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In the December message, I raised two issues that I would like to expand on in this article:

- the structure under which associations operate; and
- provision of universal access to stomal therapy nurses.

**Association structure**

By way of background, in the two months before our AGM several events occurred which gave clear indication that the Stoma Appliance Scheme (SAS) on which we all rely for our appliances is under government scrutiny. The first indication came from the Department of Human Services (DHS), which reimburses associations for the cost of products distributed to members, using claims that associations prepare from the orders placed by members.

A team from the DHS audit group visited four associations to review the way associations processed members’ orders and prepared the claims to be reimbursed for the cost of those claims. The reimbursement includes the 2.75 per cent commission paid to associations to cover their costs in administering the scheme. David Munro, the ACSA Vice-President, and I were present during one of these visits. The team showed interest and some surprise at the number of individual associations distributing product. They were also surprised that there is no formal contract with ACSA or the associations covering the SAS, which last year reimbursed $90 million of government money.

At that meeting we requested that a copy of the final report be provided to ACSA. The audit team said they would submit our request to DHS management. To date we have not received a copy of the report.

The second event is the change of director in the area of Department of Health responsible for overseeing the scheme. The incoming director has previously been involved in the National Diabetes Services Scheme. In comparing the two schemes, she has raised questions about the contractual basis under which our scheme operates, including the contractual relationship between ACSA and individual associations.

The third event was a question to ACSA from the DHS team about the size of financial reserves held by associations. Whilst this information was unable to be provided at the time, it is publicly available on the Australian Charities and Not-for-profits Commission (ACNC) website. Associations need to ensure that they are deploying any surplus they have accumulated over the years to support their stated objectives. This will ensure they continue to meet the obligations required to retain ACNC registration.

At our annual conference, associations agreed to establish a working party to identify alternative organisational structures that would provide a platform for a formal contract with government. The objective of the working party is to recommend to Council a structure that retains the services delivered to members by the 22 associations, but in a form which meets the government’s requirement for a formal contractual base. That structure must ensure there is minimal change to the nature or operation of our 22 associations.

That working party has been established, using the relevant skills of association members. We are fortunate that among our 42,000 members we have a number of individuals whose background and skillsets can address this challenge quickly and effectively. The working party is currently evaluating national structures utilised by other not for profit organisations with similar operational requirements. The committee intends to have a firm recommendation on the option that best meets association needs circulated to associations at least two months before the 2017 ACSA AGM. This will enable associations to consider the recommendation and make an informed decision at the AGM.

**Universal access to stomal therapy nurses**

In my December message, I raised the issue of universal access to stomal therapists. Members of the ACSA executive had discussions with a number of stomal therapists regarding the use of a broader range of accessory products. The clear professional advice is that the majority of these products provide significant benefits for a small number of ostomates in specific clinical circumstances, but are not required by most ostomates.

The area of the SAS has been reviewed by the Stoma Product Assessment Panel (SPAP) and a series of recommendations are before government.

The annual expenditure on this group of products, at around $23 million, is approximately 25 per cent of total expenditure on the scheme. Preliminary figures prepared for the executive indicate that if that expenditure was reduced by half, the savings would fund a national scheme for universal provision of stomal therapy services to all ostomates. That would include quarterly visits in the initial year post-surgery and annual visits thereafter.

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

**Stoma Appliance Management System (SAMS)**

As I write this message in late February, the first example of SAMS has just been implemented at the Ostomy Association of Melbourne. The implementation has gone very smoothly, with only a few very minor issues arising. These were quickly and readily dealt with. I will take this opportunity to personally thank Hermione Agee, Sue Read and Ian Samuel for the tremendous effort they have put into the development and testing of SAMS. The success of the system is entirely due to their dedication and persistence.

We now have the basis for moving into the future with a single system to support associations’ operation of the SAS. It will enable associations to streamline their support to members and provide a consolidated information base on which decisions concerning the SAS can be made.

The objective now is to migrate all associations to SAMS by the first half of 2018.

**Geoff Rhodes**  **PRESIDENT**
Dear Editor,

I’m 24 and have been an ostomate since I was 17, so I’ve been receiving this magazine for around seven years now, and sometimes attend stoma meetings too. I cannot believe that people are still unhappy about paying the annual member fee although it’s been addressed multiple times in those seven years and the reasoning for it.

‘I didn’t choose to have an ostomy, I shouldn’t have to pay.’ Some people mustn’t find perspective in what is regularly stated in the magazine so I’d love to put in my perspective. If $55 is the tiny amount I have to pay for the chance to have celebrated my 18th birthday with a great quality of life, graduated high school, turned 21, obtained a qualification, moved town, went skydiving (get the gist), I am SO incredibly lucky! But of course being sick isn’t cheap. It doesn’t only cost $55 to have Crohn’s disease and a permanent ileostomy, it costs a lot more. Specialist appointments at $250, regular GP visits at $70, medication and scripts constantly, vitamins. Not to mention sick days off work (more than the paid ten a year), and not to even mention the non-financial things it’s cost me, being as young as I am.

So the way I see it is—if I’m forking out all that money and a small $55 is all I have to pay to be a member of the most amazing scheme and have access to top products on the market for stoma care to give me a great quality of life, then I am so extremely grateful, and I think we all should be. I am by no means well-off financially but if I have to say ‘no’ to plans on a weekend with my friends, or not drive for a week because I can’t afford petrol that week, just so I can afford my membership fee, so be it. It’s sure better than not being here at all. We all know when the fee is due so there’s plenty of time to budget accordingly. Put $5 aside every month of the year, and there you go, you’ll have change.

Some females pay in excess of $30 per four months for the contraceptive pill, which is often used for medical reasons anyway, so should women be complaining because they didn’t choose to be female? No, they just do what they have to do.

At the current cost, if I live until I’m 65, I’ll have paid around $2500 for the scheme. If I lived in a country without the scheme, I’d be paying that annually! I’d rather be spending my money on things that other 24-year-olds are, trust me, but it’s a tiny amount in the big picture.

We need to focus not on what it’s ‘costing’ us financially but what it’s giving us that money cannot buy.

Sarah Larcombe, NSW

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Dear Editor,

I have recently returned from a trip to Singapore and Taiwan.

I was delighted to find an ostomate toilet at Taipei Main Station. The symbol in the top right corner of the sign (below) is displayed prominently throughout the station.

Unfortunately the toilet was closed for maintenance, along with most of the toilet blocks in the station.

However, it would be great if an idea like this caught on in other countries. As an experienced traveller and an ostomate for 13 years, anything that would make life easier for us would be a blessing.

Josh Browne, Victoria

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Dear Editor,

In June 2015 my husband had surgery for a bladder cancer. This small cancer was detected in November 2014 following the detection of blood in his urine. He had three cycles of chemotherapy before surgery and by choice three cycles after surgery. My husband was very well looked after in the local private hospital, by his urologist and nursing staff. There were minimal post-operative complications and he was discharged from hospital nine days later. He now has a stoma and wears a urostomy bag which we change every second day. We have experienced a few outbreaks of skin rash under the baseplate but have managed to control this with a trial of wipes/powders and cream and at times supervised under the wonderful guidance of a stomal therapist at our private hospital.

Sarah Larcombe, NSW

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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.
My husband has had regular six monthly check-ups and blood/urine tests with his urologist and oncologist and all are very pleased with his recovery. He has gone back to work but only works a few hours per day, and now has to keep a closer check on his fluid intake and attempt to remain in the air conditioning as often as possible, and we have had to accept some lifestyle changes as a result of this surgery.

Work shirts became a problem, mainly because the bottom of the bag was visible below the hem of his polo shirts. My young friend, a dressmaker, and my husband had this ‘light bulb idea’ one weekend about creating a pocket, so she measured the bag and set about making a ‘pocket template’ for the inside front of his shirts. This took a bit of playing around with a swatch of material and some pins before the correct positioning was achieved and a trial shirt with a pocket was sent home for feedback.

It proved a success and now he has ‘bag pockets’ in all his work shirts as well as in a couple of good shirts which he wears out to dinner. He folds the bottom of the bag/tap inwards and inserts the bag into its pocket, which is stitched to his shirts. These pockets are made of some cotton material and are machine-stitched to the overlocking at the hemline and hand-stitched on both sides. The pockets sit about 18 cm from each side seam of his shirts and measure 18 cm x 18 cm in size—these pockets suit my husband’s choice of polo shirts for length, and the position of his stoma, so these measurements may not suit everyone. They will vary from person to person and require modification depending on the length of shirts, their material (most polo shirts have a stretch component in their makeup) and difference in bag brand and size.

These pockets have proven their worth in that my husband feels more self-confident and has peace of mind that the bag is less visible and also gives extra protection to the bag itself in his everyday work environment—a simple idea which works so well.

We decided we had to share this ‘pocket’ solution with anyone who is also struggling with ways to minimise the visibility of urostomy bags in their everyday life/workplace—maybe this could be an alternative to support briefs, which my husband has not trialled at all.

Linda Nannestad, Queensland

Dear Editor,

In 1997, at the age of 52, I was diagnosed with bladder cancer. After treatment the cancer went into remission for several years, only to reappear in 2003. In August 2003 my bladder and prostate were removed and an ileal conduit and stoma were formed.

All went well till April 2016, when I was involved in a head-on motor vehicle accident at 80kph when another vehicle crossed to my side of the road. I received many injuries, some being life-threatening. The major injuries were internal, to the abdomen area, caused by the seat belt which caused traumatic ileal conduit and stoma damage with subcutaneous parastomal haematoma and urostomy haemorrhaging into the waste bag.

I spent six weeks in Canberra Hospital under the care of the urology team, who carried out many CT scans and procedures to repair the damaged ileal conduit. One of these procedures was to insert a catheter into the ileal conduit to enable it to heal, as my doctors considered surgery to be too dangerous.

After five months and several CT scans the catheter was removed because the ileal conduit had healed. However, my doctor warned not to damage it again as I would then be in all sorts of trouble. He also asked why I did not have some type of protection under the seat belt to shield the stoma.

As a result of the damage my stoma is now oval in shape; this in turn has caused problems in finding the correct pouch, as the one I had used for the previous 13 years was no longer suitable. However, with the help and support of my stoma therapy nurse we have overcome this problem.

I am now looking to find some protective product to protect my stoma and abdomen area from seat belt damage. If other ostomates are using something or have any ideas please let me know.

Rod O’Sullivan, ACT

Dear Editor,

Like Isobel Davie (Letters to the Editor, August 2016) I have forever been puzzled at the number of complaints from ostomates about concerns with Velcro closures on drainable bags.

I have been a permanent ileostomate since early 2009, use a two-piece system (base plate and drainable bag) and have never had cause to even imagine that the Velcro may let me down. Yes, I do sometimes experience problems with poor sealing of the base plate and resultant leaks, but even when occasionally waking with a near-bursting bag there has never been any hint that the Velcro won’t hold.

As suggested by the correspondent referred to, perhaps some more professional advice could be helpful.

James Newton, Western Australia
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I am still a novice when it comes to sporting a colostomy bag; I had my ‘procedure’ only two years ago, at the age of 58. Consequently, I didn’t know quite what I was in for when I packed my bags, said so-long to my Sydney home, and took off for China and Tibet on a five-week stint in the northern winter over Christmas and New Year 2016-2017.

I didn’t have much advice to go on; just ‘take more bags than you think you need, and then some’.

After some time in Beijing, getting acclimatised to the crazy traffic and the freezing cold, the day arrived when I hopped on the three-day train bound for Lhasa, capital of Tibet.

The three modest things an ostomate might look for (a small measure each of privacy, warmth, and hygiene) went out the window from the very beginning: here I was in a cloying four-berth compartment with Chinese and Tibetan strangers, in a railway carriage on the highest railroad in the world, with a single grimy toilet at one end.

Add to that the toilet being of the Chinese squat-style: a hole in the floor. I had to learn the ropes quickly: emptying a colostomy bag (or even more difficult, replacing it) in a cramped squat-loo on a wildly rocking train with impatient passengers banging on the door takes both grit and human origami, if you get my drift.

Then getting back to the cabin with everyone breathing in your face doesn’t let you check very well if you’ve successfully done what you meant to achieve over there in the stinking loo.

Fortunately, I do speak a bit of Chinese and could have some simple exchanges with my co-passengers, although I never had the need to explain what mysterious things were going on underneath my clothing.

The days and nights on the train went by without incident, although at an altitude of 5,100 metres, one of the Chinese travellers in my cabin took ill with altitude sickness and had to be treated for several hours by the train doctor. This notwithstanding oxygen being pumped into the carriage and the personal oxygen tube every passenger has by the side of each berth.

Travelling around in Tibet presented some further challenges for an ostomate: although it is a lovely, otherworldly, staggeringly beautiful place with warm-hearted and smiling and generous people, Tibet has paid little attention to its public toilets. Especially in the harsh countryside, these are little more than perhaps a concrete pen around a rudimentary trench dug into the ground. Dogs lurk about, and you are often exposed to both the elements and people’s glares. Some ostomates might find this daunting, but there are tricks to be developed and tried. Necessity is the mother of invention, Plato said.

Paradoxically, now and then I had occasion to thank my lucky star that I had been fitted with a colostomy bag! For instance, and without going into too much detail, a colostomy bag might give you that little bit more control (and extra time) if you happen to suffer what I came to call the ‘yak-runs’.

The weeks in China and Tibet chugged along and my ostomy supplies held up. Not always the most hygienic or comfortable way of doing what had to be done, but nevertheless, it worked out just fine.

I think the bottom line is that I proved to myself that a colostomy doesn’t have to keep you away from undertaking rather rough and raw and rigorous activities away from the safety of home. In other words, pack your bags (yes, those bags) and off you go into the wild blue yonder. There’s always a solution and a way of doing things. Don’t let your condition hold you back.
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I am an 81-year-old partial quadriplegic, confined to a manual wheelchair as the result of a spinal cord injury in 1980. I also have a subrapubic catheter and a stoma. A diverting loop ileostomy was surgically performed in September 2012 because of increasing problems with bowel evacuation and incontinence caused by the injury. The stoma is high on my abdomen on the right side, chosen because of my being wheelchair-bound—easier to see and more accessible for me and my carers. The chosen appliance was a drainable one-piece cut-to-fit appliance with a clear front.

In September 2015 I set out with my carer, Rhonda, and a daughter, Kerri, on what was for me an epic journey to visit my eldest daughter, Jenni, who lives with her German husband, Bernhard, in a small town near Frankfurt in Germany. A relative who flies frequently advised me to fly with a particular airline because their toilets were accessible—but this proved to be a fallacy. I dipped deeply into my savings to fly business class because of the extra care and attention I needed. However, to empty my catheter and stoma bags during the flights Rhonda had to crouch down discreetly in front of me to empty them into a bucket with a lid, secreted in a backpack.

As other wheelchair travellers would know, I had to be transferred to an aisle chair to be wheeled to and from my seat to fit into the narrow aisles. En route to Frankfurt we changed planes at Singapore and I experienced the caring attention of airport staff who wheeled me to and from the terminals and airport lounges and shops. During the second stage of the flight a bed was made up for me and I was hoisted into it for several hours of refreshing sleep.

When we arrived in Frankfurt we were greeted joyously by Jenni and Bernhard and took possession of a hire car, into which I was heaved. After some refreshing sleep we were able to explore the restored medieval centre of Frankfurt, where I was bounced over the ubiquitous cobblestones. I was even able to visit the Goethehaus, where the writer Johann Wolfgang von Goethe was born and raised—I had studied his play, *Faust*, at university. We spent the night at an excellent hotel—before we left Australia, our travel agent had booked disabled access rooms in all four hotels where we stayed, and I found the facilities excellent.

Next day Jenni drove us to Hessenpark, the open-air museum, spread over 65 hectares, which includes buildings relevant to the state of Hesse—shops, forges, workshops, churches, windmills, and of course more cobblestones. My stoma was emptied discreetly behind a secluded barn. After a night at Giessen we were taken to the Schloss Heidelberg ruins, a popular tourist attraction. Here we inspected

**Wheeling around Germany**

By Ruth V. Wilson

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Derek Wilkinson

Contraband? An open and shut case

Several years ago my wife and I were flying back from an overseas holiday into Melbourne (Tullamarine) but unfortunately got held up coming through customs and immigration and were directed into a ‘holding inspection area’ within the terminal.

Our two suitcases were placed on a table in the room and I was asked if I wanted to reconsider my answers on the incoming immigration card that I had completed on the plane. I said everything was completed to my satisfaction and reaffirmed that we had nothing to declare.

The two customs/immigration officers then asked if I had any objection to my case, in particular, being opened up by them—to which I responded positively, telling them to go ahead. My wife and I were feeling extremely tired after a long flight from the United States and watched as they sorted through my case until they reached the two full boxes of colostomy bags which I had packed before leaving Australia, along with some other ostomy-related items.

It appears that this was what they were searching for. It seems the X-ray scan of our luggage had showed up these two boxes with what they perceived to be cartons of iced ring donuts brought back from the States as undeclared food items!

Can you believe both the astonishment and embarrassment when they opened up the boxes? It was truly a moment to remember for both of us, seeing the looks on their faces when they took out one of the colostomy bags with the punched hole in the centre of the pouch.

They could not repack the case quickly enough, suggesting that we put these types of articles into our handcarry luggage in future, and apologising for the delay caused us.

Looking back, I guess it goes to show that our Australian border security is definitely working here in Melbourne!
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For my life, I had always planned that by 25 I would be married, start a family, have my own house and have a successful career. Pretty normal life goals, right? I didn’t even know what an ostomy was. I was only 21, so why should I need to know?

While I knew my chances of getting bowel cancer were very high (genetic predisposition due to FAP/Gardener’s Syndrome) I wasn’t expecting that day would come when I was 21. Earlier that year I lost my dad (aged 41) to bowel cancer, so I knew how key early detection and surveillance were in minimising the potential effects of this disease. Unfortunately, mine was a particularly aggressive early-onset form, forcing me to make a difficult decision to save my life.

I dreaded the idea of living with a permanent ileostomy as I felt it meant my life as a young female would be over. This thought was compounded by the fact that I could only find information relating to people in their Golden Years. I tried to engage with the local support groups but felt extremely disengaged, as I was a third of their age. I felt alone and isolated as a result.

It got me thinking, though, that surely I was not the only young person who must be struggling. So I vowed to document my journey by starting a blog called Feeling Ostomistic and relating both the successes I had but also the setbacks I faced as well. I felt this needed to be with full honesty and little to no sugar-coating if it was to be at all helpful to others searching, like I was.

It didn’t take long before people started reading my journey and thanking me for the tips that I shared, often things they hadn’t thought of trying themselves. As word-of-mouth grew, more and more young people were finding their way to my blog and to me in chat sessions, and I felt that I was positively contributing to the stoma community in this younger demographic.

One reader was in hospital a couple of years back, when in the bed beside her was a young female (a year older than me) who had recently had stoma surgery due to stage IV bowel cancer. She was struggling with not only the physical management of her stoma, but also in feelings of social isolation because she knew of no other young people going through what she was. It was then that the reader told her about my blog. The young girl reached out to me through my blog and she is now considered one of my dearest friends.

I felt empowered by how I had helped her change her life positively but continued to wonder how I could do more. As good as the blog was, I felt it wasn’t enough. I had more to offer and was creating contacts that could offer more insight on topics I felt inexperienced to talk about. Rather than feeling in competition with these bloggers and health professionals, I knew there had to be a way to collate everything to allow young ostomates to have a relatable trove of information. Like a magazine!

I didn’t have the resources available for a physical magazine, so an e-zine (digital magazine) seemed like the logical solution. Not only did it allow accessibility so readers all around the world could view the content and engage with the conversation, it also kept overheads down so that it could be offered for FREE.

I began working on starting the e-zine when I learned I would be needing to undergo 12 months of weekly chemotherapy. Knowing I wouldn’t have the energy or mental capacity to dedicate 110 per cent towards this, I made the decision to hold off the launch and continuation until I knew I could dedicate the amount of love this project and the readers deserved.

So excitedly, in February 2017, the first issue of The Ostomistic Life was launched and was very well received by all.

I feel this is a great resource for anyone with a stoma, although it is designed with younger women in mind. I feel very proud of what will be my legacy and that my time with a stoma, however daunting and unpleasant it has been at times, might serve as a light to other young ostomates.

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Kock continent ileostomies are among the more uncommon ostomy types in Australia: creating ‘K-pouches’ requires expertise in a specialised surgical technique that is not widespread in this country. But in recent months there has been a renewed effort by Australians with a Kock pouch to make contact and develop networks to provide advice and support.

The first formal result of this move came late last year, with the formation of a support group in Sydney by Ostomy NSW Ltd, initially convened by retired STN Heather Hill. Only 11 of ONL’s more than 6000 members are identified as having Kock pouches, but it seems certain that there are others with K-pouches dotted anonymously around Australia.

Two Sydneysiders, Meg and Corinne, are keen to make contact with their fellow K-pouchers. That might be the first step to keeping in touch, formally or informally; to discuss successes, problems and solutions; and just to feel that, with your special stoma arrangement, you are not alone.

Meg and Corrine know how important that is. Until they met for the first time last year, Meg says, ‘We had both felt isolated over a long period of time, as if we were the only Australians with that type of ileostomy.’ The meeting was ‘amazing for both of us, as this is not a common operation to have in Australia’.

What is a Kock pouch? The continent ileostomy was introduced in 1969 by the Finnish surgeon Dr Nils Kock and his colleagues in Sweden as an alternative to having a regular ileostomy.

With a Kock ileostomy, an internal pouch or reservoir is fashioned from the end of the ileum, with a nipple valve/stoma at its exit to the skin surface. The contents of the small intestine remain within the body until the patient feels it needs to be emptied. This is done using an external catheter, a simple hollow plastic tube, which is inserted about 12cm into the valve/stoma. The contents of the reservoir come out on their own and into the toilet bowl. The pouch is usually emptied four or five times a day. There is usually no need for appliances or bags, and the stoma can be covered with a piece of gauze to absorb any mucous discharge. There tends to be less embarrassment from involuntary noise or smell of flatus through the ileostomy. Over the past 30 years surgeons in the United States have improved the Kock operation to create the BCIR (Barnett Continent Intestinal Reservoir).

Meg’s story

I am 74 and have had my ileostomy for 44 years. At the age of 31, married with two very young boys, I was rushed to hospital with ulcerative colitis and given an urgent operation that left me with an ileostomy. This apparently saved my life, so I was very grateful for my surgeon’s prompt action and expertise. My convalescence was stormy because I contracted pneumonia, lost a lot of weight and became very weak.

Eventually, after weeks convalescing, I managed to pick up my life again, with lots of help from my wonderful parents. Unfortunately my marriage did not survive the stresses and the fact that we moved house during that turbulent time. I have awful memories of the ghastly big black smelly rubber bag on my stomach which leaked at all the wrong times. To top it all, my hair started to fall out in clumps, probably as a result of drugs and stress. However, I purchased a wig and gradually got on my feet, determined to get stronger for the children’s sake.

After stormy divorce proceedings and again moving house I returned to work, using a much lighter appliance and feeling a little more back to normal. But I hated having the ileostomy: it often leaked, the bag would often blow up with gas, and the stoma would make terrible noises at all the worst times.

After 11 years, at the age of 43, I elected to have further surgery—a continent ileostomy. I wanted to be rid of the bag and all its embarrassing problems. Besides, being single again, it was not at all helpful when it came to finding new relationships.

The operation was performed by a specialist in continent ileostomies at a major hospital in Sydney’s west. It was a long and difficult operation requiring about three weeks in hospital and a few more weeks recuperating. But it was worth it, even though I was disappointed that I still needed to wear a small bag, because it still leaked a couple of spoonfuls of mucous (in other words, the valve was not perfect). However, it did give me continence with bowel movements and I didn't have to worry about any big leakages, gas or embarrassing noises. Using the catheter was easy—I simply had to remember to take it wherever I went. Also, my tummy looked flatter without the ileostomy bag and it was easier to manage during intimate moments.

After 32 years I can say I have been very happy with my continent ileostomy. It has never really restricted me with anything. I eat most things and I have a normal

Meg still plays tennis each week.
appetite. I still play weekly tennis and have done snow and water skiing. I love travel and have travelled overseas with no nasty occurrences.

I remained single for 30 years but led a busy life bringing up my boys, with full-time work as a therapist with children with disabilities, and varied musical interests. Happily, 10 years ago, I met a wonderful man with whom I just clicked. We have bought a house and have been living together since. He was very accepting of my continent ileostomy and with him I have travelled the world and been on many marvellous caravan journeys around Australia.

Looking back, I am extremely thankful for my continent ileostomy—when all is said and done, I have been able to lead a normal life with very little inconvenience. I don't suppose many people, other than close friends and family, ever knew I had an ileostomy. All I have to do is make sure I don't go anywhere without my catheter. Considering I nearly died at age 31, I feel I am 'a lucky girl'. I have watched my children grow up, marry and have children—and I am really enjoying my grandchildren, whom I hope also to see married. But until I met Corinne recently I have always felt isolated and alone with my continent ileostomy. There must be other continent ileostomates in Australia. Where are you? Let's get talking!

**Corinne's story**

It was such a pleasure to meet Meg—it really helped, too, realising my ups and downs with a K-pouch are normal. I was blessed to have two amazing surgeons take on doing the K-pouch for me six years ago in Melbourne. Now I swim a few times a week and even completed a triathlon in Byron Bay after the operation. I won't say it has been an easy ride but I certainly prefer the K-pouch over the permanent ileostomy which I had when I was 17 years old. The K-pouch is not a cure but it has given me a lot more freedom in many areas of life.

Meg is proof that you can have an amazing relationship and live with the joys of a K-pouch. That is something I still look forward to. My dream was to be a mum and for a number of reasons I have decided to love a child through long-term foster care, which I am organising now. If anyone has contacts with making a better catheter it would be great to hear from you, as that is another area that can be improved.

I work as a professional learning and development trainer in Process Communication Model—a stress-management course run by NASA (the things we do to cope!). I am happy and healthy and living life as fully as possible. We would both be happy to be in contact if you would like to know more about the operation or you have a continent ileostomy.

………

Let Meg have the last word. It's good to be in touch because 'there could be all sorts of things to confer about, even if it is just to realise there are others out there dealing with the same system every day—just like you!'

**People seeking more information on Kock pouches or interested in making contact with fellow K-pouchers should contact Heather Hill at ONL at (02) 9542.1300 or through the website, www.ostomynsw.org.au.**
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“Worrying less about leakage makes things so much easier”

For 65-year-old Henry, Brava® Protective Seal is the missing link in his ostomy solution. It gives him a feeling of security and helps him live a life without restrictions.

After his operation in 2008, Henry adapted quickly to life with a stoma: “It has been very easy to live with – easier than I thought.”

Indeed, as someone who has always been active, Henry’s biggest challenge was taking it easy during his rehabilitation!

But after some time, he began to experience occasional leakages. These left his skin around the stoma irritated, so his stoma care nurse recommended he use a seal. Henry tried many types, but preferred Brava Protective Seal.

Henry was also impressed with the seal’s additional benefits. He explains: “It’s easy to apply and remove without leaving much residue.” In turn, the lack of residue also made it easier to maintain healthy skin. He continues: “Residue has to be scraped off and that can irritate your skin.”

For Henry, who works at a brewery, the biggest benefit is the feeling that he can do what he wants, when he wants: “Worrying less about leakage makes things so much easier. I’m a very active person and I think that keeps me young.”

Whether he’s working or playing one of the sports he enjoys, Brava gives Henry the feeling of security and confidence he needs: “I can travel, I can drive and I can live a normal life. I don’t give my stoma a second thought.”

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Regular exercise was beneficial for ostomates, and people should look for ways to be more active, Dr Catherine Granger, Senior Research Physiotherapist at Royal Melbourne Hospital, said in a presentation to Young Ostomates United (YOU) Incorporated at the Nurses Memorial Centre, Melbourne, on 25 February.

Physical activity was defined as any bodily movement that resulted in energy expenditure, Dr Granger said in a presentation titled ‘Returning to my new normal’, but exercise was planned, structured and repetitive.

Lack of physical activity cost healthcare systems $53.8 billion globally each year and was responsible for 13.4 billion life-days of disability, she said. In 2010 the World Health Organization recommended 150 minutes of moderate or 75 minutes of vigorous physical activity per week for adults. Higher rates of activity reduced the risk of dying, but while more activity was desirable, some was better than none.

Turning to chronic disease, Dr Granger told her audience that few people with cancer met the physical activity guidelines at the time of diagnosis, and their physical activity tended to decrease from that point until they began treatment.

However, exercise brought substantial physical and emotional benefits to people with cancer. It could improve fitness and quality of life, help them to handle anxiety and depression, reduce fatigue, and lessen both symptoms of their illness and side-effects of treatment.

With care, ostomates could begin exercising soon after surgery, Dr Granger said. In hospital people could start walking within a day of surgery. Doing so would help to prevent chest infections and reduce the length of stay in hospital, but good pain relief was essential. Sitting out of bed during the day was beneficial, but new ostomates should support their wound or stoma with a towel or pillow when coughing and straining, and follow the advice of stomal therapy nurses about stoma supports.

Physiotherapists could help with abdominal and chest exercises.

Later, ostomates should talk to their doctor, physiotherapist or STN before starting an exercise program, recognising that some people might first need a medical assessment. Ideally, exercise should be individually prescribed, taking the disease, baseline fitness and medical condition into consideration.

While an individualized program might not always be possible, activity could include aerobic exercises to strengthen cardiovascular and cardio-respiratory fitness, including walking, jogging, running, cycling, using a step machine, water aerobics and dancing. It should be performed for at least 10 minutes at a time, ideally for 30 minutes per day, five times a week.

Resistance exercises to improve strength, involving weight machines, hand-held weights, gravity exercises, step-ups, squats, wall push-ups, and sit-ups, should initially be performed under supervision. People should aim at 8-12 repetitions of each exercise, two or three times daily and two to three times a week.

Ostomates could consider setting up a chronic disease management plan. Referral from a GP was needed, but a team care management plan, which attracted a Medicare rebate, gave access to two allied health professionals and five paid consultations over a 12-month period. In Victoria, people could ask to be enrolled in the Hospital Admission Risk Program (HARP) or a chronic disease rehabilitation program.

Exercise should be enjoyable, Dr Granger said. Walking was great, but people needed to be aware of their good and bad days, maintain good hydration, not exercise in extreme weather—and always look at ways to be more active.

Exercise can make life better for ostomates

Young Ostomates United (YOU) Incorporated celebrated the Christmas season and the end of another successful year with a lunch at Doncaster. It was lovely to share the festivities with a group of members and their families.

We have celebrated our 25 years as a support group by making a photo book on our history. The book was put together by YOU Inc chair and secretary Helen Ebzery and YOU founder and treasurer Lilian Leonard. It will be available for members to borrow.
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CHANGING LIVES NATURALLY
After more than 50 years as an ostomate, Warren Rayment looks back on his experience, and sees how treatment and care have changed, and how—despite adversity—ostomates can forge fulfilling lives. The first in a two-part series.

As a co-founder of the national Ostomy Australia journal in 1992, with my fellow ACSA executive, the late Barbara Callcott, I wanted to share my stoma story with readers. Like others, my story has its share of pain, anguish and suffering, together with balancing and exhilarating episodes of pleasure and fulfilment. Where it differs is that my operation occurred in 1959, when stoma surgery was in its infancy. There were no specialised nursing skills, there was no Stoma Appliance Scheme, and appliances were primitive, inefficient and costly.

However, I am getting ahead of myself—let’s go to when my story begins...

January 1959, I was a normal healthy and happy 16-year-old, living in West Wollongong, starting my final year of high school, and very active in junior and senior cricket with Mount Keira District Cricket Club; a contented young man in that awkward transition between teenager and adult, getting ready to enter society and make a gainful professional career. I had some good mates, cycled everywhere, to the beach and school … life was good.

Then, in the ensuing months, the symptoms of ulcerative colitis began to invade and damage my body. Weight loss, bloody stools and lots of pain started to affect my wellbeing. As teenagers do, I put my trust in the wisdom of my parents and local medical practitioners. Ulcerative colitis was not diagnosed but instead a host of alternative conditions were thrown up as causes for concern. Misdiagnosis did little to arrest my deterioration.

Suddenly attending school was a nightmare, with ever-increasing and debilitating stool frequency and weight loss. Although the cricket season was over, everyday activities and pleasures were forfeited more and more.

In October that year, after somehow negotiating months of deteriorating health, my parents consulted an older and wiser medico in Wollongong, who diagnosed fulminating ulcerative colitis. I was almost comatose when I was admitted to Wollongong Hospital for intensive care, including heavy cortisone ingestion. This failed, and after an unforgettable week I was transferred to Sydney’s Royal Prince Alfred Hospital. It was a horrific 50-mile ambulance ride on a Saturday night. I was in agony all the way.

On the Sunday afternoon the senior resident told my parents and sisters that urgent surgery might save my life. “A long shot given Warren’s critical state,” he said, but there was no other option. They were advised to farewell their son and brother. A colectomy was performed on the Monday afternoon. Coincidentally, it was the day that the defining school exams, for the Leaving Certificate, began—Murphy’s Law at its most cantankerous.

You might assume that the surgery would have halted the rot and allowed a return to a normal and healthy lifestyle, and that the pleasure alluded to in the title might have started to emerge. Sadly this was not the case: the pain cycle would continue for some time to come.

However, before telling more of my story, I want to evoke a big city hospital in the 1950s—a stark contrast to our 21st century facilities. Those who have seen one of those black-and-white movies depicting a hospital ward in Florence Nightingale’s era might find it familiar.

Robinson Ward at RPAH, or D2 as it was known, was a long, solid, two-storey high-ceilinged structure of brick and sandstone. The lower level comprised both the male and female wards, separated by a short walk past the ward sister’s office and the kitchen. The building was graced by verandahs on the eastern and
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The ward sister conducted an inspection every morning in advance of the honoraries’ rounds. Sister Simmons (I still recall her name) was unchallenged as the ward authority and the medical rounds were a spectacle like those depicted in ‘Doctor in the House’ movies of the 1950s and 60s. The entourage comprised the honorary surgeon—always immaculate in his blue suit with a buttonholed red carnation—the honorary gastroenterologist, and accompanying senior and junior residents, resplendent in their respective long and short white coats, all trailed by a rapt group of attentive medical students.

There is a heart-warming sidelight to my stay in Robinson Ward. I discovered that a nine-year-old boy was a patient at the end and opposite side of the ward. A fellow ulcerative colitis sufferer, he had been given a stoma courtesy of the same surgeon. His name was Geoff Rhodes—now the ACSA president. Geoff and I were heavily involved in developing the Ileostomy Association of NSW from the late 60s onwards. This friendship, forged in adversity all those years ago, remains close and valued today.

If two youngsters had to have stomas in the 50s, we were fortunate to have surgery later in that decade, because noted British surgeon Bryan Brooke had perfected a technique for fashioning a stoma. This involved inverting the end portion of the small bowel over itself and then attaching it to the abdominal wall. Before this, bowel prolapses, hernias and infections were common for post-operative ostomates. Dr Brooke’s technique is still widely used today.

Talking of operations, when it came to anaesthesia, there was no quick needle, a cannula in a vein and a few drops of sedation and peaceful sleep. This was the era of chloroform administered by a heavy face mask, followed by three or four days of violent post-operative vomiting.

And appliances? In the late 1950s only two or three imported ostomy appliances were available. They were cumbersome and made of rubber, one with a metal frame. The rubber flange was stuck to the skin with a cement solution and the rubber pouch then attached. They were ill-fitting and leaked frequently, which meant that the flange then had to be prised off the skin—a task similar to stripping old paint or wallpaper off a wall. Bags were re-usable but first had to be washed and dried. Being rubber, they deteriorated quickly, smelt and needed to be discarded.

But back to that Monday afternoon. Operation completed, the offending large bowel removed, it was thought there would be perhaps four or five days’ recovery, time for the small bowel and stoma to start functioning and maybe home with Mum and Dad in a week to ten days. Again, this was not the case. The recovery obstacles were challenging and almost insurmountable.

Three months later I was still hospitalised, both arms numb, black and blue from hundreds of intravenous needles and feeds, but able to stand. The stoma was functioning and maybe home with Mum and Dad in a week to ten days.

Only the resident was authorised to manage the stoma and appliances and he was not always available. Such activity was off limits to the nurses. In my parlous state, attaching the appliance was painful. Knowledge of stoma care, appliances and overall management was virtually non-existent. I was emaciated, only about 45kg and unable to walk. But meals were pitiful. I remember one Sunday evening dinner that consisted of baked beans and potato crisps. Fortunately, I was not in any shape to partake of hospital fare for well over two months anyway.

Nurses wore blue tunics covered by white aprons with a white cap adorned by clusters of blue stars by white aprons with a white cap adorned by clusters of blue stars. They were marvellous and I developed a strong respect and fondness for them that lingers to this day. Nurses took temperatures (thermometer under the tongue), swept the floors and dusted the shelves, emptied bedpans and handed out pills. Blood was pitiful. I remember one Sunday evening dinner that consisted of baked beans and potato crisps. Fortunately, I was not in any shape to partake of hospital fare for well over two months anyway.

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Time for change and development

By Carmel Boylan, president, Australian Association of Stomal Therapy Nurses.

This is my final report as AASTN Executive President. As I sit here thinking of the role I am very pleased that my colleagues in Western Australia provided me with the opportunity to sit on the committee, as I have learned so much. It was a daunting prospect initially, but the executive committee welcomed me from the start and I can truly say they have been a wonderful group to work with.

I believe the greatest achievement for 2016 was the successful canvassing by the AASTN, trades, ACSA and other stakeholders to prevent the progression of the Department of Health’s proposed tender for one-piece stoma pouches on the Stoma Appliance Scheme. While this required a lot of time and energy the outcome was well worth the effort. I sincerely thank you all for your support in this cause. We can only hope that there will be no further discussion for future reductions to the products available on the scheme, but should this occur we will go into battle again.

During the last 12-18 months the education and professional development sub-committee has continued to review and develop more online educational pamphlets. These are a valuable resource for all members. An additional pamphlet that is about to be added is ‘Travelling with a stoma’. This was developed in response to a query from one of our airlines. It will soon be available on the AASTN website, http://www.stomaltherapy.com.

Please remember that the website contains a list of current stomal therapy nurses in your area and it identifies locations where outpatient clinics are held. You can self-refer to these clinics—so do not hesitate to lift the phone and make an appointment. The Western Australian Graduate Certificate in Advanced Clinical Nursing (Wound, Ostomy & Continence) was also launched in 2016. The course is the brainchild of wound management specialist Professor Keryln Carville. The theoretical content of the course is delivered at Curtin University with Joy Sear as the course co-ordinator, while the WA branch of the AASTN coordinates clinical placements.

Feedback from students has been very positive and enrolments in the 2017 course were being processed early in the new year. This is a wonderful achievement for the AASTN. Sincere gratitude to both Keryln and Joy for getting this up and going.

I commend Jan Fields and members of the Queensland branch who put together a comprehensive program for the national conference in Brisbane in March. The conference will be held as this journal goes to press, but I have been looking forward to meeting many of you there and hearing all about the amazing work that is being conducted in ostomy, wound and continence management.

We plan to revive the paediatric sub-committee during the conference. This will help to support the stomal therapy nurses working within the paediatric specialty and, in turn, benefit child stomates and their parent and carers.

WA stomal therapy nurse Tania Norman recently organised a country trip to Albany. Tania saw a large number of ostomates during the visit and ran a very successful workshop. The visit highlighted the need for stoma support for people living in rural areas. I have no doubt more country trips are on the calendar.

In summary, thank you all for your support to me as President of the AASTN. It has been an invaluable experience and I trust I have served you well. Please welcome the incoming president as you did me. ●

Continued from page 24

To make matters worse the rectum, left in place because I was too ill for it be removed on that fateful Monday, failed to heal.

I had so little confidence in stoma appliances that I became a recluse, too scared to leave home. My parents were so supportive and helpful: I would not have survived if not for their love and concern. However, their love did not help my overall welfare. Now 18, my life was on hold and I was struggling to keep it together both physically and emotionally. Any thoughts of a normal life—entering the workforce, relations with the opposite sex—became only vague considerations. Yes, many times I prayed that it might all end, so overwhelmingly negative was my mindset.

After 12 months my medical team decreed that the offending rectum had to be removed if I was going to heal and have a reasonable lifestyle. Another visit to Robinson Ward was in store. True to form, this did not go well. A rectal abscess needed to heal before surgery could take place. You guessed it, round two with the chloroform mask, chronic abdominal pain and, as a consequence, another three months before I was declared well enough to resume the challenge of establishing a life and some degree of normality.

Such was the pain during the post-operative period that I became addicted to pethidine and had to undergo a punitive withdrawal treatment.

To be continued in our August issue. ●
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There has been an important change to the Stoma Appliance Scheme (SAS) schedule which will standardise the maximum monthly allowance of adhesive remover wipes for ostomates.

The Australian Government recently decided to update Group 9(d) of the SAS schedule from 1 March, a change that will limit the allowance of adhesive remover wipes to a maximum of 60 units per month.

The new maximum monthly allowance will apply to the following products:

- Smith & Nephew Remove Adhesive Remover Wipes (SAS code 3542K – supplier code 403100)
- Hollister Adapt Universal No Sting Remover Wipes (SAS code 3554C - supplier code 7760)
- Convatec Convacare Adhesive Remover Wipes (SAS code 352J – supplier code 37443)
- Omnigon Welland Adhesive Remover Wipes (SAS code 9882D - supplier code WAD050)
- Ainscorp Salts Wipeaway Adhesive Remover Wipes (SAS code 9854P – supplier code WA1)

Members should note that, where product packaging quantities are not commensurate with the maximum monthly allowance of a SAS listed item, your association can issue supplies in quantities as close as possible to but not exceeding the maximum monthly allowance.

Registrants who are concerned that the maximum allowance of an SAS product is insufficient for their needs should speak to their STN or medical professional.

**Know your association’s processes!**

The Stoma Appliance Scheme is unique in being the only appliance scheme in the world where product distribution is managed through a network of non-government self-help organisations.

Nationally, we have 22 such organisations, or stoma associations, that provide assistance to approximately 45,000 individuals each year.

While each association essentially provides the same type of service to members, particularly with respect to distributing appliances through the SAS, the procedures involved can be quite different from association to association.

To ensure you don’t run short or, worse, miss out on your essential supplies, please make sure that you are familiar with the ordering, postal and collection processes of your association!

**Stoma fee for 2017-18**

From 1 July, the uniform national membership fee levied by associations will increase by $5 for the 2017-2018 financial year. The new fee is $60, which may be reduced to $50 upon presentation of a valid Australian Government-issued pension or health care card. The membership fee incorporates the compulsory SAS service fee levied by the Australian Government.

This increase represents the final stage of a $15 fee increase which the Department of Health approved in 2013, and which has been phased in over three years.

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**Connecting in Toowoomba**

When Margaret Brabrook looked to join a support group in her home town, Toowoomba, she found that none existed. So the 80-year-old took the initiative and launched Insideout, the Toowoomba Stoma Support Group.

Margaret had her surgery in mid-2016 and, in a scenario that will be familiar to many, she found the ensuing few months ‘a steep and lonely learning curve’. ‘I would dearly have loved to talk to someone who’d stumbled along that road, and I still have that need,’ she says.

Now, through Insideout, ostomates in the Toowoomba area have the opportunity to meet, share their successes and concerns, give and gain advice, and swap information. Margaret has found the group an energizing experience: ‘Starting this group has given me a new focus,’ she says, ‘and what’s more, ostomy is so interesting—it’s opened up a whole new world for me, and I’m meeting some lovely people.’

Insideout meets at 2.15pm on the second Wednesday of each month, except December and January, at the Dr Price meeting room, Little Street, Toowoomba. People who want more information can contact Margaret at (07) 4635.1697.

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**Sign up in Ballarat**

Ballarat and District Ostomy Support Group is looking to attract more members as it enters its second year of activities in the Victorian regional city.

The group was formed by Graeme Sutton in April 2016, with encouragement from stoma nurses at Ballarat’s St John of God Hospital. Graeme had surgery in 2014 and, like other new ostomates, was keen to find others in a similar situation to share experiences—but the nearest support group for ostomates was in Melbourne, 100kms away.

The group met for the first time in April 2016, with support from Ostomy Association of Melbourne, and since then has attracted several new members and had other expressions of encouragement.

Graeme points out that the group exists not only for ostomates but also for their carers, partners and family. ‘It’s a great way to share ideas, tips, and just to be a support for each other,’ he says.

The group meets at the Barkly Restaurant, at the corner of Barkly Road and Main Street, at 2pm on the second Wednesday of each month. People wanting more information can contact Graeme on 0400 979.942 or at grarob44@gmail.com.
We’re here for anyone whose life has been touched by a stoma

Whether you have a stoma or you’re a relative, parent or carer of someone who does, you’re not alone.

Lots of other people have been through the same things and asked the same questions. Which is why it’s so helpful to have access to an informed, supportive community. And here it is.

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New ostomate

Casper
So I am two weeks away from having my survey ileostomy – any advice? What to take to hospital?, recovery – starting to freak out......

We do have ‘a bigger life’ than just having an ostomy.
Laura Zappulla

Our members are sharing and learning about their experiences.

Join in today. www.abiggerlife.com
Dear Carmen,

I’m 66 years old, and I’ve only just become an ostomate in September last year. A radical cystectomy at the beginning of September has led to me having a stoma bag. I was then diagnosed with a blood clot in my lung, and then lung cancer in my upper right lobe (and have never smoked in my life—go figure!), which was removed. I’m well on the way to recovery, and I just have to build up my stamina and strength.

I can identify with Debbie Warwick (‘A key to comfortable travel’, Ostomy Australia, December 2016). It’s a challenge having to cope with this type of new experience. My husband and I are attempting to complete our overseas travel bucket list, and I need to ask experienced ostomates how they’ve coped with various travel challenges.

If we have a long plane flight, say an overnighter of about 16 hours, how do I cope with emptying my bag, discreetly? I’m not really wanting to stay awake for all that time just to empty my stoma bag every two or three hours.

And if there’s an on-shore excursion from a cruise, and we’re clambering around ruins and over cobbled stone paths for four or five hours, how do I empty the bag periodically, and again discreetly?

These may not seem a challenge to those with experience, but for a new ostomate, it’s a problem. Any thoughts on the above from those in the know would be gratefully appreciated.

Carolyn Brandon, Queensland.

Dear Carmen,

Congratulations on getting through the enormous surgery and treatments you must have endured to be now contemplating overseas travel inclusive of long airflights and clambering over ruins.

In many ways your travel should be easier than those contemplating this type of adventure with an ileostomy. With your ileal conduit/urostomy you should be able to connect your urostomy bag to a leg bag. Leg bags are not available through the Stoma Appliance Scheme but can be purchased from any medical supplier or possibly on line. The leg bag has straps to secure the bag to either your thigh or calf. This should give you an additional storage volume of up to a litre depending on what size bag you acquire.

I advise you to see your stomal therapy nurse or contact the ostomy company that manufactures or distributes your urostomy appliance. They may even make a model of leg bag that matches your bag. Alternatively you could still connect your urostomy bag to an overnight bag and have this discreetly placed in a cloth bag which you could shove under the seat in front of you on the plane.

Just a word of advice, though: with your history of pulmonary embolism it is probably advisable to get up and move every couple of hours whilst on a long-haul flight.

Your stoma appliance should have at least a 300ml plus capacity. I am sure your husband will be looking for a toilet as often as you. With your urostomy outlet you now have the ability to stand over a toilet bowl and point ‘the tap’ at the porcelain and not have to concern yourself with clean toilet seats or squat toilets.

I hope this advice is helpful and you enjoy a hassle-free overseas holiday.

Sincerely, Carmen

Dear Mike,

A granuloma can be many things. I suspect if you ask Doctor Google you could get a bit confused as granulomas can occur in just about any tissue in the body. They can be described as a localised and nodular inflammatory response to infection inflammation or sometimes a foreign body.

Stomal granulomas usually appear as red nodules either on the junction of the stoma and skin or actually on the stoma itself. They occur usually as a reaction to something such as retained suture material around the stoma or as a spontaneous inflammatory response. They usually bleed easily and can change the shape of the stoma if prolific. The moisture they create can also impact on the adherence of the stoma appliance. The good news is that usually they can be easily treated with silver nitrate and prevented by ensuring all stomal sutures are removed in a timely fashion and that your stoma appliance is well-fitting, with minimal exposure of the skin around the stoma to moisture.

If you suspect that you have granulomas I strongly suggest you see your stomal therapy nurse for treatment.

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

In the August 2016 edition of Ostomy Australia, Sarah from South Australia asked some great questions in the journal’s ‘Ask Carmen’ section. I answered Sarah’s first question, regarding salt intake, in the December 2016 issue, and would now like to respond to her second question, about cholesterol.

Sarah wanted to know if having the colon removed and a having permanent ileostomy reduced the risk of high cholesterol and possible heart issues in the form of coronary heart disease and the like. Very good question! First, let’s review cholesterol in general before I get to the specifics for ostomates.

Cholesterol is a substance that I’m sure you’ve heard about. It is very often reported in the media and often not in a positive light. However, cholesterol is an essential substance. The body needs it for a variety of functions. It is used to:

- provide structure and fluidity to cell membranes, thus enabling the membrane to appropriately protect, nourish and remove wastes from the cell;
- make important reproductive hormones such as oestrogen and testosterone;
- synthesise critical stress hormones such as cortisol;
- manufacture vitamin D;
- produce bile, which helps the body to digest fat and absorb important nutrients.

Therefore a certain amount of cholesterol is needed for the body to have healthy cells, appropriate hormone levels, an adequate vitamin D status and good digestive function. The critical point is having the right amount in the right form for optimal health. Too much cholesterol or not enough of the right type of cholesterol may lead to health issues.

Where does cholesterol come from?

From a dietary perspective, cholesterol is found only in animal foods. Therefore people consuming foods from animal sources gain cholesterol from the diet. Foods that contain cholesterol include meat, seafood, poultry, eggs and dairy products. Plant foods, such as grains, vegetables, fruits, and oils, do not contain dietary cholesterol. Once ingested, cholesterol is digested and absorbed in the small intestine.

However it should be noted that the human body is also capable of manufacturing cholesterol, and in fact a much greater percentage of cholesterol is synthesised in the body than is gained from dietary intake. Approximately two-thirds of total cholesterol is produced within the body, with the largest proportion of this being created in the liver. Other tissues are also able to manufacture cholesterol but to a lesser extent. As total body cholesterol increases, the rate of synthesis decreases, but the suppression of cholesterol synthesis by dietary cholesterol is unique to the liver only; it is not evident in other tissues.

In the liver, cholesterol is manufactured from fragments of carbohydrate, protein and fat, with the majority being synthesised from saturated fats and trans fat. These fats are found in fatty meats; full fat dairy products such as milk, cheese and ice cream; butter; coconut and palm oil; deep-fried and take away foods; and as well in commercial baked products such as pies, pastries, biscuits and crisps. Like cholesterol, saturated and trans fats are also absorbed in the small intestine. Once ingested or manufactured, cholesterol then travels around the body in the blood in the form of lipoproteins.

Cholesterol: a review for all ostomates

Continued page 34
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There are two main types of these lipoproteins in the blood: low density lipoproteins (LDLs) and high density lipoproteins (HDLs). They are so named because of their differing ratios of protein, cholesterol and other substances. LDLs are low in density because they contain 50 per cent cholesterol which is a light, fatty substance, and only 20 per cent protein which is heavier. HDLs, on the other hand, are heavier because they are comprised of almost 40-45 per cent protein and only 20 per cent cholesterol.

What do lipoproteins do?

Lipoproteins in the form of LDLs deliver cholesterol to the cells of the body so it can be used to repair cell membranes, synthesise hormones and vitamin D and produce bile. When LDLs reach excessive levels in the blood they may be deposited in the walls of arteries, leading to cardiovascular diseases such as coronary artery disease and atherosclerosis. As such they are often referred to as ‘bad’ cholesterol. Conversely, HDLs remove excess cholesterol from the body and carry it back to the liver, where it can be excreted via bile. HDLs therefore prevent cholesterol from accumulating in the blood and are associated with a lower risk of cardiovascular disease. For this reason they are referred to as ‘good’ cholesterol.

Ideally, it is advisable to aim for optimal levels of good cholesterol and low levels of bad cholesterol to maintain heart health.

However, changing the amount of cholesterol in the diet has only a minor influence on blood cholesterol concentrations in most people. Dietary cholesterol has only a small effect on LDLs whereas saturated fats and trans fats can cause a much greater increase in both total cholesterol and LDL levels. Therefore it is considered reasonable for most people to consume cholesterol-containing foods provided they are low in saturated and trans fats. Foods that meet these criteria include offal (from liver and kidneys, and paté made from these), prawns and eggs.

Once absorbed or synthesised, cholesterol is then either used by the body in the ways described above, or excreted. One of the principal ways in which cholesterol is used is in the production of bile, which helps with the digestion and absorption of fat. Bile is made in the liver from cholesterol and stored in the gall bladder. It acts as a detergent on fatty foods, breaking large fat globules into smaller fragments so that they can be further acted upon by digestive enzymes to facilitate absorption. Once it has fulfilled its role of facilitating absorption of nutrients, about 90 per cent of bile in the small intestine is reabsorbed in the jejunum and ileum of the small intestine. Cholesterol that is bound to fibre cannot be absorbed in the intestinal tract and so tends to be excreted as faeces. Differences in the rate of cholesterol absorption and excretion can affect an individual’s cholesterol status.

How is this relevant to ostomates?

The first point to note is that the liver synthesises the majority of the cholesterol in the body. Intestinal resection in general and stomal surgery in particular will have little impact on this. Dietary cholesterol is also absorbed in the small intestine, which remains largely intact for most ostomates (with exceptions). Therefore being aware of and monitoring cholesterol levels is important for all ostomates—ileostomates, colostomates and urostomates alike.

It is also important to note that most cholesterol is synthesised from saturated fats and trans fats, which are also absorbed via the small intestine. Altering dietary cholesterol intake will have only a minor influence on cholesterol status. It is more important to alter dietary intake of saturated and trans fats instead. This again applies to all ostomates.

Additionally, it must also be noted that fibre in the diet facilitates cholesterol excretion. Fibre in the diet can lead to increased output and possible blockages for many ileostomates and colostomates, and so is often reduced or avoided. However, a low-fibre diet may lead to increased cholesterol reabsorption, which could result in higher blood cholesterol levels.

As you can see, cholesterol status is a possible issue for all ostomates and as such should be monitored and managed. Dietary strategies need to be employed to reduce the risk of cardiovascular disease. Physical activity will also help to keep blood cholesterol levels in check, so incorporating some appropriate exercise into your daily routine will be beneficial. Moderate-intensity activity such as brisk walking has been shown to be effective.

As a nutritionist, I have developed many strategies to improve nutritional intake and dietary diversity for all ostomates. If you need assistance with changing your diet to reduce saturated fat and trans fat intake, or increasing fibre intake to support cholesterol excretion, please contact me via my website at www.nutritionforostomates.com.au.

Wishing you good health and happy days,

Margaret
NEW SOUTH WALES

ALBURY/WODONGA BORDER DISTRICT
Meets: 10.00am on the third Wednesday of each month Feb to Dec.
Venue: Hilltop Accommodation Centre, 600 Keene Street, East Albury NSW Contact: Alex Watson 0428 578 385

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

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

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

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

EUROBODALLA REGION
Meets first Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11.00am - 2.00pm
Venue: Laughter Room, Moruya Hospital.
Contact: Betty (02) 4476 2746

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

FAIR SOUTH COAST
Bega & Surrounding Areas
Meets second Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11am at a different venue each time. Flyers are sent to Ostomates 10 days beforehand.
Inquiries: Eileen. Phone: (02) 6492 2530
Geraldine. Phone: (02) 6492 2366

GRAFTON & DISTRICT
Meets first Thursday of each month from 9.00am to 11.30am
Contact: Anne (02) 6641 8200

GRIFFITH & DISTRICT
Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleamably)
Enquiries: Barry (02) 69635267 or 0429 635 267
Email: ann.bar@bigpond.com
Karin: 0434 785 309

HASTINGS MACLEAY
Meet: The Old Hospital at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries: Neil 0427 856 630 or Glennie (02) 6563 7060

VICTORIA

BAINESDALE & DISTRICT
Available for people to talk to and for home visits in the local area.
Contact: Janine: 0418 854 862
Dorrelle: 0448 458 997
Email: bdosg@hotmail.com

BALLARAT & DISTRICT

TWEED
Meets: third Tuesday of March, June, September and December from 12 to 2pm.
Venue: South Tweed Sports Club.
Contact: Jane Bright on 0409 671 162

WAGGA & DISTRICT
Meets: first Wednesday of each month from 10.00am to 11:00am.
Venue: The Men’s Shed, 11 Ashmont Ave, Wagga Wagga
Enquiries: David (02) 6971 3346 or 0228 116 084
Baz (02) 6922 4132

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

ORANGE & DISTRICT
Meet: Mar - June - Sept - Dec From 12 noon.
Venue: 15 Olver St, Orange. NSW
Contact: Margaret or Tracey on (02) 6362 6184

SYDNEY - PENRITH AREA
Meets: Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).
2016 meeting dates to be advised.
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SOUTH GIPPSLAND
Socials held on the first Tuesday of each month 2 - 4pm.
New Members: second Tuesday of each month 2 - 4pm.

MACKAY
Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov).
Venue: Gordon White Library on Phillip Street, Mt Pleasant.
Contact: Graham Stabler for further information on 0428 776 258 or email: grahamstabler@bigpond.com

REDCILFFE
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

WESTERN AUSTRALIA

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

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

Perth (WAQA)
Meet: 9 Guildford Road, Mt Lawley Weekends: third Saturday of every month 11-1pm.
General: fourth Tuesday of every month 2 - 4pm.
New Members: second Tuesday of every month 2 - 4pm.

QUEENSLAND

Beeleigh
Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beeleigh Community Health Centre, 10 - 18 Mt. Warren Bvd. Mount Warren Park Qld 4118.
Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107

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

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

New Members: second Tuesday of each month 2 - 4pm.
ENQUIRIES:
from 2pm to 4pm.
third Thursday of every month,

ostomies. Meets in Hobart on the
by colorectal cancer with or without

group for men and women affected

(03) 6326 4664

SECOND TUESDAY OF JUNE,

HOWEVER TO BE ADVISED.

MEETING DATES TO BE ADVISED

MEETS AT THE SMALL MEETING ROOM,

SOUTH AUSTRALIA

MEET 10AM ON THE SECOND WEDNESDAY OF EACH MONTH

EXCEPT DECEMBER AND JANUARY

VENUe: DR PRICE MEETING ROOM,

DECEMBER, FROM 10AM TILL NOON.

FURTHER INFORMATION:
ADRIAN KOK (03) 6326 4664

SOUTH BURNETT

MEET 10AM ON THE SECOND WEDNESDAY OF MARCH,

SUNSHINE COAST

MEETS AT THE SMALL MEETING ROOM,

FURTHER INFORMATION:
VITL: (08) 9796 6623
HELEN (03) 9796 6623

SOUTH AUSTRALIA

YOUTH GROUP
Doris Steyer,
Telephone: (02) 4296 5354

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

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

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

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

TASMANIA

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

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

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

SOUTHERN TASMANIA
A new group for southern Tasmania
began on 8 March 2017 at Glenorchy
RSL, 320 Main Road, Glenorchy.
Meetings will be held on the first
Wednesday of June, September and
December, from 10am till noon.

FURTHER INFORMATION:
ADRIAN KOK (03) 6326 4664

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

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

SOUTHERN
MEET: First Wednesday of Feb, April,
WHEN: 2pm.
WHERE: Elizabeth House,
112 Elizabeth Rd, Christie Downs.
Information: Val: (08) 8381 1646

NORTHERN TERRITORY
DARWIN
MEET: 5.00-6.00pm on the first
Tuesday of every month.
WHERE: Cancer Council NT, 2/25
Bay Road, 73 Roebuck St, Mile End.
When: 2pm.
Where: Elizabeth House,
112 Elizabeth Rd, Christie Downs.
Information: Val: (08) 8381 1646

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Email: customerservice@dansac.com.au
Website: www.dansac.com.au

Convatec
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Freecall: 1800 335 276
Email: connection.au@convatec.com
Website: www.convatec.com.au

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

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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

AinsCorp
PO Box 256, South Melbourne, Victoria 3205
Contact: Frank & Marge Noy
Phone: (03) 4921 0728

DANSAC
PO Box 575, Port Melbourne, Victoria 3207
Phone: 1800 331 766
Email: customerservice@dansac.com.au
Website: www.dansac.com.au

Convatec
PO Box 65, Mulgrave, Victoria 3170
Freecall: 1800 335 276
Email: connection.au@convatec.com
Website: www.convatec.com.au

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

Future Environmental Services
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Phone: +61 3 5985 2828
Email: health@futenv.com.au
Website: www.futenv.com.au

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