/goldcoastostomysupport

Please also note that the Gold Coast S.O.N.G. meetings are now held every 3 months.

How can "Y.O.U." help You ?

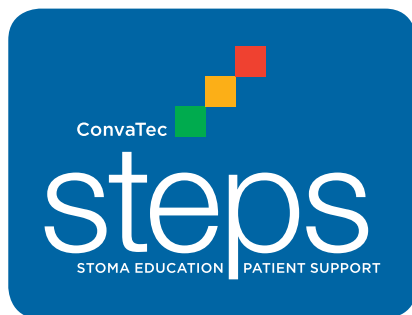
YOUNG OSTOMATES UNITED INC invites individuals with stomas, their families, friends and Health Professionals to an informal evening for an exchange of ideas on how to assist young Ostomates to cope, both before and after surgery.

Thursday 10th October 5:30pm till 8pm Nurses Memorial Centre
Suite 11, 431 St Kilda Road, Melbourne (cnr Slater Street)

The evening will commence with a panel of young Ostomates exploring the psychological impact of needing a stoma, followed by a talk from our Keynote Speaker - **Ms Jane Fletcher** (Director of Health Psycho-Oncology Services, Monash University).

Light refreshments will be served.

RSVP (essential) by 1st October 2013 to Helen (helshae@hotmail.com or 0412 144 230) or **Karen** (ksant@live.com.au or 0452 513 191).



Bringing the ostomy community closer together

STEPS is a new, educational offering from ConvaTec, helping to bring the ostomy community closer together by providing a platform for Ostomy Associations to interact and share information, training and support.

Morning tea and lunch provided. Space is limited, so to secure your place at any of the meetings below, please contact the ConvaTec Customer Interaction Centre: connection.au@convatec.com or call 1800 335 276

NSW

Topic:
**Ostomy Care –
Living Life to
the Fullest**

Date: Saturday, 21st September 2013
Time: 9.30am - 3.00pm
Venue: Wests Bowling Club
Tauranga Road
New Lambton NSW 2305

WA

Topic:
**Maintaining
healthy skin**

Date: Saturday, 21st September 2013
Time: 9.30am - 2.00pm
Venue: Western Australia Ostomy Association
15 Guildford Road
Mount Lawley WA 6050

VIC

Topic:
**Living with
an Ostomy**

Date: Saturday, 5th October 2013
Time: 10.00am - 2.30pm
Venue: Waverley RSL
161 Coleman Parade
Glen Waverley VIC 3150

VIC

Topic:
**Living with
an Ostomy**

Date: Saturday, 16th November 2013
Time: 10.00am - 2.00pm
Venue: Geelong Ostomy Association
6 Lewalan Street
Grovedale VIC 3216

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www.convatec.com.au



Having suffered severe **endometriosis** (endo) for over twenty years, and having previous but unsuccessful surgeries for this, I was finally referred to an endo specialist in early 2012. I had a laparoscopy and was told I would need to undergo some major surgeries which would include bowel resections and removal of a large section of my rectum due to the endo. My surgery was scheduled for 5th December 2012 and I was told that there was a high possibility that I would wake with a temporary ostomy bag which I would have for three months.

When I awoke ten hours later, I had my ostomy bag (I named my bag "Leo" as in "Ileo" – I know, probably not very original). It's a shame the bags don't come in assorted colours as I would have preferred a choice of colours instead of the plain beige/brown – but I wasn't going to complain.

My Stomal Therapy Nurse visited and we discussed the impact of having a temporary ileostomy and the procedure needed to empty my new appliance. She also gave me my first challenge, which was learning how to cut my appliances to correctly fit the shape of my stoma. I hadn't done any cutting out since primary school so my cutting skills were a bit rusty but I soon got the hang of it.

I learnt how to cut out and change my appliances and was discharged from hospital eight days later, feeling a little less scared. For the next three months it was all trial and error with some laughter and lots of tears. Instead of changing my appliances

every two days I was having many daily changes due to the blow-outs that I had to deal with. The disability toilet at work became a godsend for me when I had to deal with the blow-outs. I am very grateful that my work colleagues, those few who knew, were very supportive and understanding of my situation especially when I had to leave urgently and go home to shower, change and return, or leave for the rest of the day.

I enjoyed the times where I would go to work and my colleague's would comment on my work outfit and how nice I looked, as most did not know underneath it all I was wearing my bag. On the outside I was still the same person even if I was different underneath.

My reversal was completed on 6th March 2013, and I was told that my brain would need to re-learn how to go to the toilet for bowel motions. I was also told that the bowel motions would be very loose at first and it would be hard to hold plus I would have extreme urgency to go to the toilet. Well, I thought my brain was quite clever as within a few hours of having my reversal surgery I had my first extreme urgency to go to the toilet. I moved my sore, sorrowful body as fast as I could to the toilet only to pass gas, which came as a complete surprise to me as I was expecting my first bowel motion. I was a bit disappointed as the urgency to go was so strong

and this passing of gas did not even worth a rating. It was just a small puff of air. My brain also needed to re-learn the difference between passing gas and the need to pass a bowel motion.

I could be released from hospital after I was able to have quite a few bowel movements. When my nurse heard I was being released after two days in hospital she decided to give me some products to assist me through the first couple of days. She gave me some pads, as well as some stretchy underwear to wear with the pads and some sheet protectors. Now I am not talking about your run of the mill sanitary pads. No, I am talking about your adult diaper pads that cover the whole of your lower body. I wondered what she thought was going to happen.

Well I soon found out. Back home I experienced extreme urgency that made me think if there was ever an Olympics event that had people going to the bathroom, removing their clothing and sitting on the toilet in record time I had a good chance of being in the top three. I was becoming an expert at undressing on the way to the bathroom and doing a quick turn-around to sit on the toilet, all in record time. The first couple of nights I decided to utilise some of the pads and also used one of the sheet protectors, just in case. It would

be easier to throw the pad and sheet protector in the bin than have to strip the bed, wash the sheets and then remake the bed, not to mention my clothes.

I learnt about cluster bowel movements and could spend a couple of hours going back and

forth to the toilet, flushing, washing my hands and ready to leave the bathroom but having to get back on the toilet before I could leave. This was going to be my Groundhog Day for the next week. I often thought about my bag during these times and realised that the bag blow-outs were nothing compared to what I was now going through, but I was determined that my brain was going to re-learn. I also noticed that as soon as I would start to eat, I would need to rush to the toilet and would sometimes make three or more trips to the toilet before I could even finish my meal. My doctor explained that this was all part and parcel of my brain re-learning.

After a couple of weeks the cluster bowel motions stopped during the day and would mainly occur in late afternoon or at night, which made it easier for me to leave the house for longer periods during the day. I also learnt if I wanted to leave the house I could fast to avoid any accidents or sudden urgencies. I learnt what foods I could eat for breakfast that would not affect me while out and what foods I should avoid.

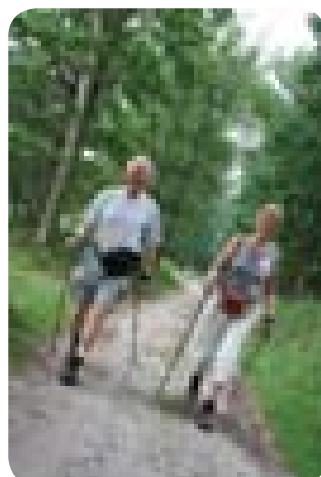
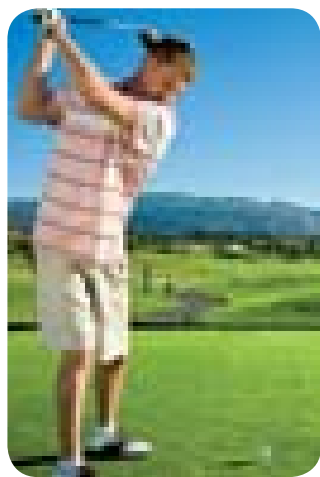
I have also been lucky to have some of my family, good friends and work colleagues share some of their own different experiences during all this. One friend explained that "you haven't lived unless you have soiled yourself" and also said that they had to

Submitted by: **Tania Place**, QLD

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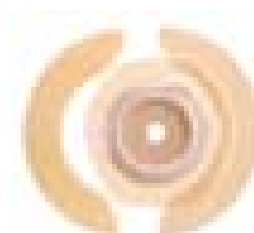


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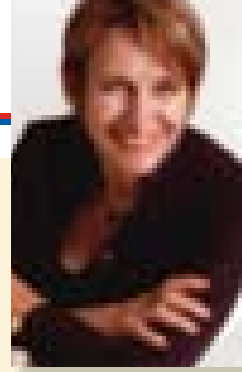
Order Code	Pack Contents	Monthly Allowance
XWAFH33	20 Pieces	3 packs (Standard)
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Dear Carmen

A year ago my husband developed a twisted bowel and had to have a colostomy. Nothing unusual about that and the surgery was a life saver. However, he has since developed a prolapsed stoma, which is giving us a lot of trouble. Unless he wears the elastic belt twenty-four hours a day, his stoma protrudes approximately three to four inches and fills the pouch, leaving no room for anything else. He has also had a couple of nasty accidents whereby he did not realise the pouch was coming away from the flange. As he is also in the early stages of dementia, it is becoming a huge problem.

Our doctor more or less told us he will not be able to withstand further surgery, and it is just something we have to live with. I was well schooled by the Stomal Therapy Nurses at the hospital and I do all the changing. After a year, I have become used to changing his pouch and keeping the area around the stoma in good order.

We would also like to hear from other readers whether this has happened to them.

Anna Bushby, WA

Dear Anna

Thank you for your letter, I am sure you will get responses from readers about their experiences with a prolapse.

You don't tell me if your husband's stoma is a loop or an end stoma, which would give me more information to inform you on the

surgery involved in reversing the stoma. Generally, reversing a loop stoma is a relatively short operation and these also tend to be more prone to a prolapse.

The best way to reduce a prolapse is to lie flat and the prolapse will generally go back in. If the prolapsed bowel is out for too long it can get oedematous (swollen) and this can make it harder to reduce.

Stomas generally prolapse during active peristalsis (when the bowel pushes its contents along) or when intra-abdominal pressure is raised such as when one coughs. A good idea is to try reducing the stoma at the time you change a full bag. If the stoma has prolapsed then reduce it at this time, and then put the abdominal binder on over the top of it whilst still lying down.

As for the pouch coming off the base-plate, you may feel more secure if you use a belt that attaches directly to the pouch and not to the base-plate. This way you will have extra security.

It sounds like you have a good relationship with your Stomal Therapy Nurse so I recommend that you make an appointment to see her/him so they can recommend appropriate ostomy appliances or help you to modify your current technique.

I wish you all the best as you care for your husband at this time.

Sincerely, Carmen



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.

Continued from page 28

travel overseas for their "living" experience. I told them "I have also lived then, but didn't even need to leave the house". Mind you, if that is the case then I have probably lived ten times over since my reversal. I had a work colleague who also shared their story of how they had "lived". It was encouraging to know that it wasn't just happening to me with my reversal but also to others, even if not all at the same stage in our lives. Having family, especially my husband, and friends laugh with me has helped during my recovery and I thank those who have a similar warped sense of humour as me and can see the funny side with me, but who have also been there for me when the tears come. As others have said, it helps to have a good sense of humour, but I think it also helps to cry as well.

At the time of writing it is five months since I had my endo surgery and two months since my reversal. I am happy to say the operations were a complete success and I have started to live life again with my new adjusted body and without further severe endo pain. I still have moments where I have cluster bowel movements during the night that can last a couple of hours at a time and I still fast when I want to be out for longer periods during the day. My diet now consists of very small meals throughout the day. I am anticipating a full recovery where my bowel movements will be down to four times a day.

It is trial and error again, only this time without my bag. ●

Endometriosis

is a gynaecological medical condition in which cells from the lining of the uterus (endometrium) appear and flourish outside the uterine cavity, most commonly on the membrane which lines the abdominal cavity. The uterine cavity is lined with endometrial cells, which are under the influence of female hormones.

Endometrial-like cells in areas outside the uterus (endometriosis) are influenced by hormonal changes and respond in a way that is similar to the cells found inside the uterus. Symptoms often worsen with the menstrual cycle.

Endometriosis is typically seen during the reproductive years; it has been estimated that endometriosis occurs in roughly 6–10% of women. Symptoms may depend on the site of active endometriosis. Its main but not universal symptom is pelvic pain in various manifestations.

Endometriosis is a common finding in women with infertility.

There is no cure for endometriosis, but it can be treated in a variety of ways, including pain medication, hormonal treatments and surgery.

NEW!

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1. *I will be travelling around Australia for twelve months and want to know what I should do about getting my supplies. I don't really want to take too much with me as I don't have the room but also don't want to be stuck in the middle of nowhere with nothing.*

As a registrant of the Stoma Appliance Scheme (SAS), you are entitled to obtain appliances (up to the maximum allowance per month) through any one of our twenty-two national stoma associations, as long as you are a financial member of one of these associations as required by the Department of Health and Ageing. What this means is that, while you are travelling, you can request supplies through any association as long as you have paid your membership/access fee for the current financial year and you haven't yet reached your maximum allowance of that supply for the current period.

In preparation for your travels it is suggested that you:

- Arrange for a full order of supplies from your usual association well in advance to your anticipated departure date.
- Make sure your membership fees are paid up-to-date.
- Carry your Stoma Appliance Scheme Entitlement number with you as you will need to quote this number and the details of your usual association when seeking supplies from an alternate association.
- Carry a list of National Stoma Associations and their contact details with you for reference.
A list is included in each edition of the *Ostomy AUSTRALIA* journal.

Please be aware that each association has its own procedures and policies with respect to ordering, product availability time-frames and postage costs so leaving it until you are down to your last few supplies to order is fraught with danger. Its best to check in advance with the closest association to where you will be visiting to ascertain their ordering policies and to ensure that you adhere with their procedures to ensure continuity of supply during your travels.

2. *I live in a regional area and only need to order most of my appliances about twice per year. Some though, like the 3M Barrier wipes, I need to order more than twice per year as my association will only send me two boxes at a time. My entitlement of these is one box per month so why can't I get six boxes twice per year to save me postage?*

The Department of Health and Ageing have produced the "Operational Guidelines for Stoma Associations" as

a practical reference guide for associations on the practice and procedures that they must follow when providing stoma related products to their members through the Stoma Appliance Scheme (SAS). As per Clause 6.4 of the Guidelines, associations can choose to adopt a two month ordering cycle for members as long as the member has had their stoma for at least six months. Accordingly, under the guidelines, associations can choose to supply a maximum issue of two month's supply (prepared bi-monthly as a single parcel) to members if requested. To supply six boxes of 3M Barrier wipes twice per year would therefore mean that your association would be exceeding the two month's maximum supply and breaching their obligations in terms of the guidelines.

3. *I have recently received an order from my association and found that one of my products, an adhesive remover wipe, was missing and had been placed on back-order. I rang my association and was told that, while there are similar products available, I would need to place an order for it if I wanted another type of wipe to be sent. I would have assumed that, as all adhesive remover wipes do the same job, my association would have just sent me an alternative. I am now out of remover wipes completely and have to wait for my order to come which could take weeks. This has been very inconvenient!*

While all adhesive remover wipes do "do the same job" i.e. remove adhesive from the skin around the stoma, they are not all the same. Furthermore, Clause 6.5.7 the "Operational Guidelines for Stoma Associations" produced by the Department of Health and Ageing states that:

6.5.7 Unavailability of Products

In the event of unavailability of a product, an alternative product should not be supplied unless an order has been placed by the member for the alternative product.

Members should be advised to seek advice from an STN or their Medical Practitioner.

Your association has therefore taken the correct action. However, most associations do carry a quantity of most accessory products in stock, so I am sure that your association would be more than happy to send you the ordered alternative product as soon as practicable if you explain the urgency of your situation and they have the required alternative wipe in stock. ●

Please send your "Ask Kylie" questions via email to feedback@australianstoma.com.au

Alternatively, hard copy submissions may be sent to The Editor, *Ostomy AUSTRALIA*, PO Box 195, Frenchs Forest. NSW 1640

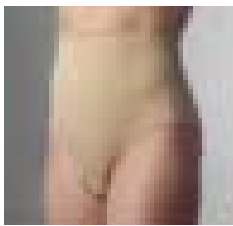
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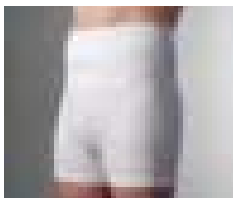
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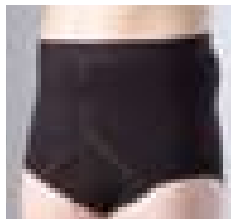
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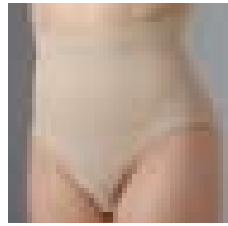
Diamond Plus Unisex Boxers



Men's Support Pants



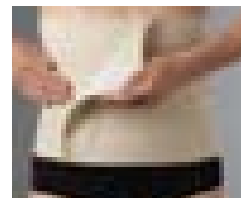
Support Briefs for Her



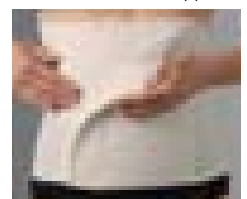
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A Sensational Seminar

Submitted by: **Warren Rayment**, President, Gold Coast Ostomy Association

Over two hundred and sixty registrants joined us on Saturday 9th March 2013 at the Gold Coast's Southport Sharks function centre for the Gold Coast Ostomy Association's (GCOA) inaugural Ostomy Seminar. Attendees included guests from Melbourne, Griffith, Lismore, the Sunshine Coast as well as Mackay, Brisbane, Toowoomba and other locations. Perhaps the most pleasing guest contingent, was the over sixty regional and local nurses with a declared interest in expanding their education and knowledge of the specific nursing skills needed for Ostomate care.

The appliance companies were well represented with their colourful product displays and exhibits a resounding hit with guests. Considerable interest was also focused on local manufacturer Knightwear, which fashions Ostomate undergarments.

Guests were treated to a comprehensive day of outstanding guest speakers and a warm and hospitable social environment, all complimented by a tantalising array of goodies for the tea breaks and buffet lunch.

The object of this seminar, our first effort at such a large scale event, revolved around our desire to give GCOA's members, interested parties and other guests, a dissemination of valuable information and material designed to improve their understanding of ostomy management and welfare. The GCOA's Committee is dedicated to lifting ostomy welfare standards whenever and wherever possible. The concept of a regional seminar provided the ideal vehicle to educate, explore and deliver relevant material.

ACSA President **Peter McQueen** opened proceedings with a comprehensive analysis of the national Stoma Appliance Scheme (SAS), its workings and value to Australia's Ostomates. Peter also detailed the representative work performed by ACSA with the Federal Government in the ongoing maintenance and preservation of the Scheme, its role in product listings and protecting Ostomate interests. He concluded by stressing the importance of Ostomate Key Performance Indicators (KPI's) in ensuring the stability of the Scheme, namely;

- Keep a reserve of stock to guard against contingent stock outs (three to four weeks supply usually adequate).
- Do not stockpile goods as this escalates the Scheme's costs and may well compromise its existence.
- Keep requisitions within the approved monthly maximum allowances.
- If extenuating ostomy conditions dictate extra supplies each month, obtain the stipulated authority from a Stomal Therapy Nurse after a full assessment of the suspect condition.

Margaret Allan, a Melbourne-based diet and nutrition expert, gave an instructive talk on maintaining a balanced food intake and achieving a healthy diet. Margaret pitched her talk around the particular nutritional needs of Ostomates where radical bowel or bladder disease and subsequent surgery, has impacted on our digestive and waste systems.

Colorectal surgeon **Dr Mark Doudle** (eminent South East Queensland surgeon) along with **Professor Les Bokey** (Sydney based) our keynote speaker, took centre stage for the mid-morning session.

Dr Doudle gave a studied and at times graphic talk on the incidence of hernias after colorectal surgery, current remedial methods and the inherent problems in dealing with hernia conditions.

Seminar keynote speaker Professor Bokey (pictured right) then captivated the audience with a marvellous walk down the Ostomy Hall of Fame. He focused on such luminaries as Professor Bryan Brook and Sweden's Nils Kock, both of whom perfected ostomy surgical techniques back in the fifties and sixties. The Professor also highlighted the discoverer of the revolutionary Karaya gum, which so advanced appliance product development.



He drifted to other marvellous surgeons and individuals whose discoveries resulted from 'simple observations', but which dramatically impacted and changed the course of surgical techniques, thereby leading to increased well-being for Ostomates. Two of the distinguished names mentioned were Rupert Turnbull (Cleveland Clinic's surgical mentor) and Norma Gill (widely acclaimed as the mother of stomal therapy nursing).

The general post seminar consensus was that Professor Bokey's keynote address was a very special and privileged treat. The fact that Professor Bokey had either worked, or been associated with these distinguished persons during his professional career, gave added lustre to his presentation.

'Life after Illness' was tackled by Brisbane's Emotional Balance director, **Nic Marcon**, who examined coping mechanisms and strategies for dealing with illness, depression, grief and anxiety. In particular, where these conditions stem from chronic illness and life changing surgery. He delved into the emotional and psychological aspects of chronic bowel and bladder disease coupled with a subsequent ostomy. His talk was thought provoking, reassuring and seemed to resonate with an enthralled audience.

Stomal Therapists, **Elaine Lambie** (AASTN President at the time) and **Bill Tyrrell** (noted NSW northern rivers identity) completed the day's speaker list as they dealt with appliance selection and applications. The importance of regular stoma reviews was stressed as essential ongoing maintenance and well-being. Elaine spoke on the academic role and development of Stomal Therapy Nurses (STN) in Australia, the changing nature of the profession over many decades and the need for more STN's to service the growing numbers of Ostomates.

In summary, GCOA's initial seminar was hailed a huge success. The project was strongly aligned with our overall aim of working vigorously towards maintaining the best possible standards of Ostomate welfare and management for members, and a legitimate use of membership funds.

Feedback has been most favourable and complimentary and fully justifies the significant cost outlay in staging the event. The GCOA Committee views this expense as consistent with our regional charter of ongoing education and support for Ostomates. The project's success is a firm indication that GCOA may well contemplate a similar type project in future years.



TWO
NEW SIZES

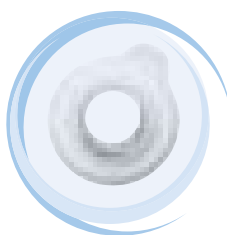


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Sailing Solo Around Australia Non-Stop

By **Len Surtees**, QLD

Something in my DNA seems to surface from time to time and demands that I get out of my comfort zone, which stimulates ideas that can be developed and acted upon.

So in May 2012, I decided to set myself a "fair dinkum challenge".

I had recently designed, built and launched a prototype nine metre sailing catamaran that folded onto a trailer and could be transported by road. In the back of my mind I had always looked for an opportunity to raise the awareness of cancer survivors and raise some money for the Cancer Council. So, I decided to risk my life by sailing solo around Australia while also raising money for the Cancer Council.



Back in 1987, after having major surgery and several weeks of radiation treatment, I was told all was well. However, within two weeks a large lump had formed in my groin and each day it became larger and more painful. It became so extremely painful that I was forced to take morphine to combat the pain. The cancer had returned so aggressively and quickly that I was told I only had six weeks to live.

This was a shocking situation but with a very supportive wife and two young daughters (three and six years old) who needed a father, the thought of dying at this stage of my life never entered my head.

The only avenue left was to have radical surgery. When I asked my odds of surviving I was told I had a twenty per cent chance of pulling through. Well, that was music to my ears and I said "Let's do it!".

The result being a nice smiling stoma that I made my best friend the moment I set eyes on it. It so happened that so much was cut out of my body, I was told two weeks later that the wounds would not heal unless I underwent a world's first radical procedure which may solve the problem. Well, let's get on with it then.

The procedure was a success. I also went on to develop a device called the "AUSTomate Stoma Cover" to protect and support my stoma, which allowed me to continue playing hockey as centre-forward. AUSTomate is a dome shaped plastic cover with an adjustable elastic belt. The belt is attached across the middle of the cover with velcro and covers the stoma and the top half of the bag. These are now sold world-wide.

So back to May 2012, at age 62 I broke the news to my wife and family that I wanted to risk my life by sailing solo around Australia. With their understanding support I set about organising all the bits need for such an epic voyage. I hadn't sailed solo before and the last time I had ventured out into the ocean was as a young man in my twenties after building a thirty-one foot sailing trimaran whilst working in Canada, and sailing it with a friend down to Mexico.

A major item I had to pre-plan was my ostomy supplies as I expected to be at sea for at least sixty days, possibly more. For the past twenty-five years I had used a two-piece system but due to a growing hernia I found the base-plate was starting to make my skin very red and sore. So reluctantly I tried a one-piece sealed bag with filter. Wow! Instant fix. I should have done it years ago.

I also asked around for financial help for my world record breaking voyage attempt (being the oldest sailor to do so and in the smallest boat) and many sponsors helped in many ways. Thankfully, one sponsor paid for all my foul weather clothes and thermal underwear.

I set sail on 20th September 2012 from my home port of Tin Can Bay on the Sunshine Coast of Queensland. After a minor problem which had to be fixed at Hervey Bay, I set sail again and headed outside the Great Barrier Reef and round Cape York, which was my first land sighting after ten days of sailing.

I then plotted a course across the Gulf of Carpentaria, which took a further five days. Then around Melville Island (north of Darwin) and I had started my journey down the coast of West Australia. This leg proved difficult due to my falling heavily onto my auto-pilot and bending the ram shaft. I was forced to pick up a replacement in Broome, which unfortunately also meant that my world record attempt was cancelled. However, this was not all that important, as just getting out there and "doing it" is what really mattered.

I eventually made it down the west coast but ninety nautical miles north-west of Cape Leeuwin (the last Cape to round before I headed south of Tasmania) I was hit by very big seas coming up from the Southern Ocean. Unfortunately, a large low pressure system came over me, bringing gale force winds that made the already big seas very dangerous with waves reaching ten metres.

I decided to "hove to" (rudders lashed hard over and a very tiny head-sail) during the night. At 3am I was violently thrown out of my bunk as my boat (named Zeavard) was hit by a rogue wave. Much larger than the prevailing waves, it held me in its grip for several seconds as it rotated Zeavard and sent us sliding backwards down the wave. I said out loud to myself "This is it Len!" and expected to die. It felt like a Mack truck had just smashed into Zeavard's port-side and water came in with hydraulic force through the air-vents in the upper cockpit bulkhead, which meant the wave had also come right over the boat.

The steepness of the angle at which Zeavard surfed backwards down



What Else Is In My Medicine?

Reproduced with permission.

National Prescribing Service Ltd, MedicinesTalk, June 2013

All medicines contain at least one **active** ingredient - this is the chemical that makes the medicine work. Most medicines also contain a range of **inactive** ingredients (known as excipients) that help to make the end product (e.g. tablet, capsule, syrup).

Inactive ingredients are used in prescription and non-prescription medicines. Examples include gluten, lactose, preservatives and dyes.

The inactive ingredients are needed for a variety of reasons, including:

- ▶ as a filler if the quantity of active ingredient is very small.
- ▶ as a binder to hold all the ingredients together.
- ▶ to sweeten or flavour the medicine to make it easier to take.
- ▶ to coat tablets or capsules so they're easier to swallow.

For most people, these inactive ingredients won't be of any concern. However, for some people - such as those with particular allergies and sensitivities (e.g. to preservatives or dyes), or who need to avoid certain ingredients (e.g. gluten, lactose) for religious, cultural or medical reasons, or who need to be aware of what they eat and drink for ethical reasons - the excipients may be undesirable or even harmful.

Different brands of a medicine may have different inactive ingredients. This can result in the medicines being different sizes, shapes and colours. It's important to remember that even though different brands of the same medicine may look different, they will work the same way in your body, because they have the same active ingredient.

Ask your doctor or pharmacist

If you need to avoid certain inactive ingredients, ask your doctor or pharmacist for information when you use a medicine for the first time. It is also useful to check the inactive ingredients when changing the brand or strength of a medicine. If there is a particular brand of a medicine that you

know is suitable for your intolerances, ask your doctor to **tick** the '**Brand substitution not permitted**' box on your prescription, or tell the pharmacist you want a particular brand.

Read the CMI leaflet

You can find a list of a medicine's inactive ingredients under 'Inactive ingredients' in the consumer medicine information (CMI) leaflet for prescription and pharmacist-only medicines. If you don't have a CMI leaflet for your medicine, ask your pharmacist for one or download it.

Medicines Line

You can also call Medicines Line on **1300 633 424** (1300 MEDICINE). *NPS MedicineWise* works with *healthdirect Australia* to provide consumers with information on prescription, over-the-counter and complementary medicines. The service is available Monday – Friday, 9am – 5pm AEST for the cost of a local call (calls from mobiles may cost more).

Corsinel®
Ostomy Support Underwear.

Optimal balance between compression and comfort
Corsinel has been developed especially to support a paraumbilical bulge which has appeared in connection with a stoma.

The upper part of Corsinel underwear supports the hernia and makes the user look good. The lower part is made from a softer material making the garment easier to apply and take off. The combination of the two kinds of material makes Corsinel more comfortable and makes it stay in place.

A technological landmark
Tests show the Corsinel underwear reestablishes a normal body profile, both sitting and standing.

Corsinel®
Leaders in Ostomy support garments.
Contact your local Stoma Association or
Statina Healthcare Australia Pty Ltd on:
1300 365 424.

statina
Stoma Healthcare Australia

www.statina.com.au

the wave threatened to pitch-pole us end over end but thankfully it soon passed. I knew there would be damage and after inspection early the next morning, found two of the sixteen millimetre outer bolts that help secure the folding beams to the outriggers or hulls on the port-side had been snapped. Luckily, the two inside bolts had held so I was able to make it back to shore safely some 120 nautical miles away (approximately 220 kilometres).

The force needed to snap these stainless steel bolts is several tons but no other damage occurred except for a leaking lower rudder-bearing that needed tightening. I decided that my small mini coastal cruiser was no match for the many Southern Ocean storms that still lay ahead so I ended my voyage then, much to the relief of my wife and family. I had sailed 5,340 nautical miles (nearly 10,000 kilometres) and many times I was 100 to 200 nautical miles off the coast.



Although I didn't complete the circumnavigation of Australia it is the "getting out there and living life to the fullest" which matters most to me, as life is short. I had achieved most of my goals, being:

1. **Get out of my comfort zone** (I spent nearly sixty days at sea, with no refrigeration or shower and with soups as my main diet).
 2. **Do a vigorous sea trial for my new design.**
 3. **Make some money for Cancer Council of Queensland** on their "I can for cancer" program for which I thank all those who have made donations.
- Some commonly asked questions:

- "How many sail boats did I see?" - None.
- "How many ships did you see?" - Too many.
- "How many whales did you see?" - None.
- "How many mermaids did you see?" - None (but I was probably just unlucky - Ha, Ha).

Smile A'While

THE WICKED, WILFUL WOG

by Wilbur G Howcroft

Born: 28 Aug 1917 - Kerang, Victoria
Died: 11 Apr 2004 - Culgoo, Victoria

A much dreaded event, which all bush-folk resent, is that terrible scourge called the Wog. This pernicious disease, can quite suddenly seize, with a grip like a rabbit's dog.

A tough drover out west, was attacked by the pest as he sat by his camp fire one day.

On his quart-pot he wrote, this pathetic last note:
"I bin struck down — an' ain't drawn me pay!"

A poor cocky, it's said, was confined to his bed when the pestilent bane laid him low. For a fortnight or more, he hung close to death's door, as he sweated and tossed to and fro.

A kind neighbour, one day, who rode over the way, was informed by their young son aged ten:
"Dad's much better, thank you, an' we think he'll pull through, 'cos he's startin' to swear once agen!"

An aged bagman out back, was struck down on the track and collapsed by his swag like a log. When discovered he sighed, and then plaintively cried:
"Gimme rum — I've bin bit by the Wog!"

An expatriate Greek, was once swimming a creek when the deadly germs started to gnaw. With a heart-rending moan, he sank like a stone, but the virus all swam to the shore.

A prospector named Ned, was discovered half-dead from a fall in a high mountain chain. He was taken, perforce, firmly tied on a horse, to a hospital down on the plain.

For three weeks or so, it was just touch and go 'til his fevered mind burst through the fog. Then he boastfully said, to the nurse by his bed:
"This ain't nothin' — I once 'ad the Wog!"



★ NEWSFLASH! ★

Introducing our **NEW**
Gastronaut Puppets



Kylie McGrory and Lisa Jurkowski (Queensland Stoma Association Inc) with some of the new Gastronaut puppets

The Gastronauts have welcomed some new friends to their range of Ostomate hand-puppets. In addition to Sally, Max, Simon and Lucy, we now have Grandma Ruth and Grandpa Ron, Sergeant BJ Stoma, Jolly Janet the Cheerleader, Fire Chief Mike and Nurse Sue available for purchase in Australia at a cost of just \$22 each plus postage.

The Gastronaut puppets are a wonderful tool to help children (and others!) achieve a basic understanding of an ostomy both before and after their own surgery, or the surgery of a loved one.

For further information about purchasing a puppet, please email:
feedback@australianstoma.com.au



Body shapes change over time exposing you to an increased risk of leakage and skin irritation.

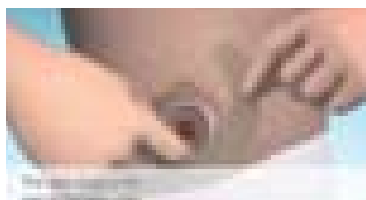
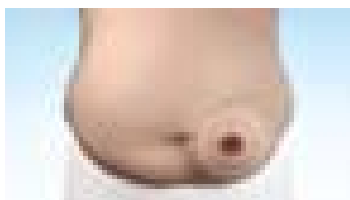
In fact, over 60% of people report leakage whether they have had their stoma for 6 months or 6 years.*

That's why it's important that you regularly check the fit of your ostomy appliance.

Are you still getting the best fit from your ostomy solution?

Now with BodyCheck you can take control and stay sure of your ostomy solution...

Developed in collaboration with Australian Stomal Therapy Nurses, BodyCheck is an innovative online resource that enables you to assess your individual profile and find the products that best suit you. By answering 8 simple questions, confidence in your ostomy appliance is just a few clicks away.



Easy to understand language and diagrams

BodyCheck animations will help you to select and use products that are appropriate for your body profile.

www.bodycheck.coloplast.com.au

Coloplast
Customer CARE
Specialists are
trained in
BodyCheck



Use your smart phone QR reader to watch a video of BodyCheck in action

*Coloplast market research 2010

www.coloplast.com.au

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My Roller Coaster Ride

Submitted by: **Hans de Nys**

About seven years ago I was diagnosed with prostate cancer. However, by the time the cancer was discovered (due to having a smaller than average prostate gland) it was quite advanced and a "Radical Prostatectomy" was performed.

My PSA blood-count started to rise again (slightly), hence I was being regularly monitored by my GP.

In November 2010 the postman dropped one of those BowelScreen Australia® test-kits into my mail box, which I put aside thinking "Yes, I'll do that when ..." and "Yes I'll do that after ...". Eventually I got around to doing it (after many reminders from my wife, Jeanne) and didn't give it another thought.

Then a letter from the Bowel Cancer Australia organisation arrived, advising me to see my GP as soon as possible to arrange to have a colonoscopy.

My GP said not to read too much into it, as most colonoscopies usually showed up less worrying things like piles or fissures. Unfortunately she was wrong this time, as a large tumour was discovered wrapping itself around my sphincter, which is the muscle controlling bowel motions.

From then on the ups and downs of my roller coaster ride began.

Due to the position of the tumour and the fact that I had already undergone a radical prostatectomy, I was referred to the specialists at the Royal Brisbane and Women's Hospital where I underwent almost two months of radiation and chemotherapy.

The tumour was reduced in size and removal of my bowel was the next and final stage for which I was mentally well prepared with the knowledge that I would have a stoma after my surgery. However, I was not prepared for the next saga.

I was aroused from the anaesthetic and recalled not feeling any stoma



on my stomach, feeling a great "up" of relief and thinking that all must have been OK! I was not really cognisant of what the surgeons were telling me.

In actual fact they had found cancer covering the Peritoneum plus more prostate cancer. Deciding that I should have quality of life, they took more biopsies and aborted the surgery.

Later that day with Jeanne and a dear friend by my side, three sombre faced surgeons did their "rounds" and gave their prognosis which was not good. They suggested that I get my affairs in order and basically to fulfil my "bucket list". The roller coaster came down with a crash landing and I was released from hospital the following morning.

By this time we had been living in a Cancer Council unit in Brisbane for almost three months and needed to stay yet another week so I could undergo more key-hole surgery to take more biopsies.



We then flew to South Australia to spend two weeks with our sons. Whilst there, we received a phone call from the hospital saying that my biopsy reports had shown promising results and that the growth on the Peritoneum had responded to chemotherapy (which I had been wearing attached to my arm 24x7) and offered me another appointment for surgery the following week. So the roller coaster took another sharp rise of elation.

My anus was removed and I now have a stoma. The Peritoneum was removed, the prostate cancer was again cut out and after eight months on an up-and-down roller coaster ride, I was back on the job driving my truck.

I've been back at work for almost eighteen months now and cannot thank my employer and work colleagues enough for all their support. I also believe in the power of prayer and thank my church family for their prayers throughout the whole "Roller Coaster Ride".

I must admit that it's not always been "all beer and skittles". There have been a few embarrassing moments where I've been caught out on the job; such as the time when (on the way back to base, in the confined space of a "troop carrier") my colostomy bag began to leak. Most of my work colleagues were aware of my stoma, but unfortunately on this occasion there was a "new guy" on board who kept complaining "who's s... himself?". A work mate spoke up in my defence and joked "The fox smells his own first". We all laughed and I gave him a dig in the ribs. Embarrassing as it may be, I have learned to live with, look back on, and laugh at ... whatever comes.

I still have three-monthly checks and scans but the head surgeon (of the team) now calls me "a walking miracle".

For the first few years after I had my Ileostomy I was afraid to do many things. Mostly because I didn't feel confident with this "thing" attached to the side of my stomach, but then I realised that I had to start trusting "it" to behave itself.

My first attempt at swimming was disastrous! I had obviously had a gas producing meal the night before and hadn't realised the consequences. I felt embarrassed and uncomfortable. So the next time I went swimming I made sure I only ate the "right things" the night before, and it was very successful. I even designed a pair of bathers with a lining that held my appliance close against my stomach, which gave me all the confidence that I needed.

I think once you feel confident you will try anything. I had been contemplating going to Vietnam for quite some time but was very unsure of conditions in these developing countries, particularly the toilets. I have had my Ileostomy for nine years and thought it was about time. So I had a chat with a Stomal Therapy Nurse and then contacted a travel agent to discuss what and where I wanted to go.

I thought about what I would need:

1. *Small packets of tissues (I wasn't sure about the availability of toilet-paper)*
2. *Hand sanitiser*
3. *Bottled water (sealed top)*

All of these were invaluable. Many, many toilets in Vietnam don't have toilet-paper and many of those that do, have only a small amount (one sheet) and you mostly have to pay for it. Not much but you may not always have the correct change. Also, most toilets don't have running water and only a few (mostly in Saigon) have soap or sanitiser.

The food was fantastic and only once did I have an upset stomach. Maybe the food was too spicy that time or it was something to which I would normally have reacted. Dehydration was a slight problem, but it is a problem for me at home as well, so I made sure that I was well hydrated. I was okay as long as I only drank boiled water (hot teas and lots of Vietnamese coffee) or bottled water, though I did occasionally have a cocktail.

The heat and the humidity were extreme, but after a few days I adjusted and made sure that during the hottest part of the day I would either sit and read, or have a nap. I did the bulk of my sightseeing / shopping in the early morning or late afternoon.

My daughter, Kate, came with me and I don't think I have ever had a better holiday. We saw some of the greatest sights, met some of the most beautiful people and learnt a lot about

a very unique culture. I met people who had absolutely nothing yet were as happy as I have ever seen anybody. The little children laughed hysterically at the bubbles we took for them to play with.

I met an old lady who made exquisite pottery on a wheel that was kept moving by a revolving team of grandchildren (as there was no electricity). This old lady kept a whole family sustained through her beautiful work. She was eighty-years-old, or that is what they thought she was as there weren't any birth records.

We also went to the War Museum and saw the result of some of the worst atrocities in history.

I had one of the best meals of my life at a shack on the side of the Mekong Delta (the dirtiest river I have ever seen). Elephant Ear fish which was taken straight from that river.

We stayed in the beautiful city of Hoi An, which is very pretty with a French influence. Our accommodation was the Phuoc An Motel on the Phuoc An River ("Phuoc An" means "river of life" and is pronounced as it is written). I would have to say Hoi An is one of the prettiest places. Its quaint houses, kind and lovely good people, noisy markets and crazy street vendors all added to make some of my most wonderful memories.

Sometimes the fear of doing something is far worse than actually doing it - and for me this proved to be very true. I have travelled quite a few more times to countries in Asia, both with company and on my own, and I highly recommend it.

I could write forever about the joys of Vietnam, Northern Thailand, Burma and Laos, the wonders of the opium addicted H'mong hill-tribe, the hippy town of Pai, and of course, beautiful Bali, all of which I have visited. I hope to visit many more Asian countries now that I have my confidence.

So if you are contemplating travelling but are feeling unsure, do what I did and just go. Make sure you have all the necessary health-checks and take three-times as many ostomy appliances as you would normally need (just in case). Make sure these are not all in the one suitcase as if it gets lost there may not be a place to get more supplies. I carried some in my very large travel handbag, some in my cabin luggage, and the rest in my suitcase. Luckily nothing happened, but it pays to be prepared.

My most valuable travel tip? Well it has to be "small packets of tissues"! I never worried about any of the very basic toilets I encountered as long as I had my tissues with me. ●



National Directory of Ostomy Support Groups

NEW SOUTH WALES

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: 2.00pm to 4.00pm on 20th Feb - 15th May - 21st Aug - 20th Nov
Meet at a different venue each month.
For further information, phone the Stomal Therapy Service on (02) 4320 3323

COFFS HARBOUR

Meets 2:00pm to 3:30 pm
14th Feb - 11th Apr - 13th Jun - 8th Aug - 10th Oct - 12th Dec
Venue: Club Coffs, West High Street, Coffs Harbour.
Ostomates & friends welcome.
Contact Mandy Hawkins STN on (02) 6656 7804

EUROBODALLA REGION

Meet first Sunday in Feb, April, June, Aug, Oct, Dec. 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

Meet: first Thursday of each month from 9.00am to 11.30am
Venue: Community Health Centre, 175 Queen Street, Grafton.
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 in Room 4 at 10am to 12noon on Wed.
20th Feb - 17th Apr - 19th Jun - 21st Aug - 16th Oct - 18th Dec
Inquiries: Keith (President) (02) 6583 3970 or Barbara (Secretary) (02) 65824206

ILLAWARRA

Meet: 10.00am to 12 noon on Wed.
13th Feb - 10th Apr - 12th Jun - 14th Aug - 16th Oct - 18th Dec (Xmas party - venue TBA)
Venue: Education Room, Figtree Private Hospital, Suttor Place, Figtree 2525
Contact: Helen Richards STN Monday only: (02) 4225 5046

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 last Saturday in Feb - May - Aug (AGM) - Nov.
Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.
Enquiries: Geoff 02 4981 1799 or Eleanor (02) 4997 5141 or Maree (02) 4971 4351

ORANGE & DISTRICT

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

PENRITH DISTRICT

Meet: at 2.00pm on 22nd Feb - 3rd May - 19th Jul - 20th Sep - 29th Nov
Tresillian Meeting Room, Tresillian, Penrith (next to Nepean Specialist Centre and Nepean Private Hospital). Parking is at Nepean Private Hospital or on Barber Ave.
Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

SHOALHAVEN

Meet: 2.00pm on 4th Feb - 6th May - 5th Aug - 18th Nov
Venue: Nowra Community Health Centre, 5-7 Lawrence Ave, Nowra.
Contact: Margaret or Tracey on (02) 4424 6300

ST.GEORGE / SOUTH EAST SYDNEY

Meet: 11.00am first Wed. each month Feb through to Dec
Community Centre, Premier Street. Kogarah
Contacts: June: (02) 9311 0201
Allan: (02) 9556 3268

SYDNEY SOUTH-WEST AREA

Meet: Saturdays 3pm - 5pm on 9th Mar - 18th May - 17th Aug and 6pm - 7pm on 16th Nov (followed by Christmas Dinner)
The Macarthur Room, Revesby Workers Club, 2b Brett St.
Revesby (closest parking at front of Club)
Contact: Ann-Maree McDonald STN Phone: (02) 9722 7196

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

WAGGA & DISTRICT

Meetings on first Monday of the month from 10am to 12 noon.
Venue: Horizon Club, Yathong St, Wagga Wagga (located rear of Yathong Lodge, Wagga Wagga Base Hospital)
Enquiries: David (02) 6971 3346 or 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

BENALLA / WANGARATTA

Meetings held Mondays at 2.00pm: 20 Feb - 18 Jun - 15 Oct at Delatite Community Health Service, 45 Coster St, Benalla
16 Apr - 20 Aug - 17 Dec at Wangaratta Masonic Centre, 101 Appin St, Wangaratta
Contact: Rex Nankervis (03) 5762 2080
Email: rexmarn@bigpond.com

OSTWEST

Meetings held third Monday of the month in February, May, August and November.
7-9 pm at Melton Health, 195 - 209 Barries Road, Melton VIC 3337
Contacts: Jenny Brown (03) 9746 9121
Tricia Young (03) 9743 5868 or 0416 128 069
Cheryl Prendergast (STN): 9747 7600 (Tuesday and Fridays, every second Wednesday).

MILDURA

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

NORTHERN

A Melbourne based Support Group with a welcome to all with a stoma.
Venue: Darebin RSL Function Room, Preston.
Contacts: Peter: (03) 9460 1125 and Krys: (03) 9431 2779
STN Email enquiry: genevieve.cahir@nh.org.au

SOUTH GIPPSLAND

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

SUNRAYSIA / RIVERLAND

(2013 meeting dates TBA)
Venue: Sunraysia Cancer Centre
Enquiries: Norma Murphy 0409 252 545

WESTERN AUSTRALIA

ALBANY

Meet at Albany District Hospital Conference Room
At 9.30 - 11.00am. third Friday every three months
For details: Terry: (08) 98474701

BUNBURY

Meets: 1.00pm second Monday of every second month. Feb - April - June - Aug - Oct - Dec
Venue: Cancer Council Meeting Room, Plaza Street, Bunbury.
Contacts:
Kevin Jones: (08) 97959229
Fiona: (08) 97216797

GERALDTON

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

MANDURAH / ROCKINGHAM

Meet third Friday of each second month from Jan.
Meetings are held at different locations each time normally over a barbecue lunch.
Visitors welcome.
Contact: Bethwyn: 0439 927 491

QUEENSLAND

BEENLEIGH

Meets 10am - 12noon on last Monday of month - Feb to Nov at Beenleigh Community Health Centre, 10 - 18 Mt. Warren Bvd. Mount Warren Park QLD.
Contact: Pat Miers (07) 3827 9811

LOGAN

Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre Corner Wembly & Ewing Roads
Contact: Pat Miers (07) 3827 9811

BRISBANE

Operated in the Greater Brisbane Area by QLD Colostomy Assn and QLD Stoma Association
Phone: (07) 3359 6500
Website: qldstoma.asn.au/bosvs.htm
Operating hours:
7 days, 8am to 8pm

GOLD COAST

Supporting Ostomates Needs Group.
Meet every 3 months at various venues.
Private and Confidential
C/- PO Box 703
Labrador, QLD 4215
Phone: 0429 126 163
Email: gcson@live.com.au
Facebook: www.facebook.com/goldcoastostomysupport

MACKAY

Meets at Gordon White Library Philip Street, Mt. Pleasant
At 2pm on the second Friday every second month.
Feb - April - June - Aug - Oct - Dec
Contact: Fay: Phone (07) 4942 5135
Gerry: Phone (07) 4956 3409

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 Headland Bowls Club, Syd Lingard Drive, Buderim third Monday each month at 10am
Enquiries: Winifred Preston:
(07) 5476 6313
presto70@bigpond.net.au
Don Lindsay: (07) 5477 0864
lindsaymar@optusnet.com.au

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 impacted by Colorectal cancer. Meets in Hobart on the third Thursday of every month, from 3.00 pm to 4.15 pm.
Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on
(03) 6233 2072.

SOUTH AUSTRALIA

CENTRAL

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

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

YOUTH GROUP

Doris Steyer,
Telephone: (02) 4296 5354

YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623 or Karen 0452 513 191
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



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 575, Port Melbourne, Victoria 3207
Phone: +61 3 9673 4144
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



Future Environmental Services

PO Box 155, Caulfield South, Victoria 3162
Phone: +61 3 9569 2329
Email: health@futenv.com.au
Website: www.futenv.com.au



Hollister

PO Box 599, Port Melbourne, Victoria 3207
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 171, Moonree Ponds, Victoria 3039
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

DOES THE SKIN AROUND YOUR STOMA SOMETIMES BECOME SLIGHTLY RED OR IRRITATED?



Eakin Cohesive™ is the gold standard in skin care and protection. Eakin Cohesive will provide a complete seal around your stoma and prevent leakage and skin irritation.

By preventing leakage Eakin Cohesive will make your pouch more secure and your skin more comfortable.

Take the Eakin Cohesive Healthy Skin Test

Do you have:	Yes	No
Slightly red or red skin	<input type="checkbox"/>	<input type="checkbox"/>
Sore skin	<input type="checkbox"/>	<input type="checkbox"/>
Itchy skin	<input type="checkbox"/>	<input type="checkbox"/>
Irritated skin	<input type="checkbox"/>	<input type="checkbox"/>
"Weepy" skin	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked yes for any of the above please contact Omnigon Customer Service for more information and a free sample of Eakin Cohesive seals.

✓ **Compatible with all stoma appliances!**

Your skin will thank you.



If you have any questions or require information, please call our Customer Service team on **Free Call 1800 819 274**

 **omnigon**
Your healthcare partner