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This year is fast becoming a year to remember, but for all the wrong reasons.

Summer started with terrible bushfires which gained world-wide attention and affected much of our country. Lives were lost, rural communities were laid waste and peoples lives were devastated. To many of the same areas received more rain in just a few days than they received in the last couple of years.

Around the same time reports were coming from China of an outbreak of Coronavirus (COVID-19) and how large numbers of the population were becoming infected and sadly a number of deaths reported. We are now beginning to have the virus very quickly spread around the world, with millions of people being quarantined and usually the death toll increasing. Countries are now scrambling to prevent the spread of the virus and emergency plans are being implemented, including travel restrictions being put in place for the worst affected areas. We are also now starting to feel the economic impact this major health crisis is having, not just on our health system but on employment and finance as well.

These events have brought home to me just how reliant we are on receiving regular deliveries of our ostomy related products from our local stoma association. All associations operate on a just in time system which means that only minimal quantities of ostomy products are kept on their shelves. Most products are only sourced from the supplier when a member orders that product. Our associations have chosen to operate in this way because it’s not possible to stock every product through the scheme due to the sheer number of products available and the diverse needs of members.

The message we have been receiving from the major Australian ostomy suppliers is that they retain adequate stocks of ostomy supplies in Australia to manage normal usage and that international supply should not be affected. Most ostomy product manufacturers have multiple production and distribution sites around the world. This ensures that production volumes can be maintained.

The message I have for you all is don’t panic and for as long as we all continue to order our ostomy supplies in the quantities and timeframes we would normally, there should not be any impact in the supply of our ostomy products. Ordering more than you need can cause a shortage and adversely affect all members.

We will not be able to get through this crisis without our associations and they cannot operate without volunteers, so their health and wellbeing is paramount. Many associations are beginning to experience a drop in the number of volunteers coming to help at the association as unfortunately most volunteers are in the high-risk groups of the elderly and those with serious health conditions. For this reason, you may have found your association has changed some of its processes and procedures in order to manage personal interactions. All associations are monitoring the situation and reacting accordingly.

Associations are always eager for new volunteers so if you are in good health and have some time available contact your association, I am sure they would have just the job for you.

I do hope that by the time you get this magazine the worst is behind us and that you can be sure that the staff and volunteers from every association tried to minimise the inconvenience to their members during this difficult time.

David Munro
President
blood test results to determine the status of his electrolytes and other minerals, an action that highlighted his blood sodium level was at the upper end of the normal range. This is unusual as many people with an ileostomy struggle to maintain adequate blood sodium levels.

This finding on the blood test results led me to initially focus dietary changes around reducing salt intake as a means of reducing blood sodium levels and blood pressure. Alternative options to his current dietary choices were discussed. This is when the conversation that highlighted the dietary difficulty that many ostomates occurred.

The factors that needed to be considered
My client’s usual breakfast included cereal and toast, and his toppings for the toast alternated between Vegemite and Peanut Butter according to whim. Whilst on the surface it appears that both toast toppings are harmless and therefore okay to consume, from my perspective the factors that needed to be weighed up and considered in this particular scenario were:

- Vegemite is very high in sodium (3,300mg per 100g) and therefore not a good choice for people needing to reduce their sodium intake
- Vegemite appears to have no impact on stomal output
- Peanut Butter is much lower in sodium (12mg sodium per 100g) and therefore a better choice for people needing to reduce sodium intake
- Peanut Butter can make stomal output slow and sticky
- Peanut Butter is much higher in fat, which may increase stomal output for those with issues with fat malabsorption
- The higher fat content of Peanut Butter may lead to weight gain in those for whom fat malabsorption is not an issue.

In addition to the above, knowing what the goal is in relation to stomal output is also important to help determine if a food is going to be beneficial or otherwise for each individual. For example, a person who is experiencing high output from their stoma needs to be cautious about consuming foods that may increase the output. In this case, a person with high stomal output may benefit from consuming Peanut Butter if there are no issues with fat malabsorption, which could further increase the output. Conversely, a person with slow, difficult output needs to be wary of foods that can make output even slower and more difficult to pass, which Peanut Butter may do on occasion.

As my client did not have any great concerns with stomal output, my recommendation for reducing his salt intake was to focus more on Peanut Butter as a topping for his toast rather than Vegemite. However, I advised caution in this recommendation in terms of quantity of Peanut Butter as my client also wanted to lose a few kilograms of weight. He was happy with this advice.

Juggling dietary challenges and managing stomal output in conjunction with achieving individual health goals is a constant exercise for many of my clients, and a factor that I give considerable focus to during a consultation. However, with collaboration and negotiation, it is usually possible to find some middle ground that suits all scenarios and keeps everybody happy.

If you are having difficulty making choices to enhance your health and suit your stoma and would like assistance with this, please contact me to schedule a nutritional consultation.

Wishing you good health and happy days,
Margaret  •

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Peanut Butter or Vegemite?

In a recent nutritional consultation, I had a discussion with a client that highlighted the dietary difficulty that is often experienced by ostomates – making a choice between the best food for health and the best food for comfortable stomal output.

Sometimes the choice can be straightforward and little consideration is required. However, on other occasions, it is necessary to weigh up the pros and cons of each food option a little more carefully.

The client I was having this discussion with was a 70-year-old male who has had an ileostomy for 10 years. He was in semi-retirement and in very good health for his age and circumstances. However, he had recently been to see his doctor who had reported that his blood pressure was a little high and should be addressed. His doctor did not feel that medication was warranted but recommended that the client seek dietary advice to reduce his blood pressure.

My client contacted me as a source of dietary advice that is specific for ostomates, and we commenced the process of collaborating on what dietary changes were appropriate and favourable to reduce his blood pressure. As part of this process it was necessary to review my client’s usual breakfast included cereal and toast, and his toppings for the toast alternated between Vegemite and Peanut Butter according to whim.

Whilst on the surface it appears that both toast toppings are harmless and therefore okay to consume, from my perspective the factors that needed to be weighed up and considered in this particular scenario were:

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Dear Editor,

With so much publicity concerning safe and appropriate disposal of WASTE, I am wondering if there is a better way to dispose of my waste relevant to being an ostomate. At present I use disposable bags [it is unclear if they are biodegradable] and place them with contents in the ‘land fill’ bin. I very much doubt that the appliances we use are biodegradable but perhaps the manufacturers could advise ostomates on this. I have certainly been slow to start inquiring, but better late than never.

I do support the proposals in Letters that identify the need for a Stomaline. I haven’t heard if there has been any development in this direction. I live in a capital city but after 12 years as an ostomate I can still feel the need from time to time for a chat and to ask a question or two of an informed person.

It would seem to be an ideal project for one or more commercial suppliers to establish. Once many years ago I consulted the District Nursing Service Stoma Nurse who was very helpful and even visited me at home to make sure that I was using the appliance correctly. This service has been long discontinued.

Thank you for providing us ostomates with such an excellent journal.

Katherine Kingsbury, VIC

Dear Editor,

Now in my 90th year, a widower after 62 years of marriage and 11 years ago having undergone a proctocolectomy, I am enjoying excellent health.

In the November 2019 issue of the Ostomy Journal there are inspirational stories by Jodie Nelson and Kerry Kimbey which should encourage those ostomates experiencing feelings of self-doubt that they do not need to pay an “expert” for counselling as they are in control of their own destiny.

There are only two things you need to do.
1. Thank God that you have been given a longer life.
2. Love yourself.

John Geeves, QLD

Dear Editor,

One thing that I always find a little bit irksome when I receive my monthly order is noting how much packaging the various product manufacturers use. This applies across the range of products I use but for me, it is particularly apparent in the packaging of the support garments I receive.

No doubt, the various bodies operating the stoma product scheme and distributing products to ostomates in Australia undertake appropriate due diligence into the products that are available for purchase, but the question is begged in my mind as to whether manufacturers’ packaging practices are part of that due diligence. We are in an age where we really need to find ways of reducing the amount of packaging we are responsible for – rather than taking comfort in the notion that most of the packaging can, in theory be recycled, the better outcome for the environment would be if the amount coming into the system was significantly reduced in the first place. As a group, ostomates can make a significant difference if product manufacturers are aware that this matter is considered important.

Andrew Berryman, WA

Dear Editor,

I don’t see to use a computer, but I use a magnifier to read the Ostomy Australia magazines when I can get them. I like to read about people’s stories.

I would clearly like a pen pal to correspond with. I am no good with technology.

Recently my stoma bags were changed and I’m having great difficulty finding any as good, I have many leaks and my night’s sleep is affected badly.

Hoping you can help me.

Thank you

Beryl Shiplick, QLD

Dear Editor,

I am writing this to ask for HELP! I have had my stoma since January 2014, after surgery for bladder cancer. All went well and my life went back to almost normal, travelling and a good social life.

Then I developed a parastomal hernia in 2016 and had the hernia operation in May 2017. My life has not been the same since... the surgery left me with virtually no stoma, the opening is at the bottom of a deep cavity and is almost completely flat so it is impossible to get a baseplate to work.

I live with constant leakage and a wet bed on many mornings. I am almost too frightened to even go to the shops as the whole plate and bag have come off as I walked down the aisle, it was so embarrassing! Travelling on public transport causes me unbelievable stress, will I or won’t I get to my destination without a major problem. I have seen the stoma nurse (who is absolutely wonderful) on many occasions but she has not been able to come up with a solution.

The skin around the stoma is sore, weeping and often bleeding, this and the fact that the urine fills the cavity before it runs down into the bag, means that the base plate will not stick the way it should. I am at my wits end to know what I can do. My confidence level has plummeted. The urologist can only suggest that they close the stoma and make another one on the opposite side. I am nearly 80 and don’t feel as if I can face more major surgery.

Is there anyone out there who has a similar problem or who can come up with a solution? Any help would be appreciated.

Thankyou.

Anonymous, NSW

WRITE TO US
Send your letters to the Editor PO BOX 267, Gosnells WA 6990 or email: Journal@AustralianStoma.com.au

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 their treating doctors prior to embarking on any course of treatment.
The exact thing that is the cause of the reaction is. The causative factor can be anything from the way in which your skin is cleaned, to remove wipes, wash cloths, barrier wipes or the appliance itself. Many of my stomal therapy colleagues often say, ‘less is best’.

However, if by simplifying your regimen or removing the suspected allergen provides little relief, it is important to seek expert advice. Your stomal therapist/medical specialist, may ask you to see a dermatologist. Common treatments for dermatitis include topical steroids. It may also be necessary for ‘patch testing’ to occur. This is where your dermatologist will adhere suspected allergens to your body (usually your back). Then several readings will be taken throughout the week to see if there has been a reaction/allergy.

Fungal infections

Like ACD, one may experience redness, itch and skin flaking. Unlike ACD, fungal infections tend to have irregular edges. They commonly extend beyond the border of the appliance or may present under the pouch/bag part only. There may be other lesions extending onto the body, such as little red dots (known as ‘satellite lesions’). Sometimes it can extend to other bodily folds.

Treatment

Fungal infections are the result of excessive moisture. Fixing this problem may be as simple as ensuring your skin is dry before you place on your appliance. Prolonged ‘wear time’ of appliances (e.g. one week) may contribute to fungal infections of the pouch/bag if your skin is constantly wet and not dried sufficiently after showering.

However, if the rash persists, even after ensuring your skin is adequately dried and kept dry, antifungal treatments may need to be prescribed for your skin for it to heal.

Irritant dermatitis (ID)

ID is the result of stool, urine or bodily fluids coming into contact with your skin. This essentially causes a burn-like reaction. It is usually painful and can result in skin loss.

Treatment

Treatment of ID is simple and does not require any medical management (that being prescribed treatments). It is important to ensure the hole in your base plate (known as the ‘aperture of your appliance’) fits snugly around your stoma (but not too tight that it causes trauma, such as bleeding or ulcers). Unfortunately changes to body habitus, a retracted stoma, having a custom or ileostomy, tend to increase one’s risk to ID.

Access to specialist teams

It is important to engage your stomal therapist as they are the experts in all the different appliances and accessories that may be required to improve your skin condition. Appliances or accessories may need to be modified or changed to assist the process of managing and healing your skin condition.

About Monica Stankiewicz

Monica is a wound management, stoma therapy and dermatology nurse practitioner for community and oral health, metro north, Queensland health and can see ostomates with any skin or general concerns, through a referral from a GP.

Your GP can refer you through Central Patient Intake (via e-referral CCi-Portal icon) OR Fax the referral to 1300 364 952.

Patient Intake (Via e-referral CCi-Portal) OR Fax the referral to 1300 364 952. Attention to: Nurse Practitioner Wound-Stoma Community and Oral Health.

The cost of attending the service is covered by Queensland Health (therefore there is no out of pocket fees for the ostomate); appliances are covered on the PBS stoma appliance scheme.

* A Nurse Practitioner is a Registered Nurse with the experience and expertise to diagnose and treat people of all ages with a variety of acute or chronic health conditions. Nurse Practitioners have completed additional university study at Master’s degree level and are the most senior clinical nurses in our health care system* (Australian College of Nurse Practitioners, 2020).

My Best Friend

Happy As

After retiring in July 1999 at the age of 62 and leaving the red centre after 17 years we decided to retire at all our favourite place, Bribie Island. This was backed up with the purchase of the property to retire in Australia. It sets out various things to take into consideration one being good medical facilities.

After purchasing a house we went on a couple of caravan trips and I started to get a sore backside - sitting too much I thought. I decided to go for a medical check-up as I had not had one for some time. In January 2000 I found an excellent Doctor here on Bribie Island who did a thorough medical and ordered a colonoscopy.

I was diagnosed with anal cancer and was told I needed an urgent operation. The tumour was too close to the anus to reconnect the colon, so this would result in a permanent colostomy.

During pre-op at the local hospital I was confronted with specialists from Royal Brisbane and Women’s Hospital (RBWH) and a chemo specialist from Redcliffe Hospital who had a plan that would allow me to be reconnected. Their treatment plan involved radiation and chemotheraphy.

What followed was three months of daily radiation which included a picc-line for continuous chemotherapy, weekly blood tests and a very sore bum from sitting in salt baths due to a reaction to the radiation.

My operation happened in July. They marked my tummy on the left side to show where the colostomy would go. I awoke from surgery still groggy from the anaesthetic I felt down my back and there was no bag. Instead what I had was a temporary ileostomy bag on my right side. They weren’t able to join the colon up so the ileostomy was to allow time for it to heal before attempting to reverse the ileostomy.

After another 10 weeks of chemotherapy, an MRI gave me the all-clear. I settled into life with my ileostomy with a lot of help from a support group. I eventually named my pouch ‘Charlie’, who I was told would be around for up to three months, I finished up having a good relationship with Charlie for six months, when the doctors decided to reverse the ileostomy and take him from me.

That’s when the real trouble started, I had to wear pads and be in range of a toilet at all times. I kept being told it would settle down and over the following years they gave me all sorts of instructions on how to manage—all to no avail. Imodium did help but that’s about all.

This went on for 12 years with repeated requests to give Charlie back to me. I kept being told it was too dangerous now that I was 80 years old (a very fit 80-year-old on no medications, I’ll have you know).

Eventually I was advised to go the stoma association where I met with a very experienced stoma nurse. When I told her my story, she said that I should make an appointment and talk to my doctor about keyhole surgery.

My doctor agreed and arranged for RBWH to contact me. I heard from RBWH within a week and had an interview a few weeks later. They agreed that I needed ‘Charlie’ back.

In 2017, the week before Christmas, the hospital called saying there was a spot for me. ‘We know it’s close to Christmas but it’s yours if you want it.’ I immediately said ‘yes, it’s mine’: bugger Christmas that can wait till next year.

So I spent Christmas in hospital and now happily have Charlie back.

And at last I can go anywhere. I’ve had a trip to Victoria to catch up with relatives and friends, another one to Canberra for the flower show and a trip overseas. I suppose the moral of the story is that early detection is the answer, particularly now as test kits are available, which weren’t around in my time.

Ian Draper

In late December the ileostomy Association of South Australia suffered a great loss with the passing of Ian Draper.

Ian was our Vice-President, Treasurer, IT Guru and a great friend to many.

The Association always knew Ian was a valuable member but we are only just realising how much he truly did behind the scenes. We held a Memorial for Ian at the Association in early February and the amount of people that came to give their respects reflected on the character of the man.

Ian was our go-to guy and his humor and helpfulness will be greatly missed.

Kerry Clarke, President Ileostomy Association of South Australia
An Ostomate’s Journey Through Yoga

By Moira Yeldon

My life as an ostomate started in 2012 when I had an ileostomy due to Crohn’s disease. My journey through yoga really started in 2003 when I trained to become a yoga teacher. One of the many things I learned was how to breathe effectively which proved extremely valuable when I was in hospital post-surgery and needed to get air into my lungs while my abdomen was too painful to move. The other was how to meditate in order to relieve pain, stress and anxiety.

Yoga first came to me at a crucial time in my life when I was surrounded by personal family crises. While some may be aware of the physical benefits of practicing yoga, it also provides a spiritual path of wisdom through meditation. For me it offered a way in which to relax and discover meaning in my chaotic life.

When preparing for the ileostomy surgery there were two things that I wanted to be able to do. One was to keep practicing yoga and the other was to visit India. When I mentioned this to the STN she got me to do a few yoga bends and twists before marking the spot where the incision would be. Dodging fat and skin folds, she found an optimal location which was low enough to sit beneath yoga pants and would not interfere too much with forward bends. Fortunately, I have been able to keep practicing yoga albeit a gentler version while I still use the breathing and meditation techniques.

Visiting India though looked like it wasn’t about to happen. After numerous surgeries for strangulated hernias, obstructions of the small bowel and a cholecystectomy for good measure I had spent many weeks in hospital and many more recovering. In between surgeries we were travelling around Australia in our caravan and on one occasion I experienced a prolapse of the stoma. After driving six hours from Eden in NSW to Melbourne I underwent further repair surgery in a hospital in Melbourne.

It took many years for my health to fully recover and I thought I might never get to India. My health and age were both against me. In an attempt at rest and recuperation, I was camping in a remote part of the Kimberley in Western Australia’s scenic far north. I went into a laundry block to do some washing where people tend to leave books they no longer want. This gives the next person an opportunity to borrow or swap them with one of their own.

A solitary book lay on the bench although not a soul was in sight. It was the Lonely Planet Guide to India. I decided to borrow the book to read about the country that had eluded me all these years. The very next day when I was leaving the campsite, I noticed a man about to put some newspapers in the rubbish bin. Not having read a newspaper in weeks, I ran over to retrieve them. In a current copy of The Australian, one of the first things I discovered was a full-page advertisement for a trip to India which was surprisingly cheap. Interpreting this to be serendipitous, I rang my friend to see if she was still interested in going to India.

Continue page 18
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An Ostomate’s Journey Through Yoga

It was not my intention to write a book when I went to India. Captivated by the sensorial images of the people and their culture, I picked up a pen and couldn’t stop writing. Of course, my appetite was whetted long before I went and despite having waited some years to get there, my passion was not dampened. The yogic wisdom I had learned in order to become a yoga teacher gained new meaning as I observed the daily rhythm of the ancient culture from which yoga had originated.

Riding camels in the desert at sunset and zipping above ancient forts thousands of kilometres above the ground was a wonderful adventure for me and I was determined to love every minute of the four weeks I spent traveling through India. I also managed to eat three Indian meals each day for a month.

One aspect of yoga teaches us to embrace dualities such as happiness/sadness, suffering/joy. For it is only by experiencing suffering that we appreciate joy. In the same way we can only understand happiness by first knowing sadness. Similarly, we can only learn to live by first confronting death. Having come close to death has taught me to embrace life wholeheartedly and make each day a moment of bliss.

I wrote a book because I wanted to share some of the ancient wisdom and insight that is as relevant today as it was when first written thousands of years ago.

My book ‘Chasing Marigolds’ is available on Amazon, Book Depository or through all major book distributors.

Do you have peristomal skin itching?

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87 percent of people with stomas reported peristomal itching.

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2. A randomized, blinded, controlled trial performed by the University of North Carolina, USA. Results were published in 2011.
3. As compared to Hollister’s traditional barrier products and measured in a double-blinded, randomized, controlled trial performed by the University of North Carolina, USA. Results were published in 2011.
4. As compared to Hollister’s traditional barrier products and measured in a double-blinded, randomized, controlled trial performed by the University of North Carolina, USA. Results were published in 2011.
5. Hollister is a registered trademark of Hollister Inc., USA. Remoist is a trademark of Alleric Co., Ltd.

Ostomy Care
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Celebrating 21 years
By Lesley Gluckman

In May 2020, I will have been an Ostomate for 21 years. In 1999 I was diagnosed with cancer of the lower bowel. During surgery to remove the tumour I started haemorrhaging, which necessitated an emergency transfer to another hospital, an induced coma for three days and a temporary stoma. After six months of chemotherapy and radiotherapy and in consultation with various specialists, I underwent a series of operations to reverse the stoma. All was going well until the final stages when the bowel burst. For the second time, my husband was warned that I may not make it through the night. But again, emergency surgery saved my life but left me with a permanent stoma.

If it wasn’t for that stoma I would have missed the last 21 years of my life. And they’ve been good years. I’ve seen our two children grow from being crazy, carefree teenagers, into responsible, hard-working adults and wonderful, loving parents. I’ve had the joy of knowing our five beautiful, funny little grandchildren. I have had the unexpected pleasures of 10 years of retirement - the ability to travel anywhere and have nanny naps anytime. We’ve travelled to Vietnam. We’ve snorkelled off islands in Fiji, the Cook Islands, Lord Howe Island and the Great Barrier Reef. We’ve swum with whale sharks and giant manta rays. We’ve walked the Queen Charlotte track in New Zealand, the Cape to Cape track in Western Australia and the Three Capes Walk in Tasmania. We’ve ‘done’ the Kimberleys and we’ve driven to The Tip, Walk in Tasmania. We’ve ‘done’ the Kimberleys and we’ve driven to The Tip, New Zealand, the Cape to Cape track in Western Australia and the Three Capes Walk in Tasmania. We’ve ‘done’ the Kimberleys and we’ve driven to The Tip, Western Australia and the Three Capes Walk in Tasmania. We’ve ‘done’ the Kimberleys and we’ve driven to The Tip, The Kimberleys and we’ve driven to The Tip.

To begin with it’s a lot like going back to the toilet training years. I had a lot of accidents to start with. The worst was probably at the opera. If you’ve been to the opera you would know that even a heart attack cannot be allowed to disturb the performance. I recognised all the tell-tale signs of a leak but could do nothing about it but sit, unmoving, until interval. It was pretty bad. I washed my pants in the toilet, changed the appliance and went out to the bar. ‘Would you like a drink?’ asked my friend. ‘Absolutely!’

Like growing up, it wasn’t the only accident and it probably won’t be the last. You can’t let it get you down. Clean up and move on. You do, however, need to recognise when you might need help in solving a problem. I am really grateful to the stomal therapy nurse who identified the need for me to use convex appliances because of the shape of my stoma. How would I have known that without the help of a professional? Since changing the appliances I use, I have had very few problems.

Early on, I also suffered from very sore skin around the stoma. With this, I was helped by an article I read in an Ostomy Australia Journal about the use of Questran Lite to reduce the acidity of the output. It’s a prescription medication. I also find it useful to have a medical appointment every six months to renew the prescription, have a blood test, to get a B12 injection and a medical certificate for extra supplies if needed.

Extra supplies are an essential part of my survival package. I was caught out in a supermarket in Hobart and they gave me my next week’s supplies. I had packed extra supplies but not enough to last another week or more. I went to the Ostomy Association in Hobart and they gave me my next week’s supplies. It is good to know that wherever you travel in Australia there is an ostomy association that can help if needed.

As is customary for a 21st speech, I would like to thank some of the people who have helped make these years cause for celebration. Firstly, I would thank the doctors, nurses and hospitals for keeping me alive. Next, I thank my husband for his constant acceptance and tolerance. He has enabled me to keep being the person I was. I also thank my friends and family for not taking any notice. Funny that. The less you talk about it, the less people think about it and I really do not want it to be my defining feature.

Most importantly, I thank the Ostomy Association of Melbourne. Without those supplies, we could not do any of the things we do. We could not function. It’s as simple as that. The system we have in Australia is the best in the world and I am eternally grateful for it. I am reminded of the old adage – ‘Never go anywhere without extra supplies’. •

Traditionally, a 21st is a significant milestone in terms of maturity and responsibility. In reality, it’s probably more a celebration of having survived the growing up process, learning a lot from those experiences and thus being better prepared to keep on going. That’s how I like to think of my 21 years as an Ostomate.

To begin with it’s a lot like going back to the toilet training years. I had a lot of accidents to start with. The worst was probably at the opera. If you’ve been to the opera you would know that even a heart attack cannot be allowed to disturb the performance. I recognised all the tell-tale signs of a leak but could do nothing about it but sit, unmoving, until interval. It was pretty bad. I washed my pants in the toilet, changed the appliance and went out to the bar. ‘Would you like a drink?’ asked my friend. ‘Absolutely!’

Like growing up, it wasn’t the only accident and it probably won’t be the last. You can’t let it get you down. Clean up and move on. You do, however, need to recognise when you might need help in solving a problem. I am really grateful to the stomal therapy nurse who identified the need for me to use convex appliances because of the shape of my stoma. How would I have known that without the help of a professional? Since changing the appliances I use, I have had very few problems.

Early on, I also suffered from very sore skin around the stoma. With this, I was helped by an article I read in an Ostomy Australia Journal about the use of Questran Lite to reduce the acidity of the output. It’s a prescription medication. I also find it useful to have a medical appointment every six months to renew the prescription, have a blood test, to get a B12 injection and a medical certificate for extra supplies if needed.

Extra supplies are an essential part of my survival package. I was caught out in Tasmania once when our flight home was cancelled because of ash from a volcano. I had packed extra supplies but not enough to last another week or more. I went to the Ostomy Association in Hobart and they gave me my next week’s supplies. It is good to know that wherever you travel in Australia there is an ostomy association that can help if needed.

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ConvaTec Scholarships for Stomal Therapy nurses announced

ConvaTec ANZ is delighted to collaborate with The Australian College of Nurses (ACN), the Australian Association of Stomal Therapy Nurses (AASTN) and The New Zealand Nurses Organisation (NZNOCSTN) to offer ConvaTec scholarships to three nurses for the Graduate Certificate in Stomal Therapy Nursing, commencing in July this year.

Stomal therapy nursing is a dynamic and demanding area that requires specific skills and expertise and it is intended that in offering these scholarships, future leaders, who might otherwise not have been able to participate, will be supported to do so.

The stomal therapy role is highly specialised and multifaceted, encompassing the acute care environment, outpatient setting and the community. This course equips nurses with the knowledge and clinical skills to excel in this area and provides them with the knowledge to deliver and coordinate evidenced-based care for patients who are referred for stoma therapy.

“ConvaTec is very excited by this collaboration with the nursing organisations to provide opportunities for nurses who are keen to become specialists in stoma therapy,” explained Karen O’Connor, General Manager of ConvaTec Australia and New Zealand. “Stomal Therapy Nursing requires very specific skills and this course will help them develop the knowledge, clinical expertise and leadership required, while enhancing their clinical decision-making and critical thinking.”

It is envisaged that applicants for the ConvaTec scholarships will already be working as graduates in a clinical setting and that completion of this certificate will lead to opportunities in specialist stoma therapy nursing roles.

“Each of the scholarships is valued at just over $12,000, presenting an enormous saving for participants and opening a door that enables them to embrace the journey and thrive while addressing the ongoing needs of the stoma therapy care space.”

“ConvaTec is committed to improving stoma therapy care and by supporting nurses with education and pioneering trusted medical solutions, we aim to help people with stomas to live the life they want,” she concluded.

Applications for the ConvaTec scholarships can be made through the ACN website, at https://acnfoundation.org.au/stomal-therapy-scholarship, and are open until 15th May 2020.
An Australian Day Honour for
YOU Inc’s Lilian Leonard OAM

By Genevieve Cahir

Lilian Leonard, founder of YOU Inc and former nurse, was awarded the medal of the Order of Australia (OAM) for service to community health on Australia Day 2020. Lilian nearly missed out on the award. The invitation being received by email that she thought was spam and nearly deleted.

A very special celebration was held at the Nurses Memorial Centre, St. Kilda Road, to celebrate the award which also recognised Lilian’s extensive voluntary work with ostomy support groups. The celebration was a total surprise for Lilian who was overwhelmed when family, friends, support group members, stoma therapy nurses and past colleagues gathered to extend congratulations to this passionate, caring and wonderful friend to all in the ostomy community.

Lilian graduated from the Melbourne School of Nursing in 1959 and started her career at Cabrini Hospital. She became a stoma therapy nurse after training at the Nurses Memorial Centre, St. Kilda Road, to celebrate the award which also recognised Lilians’s extensive voluntary work with ostomy support groups.

YOU Inc, which celebrated its 30th birthday last year, aims to encourage support and friendship between young ostomates requiring support and encouragement. It was founded in 1989 by Lilian Leonard, founder of YOU Inc and former nurse, who was awarded the medal of the Order of Australia (OAM) for service to community health on Australia Day 2020.

In 1987 she set up an Ostomy Support group for patients at PANCH which met once a month.

In 1989 Lilian founded Young Ostomates United Support group (YOU) Inc after a young ostomate mentioned to her that there was nothing specifically available for young people.

YOU Inc which celebrated its 30th birthday last year, aims to encourage support and friendship between young people including children with a stoma.

PANCH closed in 1988 but Lilian continued to volunteer her time working with the Ostomy Support Groups. Lilian semi-retired in East Gippsland working part time at Bairnsdale Hospital for six years setting up stoma and breast cancer support – capping off a ‘wonderful career’.

Left to right: Lilian Leonard OAM, Assoc. Prof. Hamish Ewing and Genevieve Cahir (STM TNH) celebrating the occasion.
The littlest ones

By Jo-Ann L. Tremblay

‘Promise me you’ll always remember you’re braver than you believe, stronger than you seem, smarter than you think, and loved more than you know.’
— Christopher Robin

As ostomates we are constantly aware of what we eat, our output patterns, our pouching system status and so on. Parents of children with ostomies have these challenges and much more.

‘Miracle Mallory’ of the Mayo Clinic is now four years old. Mallory and her family’s ostomy journey started on the second day of her life. She was born with 15 congenital defects and her bladder was open to the outside, a condition known as cloacal exstrophy. This is an uncommon birth defect occurring in only once in every 400,000 live births. Mallory has an ileostomy. Her mom states, ‘We believe her ostomy is permanent at this time, but science is amazing. Time will tell’.

‘At first Mallory had a colostomy, but it failed to work. After 10 days of no poop, it had to be modified to an ileostomy. We lived in the hospital for the first 104 days of life. We were in the NICU (neonatal intensive care unit) for the first 84 days. Support in the NICU was high. Meeting with the Ostomy nurses, while Mallory was an inpatient, was a blessed time for us, allowing us to learn as much as possible. I did as many bag changes as possible. We have the support of 12 specialists, who are available 24/7. We have direct contact with a WOC (Wound Ostomy and Continence) nurse (by email and phone)’.

Delia’s ostomy journey began at eight years of age when she spent four weeks in hospital. Inflammatory bowel disease was the diagnosis. At nine, she developed clostridium difficile. She was very ill. The medical professionals administered various infusions, bowel rest, and other treatments. Nothing worked. After five weeks in the hospital, a portion of her colon was removed and an ileostomy was created.

‘There were no professionals specialised in wound and ostomy care assigned to us’, says Delia’s mother. ‘We eventually got a paediatric home nurse, but she was not experienced with ostomies, so we continued. We once went to a wound care unit at our local hospital, but needed special permission to get an appointment, because they didn’t take kids. We didn’t find them helpful’.

‘My biggest challenge is the medical community I deal with. They seem to prefer J-Pouches to ostomies. I think they are finding it hard to believe that my child can be this comfortable with her ileostomy. They are putting off surgery, in order to wait for her to change her mind. I think this shows lack of respect for her choice and her decision. I think this medical bias is a reflection of the greater society’s attitude toward bodies and ostomies’, reveals Delia’s mother.

As with most adult ostomates, paediatric ostomates and their families rely on peer support. This can be involvement with ostomy support groups, ostomy associations or societies, and through social media.

We are a part of a Facebook group filled with other families and patients, most of whom have ostomies. It’s a great place to share information and exchange ideas, for Malloy’s care,’ says Mallory’s mom.

Delia and her family are not in a region with ostomy support. ‘There are no groups in our region for parents of kids with ostomies. There is a support group for parents of kids with IBD (inflammatory bowel disease), but none of their kids have ostomies,’ says Delia’s mom.

She belongs to social media sites for people living with J-Pouches and ostomies. The sites have helped her and Delia gets answers quickly as well as allow them to help others.

‘This has also helped both Delia and me to feel connected to the community of people living with ostomies, which is important to us. In some ways I feel isolated. We have only met two other families with children who have ostomies. One is getting a reversal soon, and the other is ashamed and keeps her hidden. This was not helpful to Delia, because she has taken the approach of embracing and accepting her ileostomy,’ Delia’s mom confesses.

Body image for those of us with an ostomy is a challenge at any age. In the case of children they are still developing their self image. The parents of children with ostomies are addressing this issue as well.

‘We talk about Mallory’s body a lot. It is important to normalize her thoughts, ideas and images of her body. We are able to tap into resources with our online Facebook group, she could see others just like her. We also talk about how and why things are this way. We have taught her to love her ostomy because without it she would most likely not be alive,’ admits Mallory’s mom.

Delia illustrates and writes. Her characters are drawn with an ostomy. She has made her own ostomy doll and created an ostomy bag for it. Delia and her family feel there needs to be more representation for kids in books, toys, and the media.

‘We use humour with Delia to deal with all the challenges and an attitude of acceptance and honesty. We try to live life fully. I was determined that Delia see this as a small part of a big and wonderful life. I didn’t want her life to be a medical life or the ileostomy be her identity. Nor did I want her to see it as anything to hide. I wanted to de-stigmatize it immediately. I was very clear with family and friends that we were going to be open and honest about it, not whispering about it in shame,’ Delia’s mom said.

Parents of children with an ostomy need to be creative and innovative, here are some of the tips they want to share.

• Talk with your resources, request sample products, play with ideas. It’s medical arts and crafts, you have to play a bit to figure out the perfect combination

• For young ostomates, Mallory’s parents built a change table for her. As a four-year-old, she outgrew the standard baby size

• When it seems like every single bag is leaking, it’s not you. Whenever we hit a big growth spurt, bags do not stick. Mallory’s parents, who feel they walked into this blind, wish they would go into a manufacturers lab and play with products. ‘We wish we could go in and learn what products exist, get a few samples, and increase our basic knowledge. We would love to give them feedback on what we notice and see in the products. It would be an amazing resource’

• Never blame your child for issues with the bag. It’s not their fault and it is just poop. Mallory articulates non-stress mannerisms when things go wrong. ‘It’s just poop, right mom? I’ve helped her understand it is not the end of the world’

• Use technology like YouTube to educate caregivers

• Let your child control their privacy level. If your child wants people to know about the bag, we can help explain it to others. If the child wants to keep it private, we help them do that too. Our children were not in control of what happened to their bodies but, they are able to learn control of who knows about it.

• Give your child a vocabulary and narrative to talk about the ostomy with others. All children are honest, they will just plain ask

• Normalize. Normalize. Normalize. Do it as much as possible

• Keep an extra supply of equipment on hand. An emergency ostomy supply will give you a ton of relief

• Children are people and when they have a medical issue, they are the authority of what’s best for them.

No matter our age, an ostomy saved our lives and offer us another chance at life. Here are some important messages from the two families who have shared their stories with us.

‘It’s just poop’. We have stressed this over and over with Mallory’s caretakers and it helps them so much. No matter what goes wrong, in the end it is just poop. It is not an emergency. If you can figure out a way to catch poop, you win. This has given her caretakers the ability to take a more relaxed approach, and be creative when needed,’ explains Mallory’s mom.

Delia and her family want everyone to know; ‘Having an ostomy doesn’t change who you are. You can love yourself well, embracing whatever challenges you have. There is no shame in having an ostomy. If more people showed their bags, the stigma wouldn’t prevail.

‘You can’t look at an ostomy as a negative or as a failure. It can be the best thing that ever happened. It saved Delia’s life and we’ve learned acceptance. If you want a J-Pouch, that’s okay too. It is up to the person who is going to live with the choice. The choice is yours, if it’s your choice. Judgement is bad and when people judge, it’s about them not you,’ Delia’s mom comments.

The littlest ones and their families are extraordinary. Sometimes in life, moving forward takes bravery. Ostomates of all ages can attest to that. We do our best to run towards, not away from the challenges. We muster up the courage to stand up and face our realities. Having and facing ostomy sure has a way of testing us, rewarding us with a second chance at life. Paediatric ostomates are the future and they march steadily towards it. They inspire us by their true-life stories. By their journey. By their messages. As they enrich the lives of their families, they also enrich ours.

Jo-Ann L. Tremblay is an ostomate, blogger (The Ostomy Factor – www.joannltremblay.wordpress.com), and speaker in support of adult and paediatric ostomy awareness and advocacy. After her colostomy in 2011, whom she affectionally calls ‘Percy’, Jo-Ann has authored three adult (ostomy) books; Better WITH A BAG Than in a BAG, Another BAG Another Day, BAGs Around their World. Her fourth book is for young children with an ostomy titled, Why Buttercup Wears A BAG! All books are available from Amazon. For more information on Jo-Ann L. Tremblay, and the books go to – www.jo-annltremblay.com
Free samples

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really, it’s just about feeling comfortable in your own skin!

Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions.
For more information and to order a sample, please call Customer Care on 1800 880 851 or visit www.dansac.com.au

AUSTRALIAN CAPITAL TERRITORY

WODEN VALLEY

30 NW Corner, 11th Flr, 10th March, 14th April, 12th May, 20th June, 2020.
Address: Hospital Club - Modern, Malhiba St Phillips, ACT, (02) 6201 0999
Contact: Your stoma therapy nurse or Clare Jacobson on (02) 6201 901 or audiondesk@stnnsw.com.au for further information
Everyone is welcome! Please RSVP for catering purposes.

NEW SOUTH WALES

ALBURY / WODONGA

BORDER DISTRICT

Meet: 3.00pm on the second Tuesday of each month Feb to Dec.
Venue: Millers Accommodation Centre, 603 Kaniva Street, East Albury NSW
Contact: Alex Walker 0414 578 365

BANKSTOWN AREA

Time: 10.00 - 12.00 – morning tea
Address: Reverb Workers Club, 280 Brt St, Reverb, Ph 02 9772 2100
Access: Cheo to public transport and lots of free parking
About: A stoma support group hosted by Bankstown Hospital STNs for you and your family - everyone welcome.
RSVP: Please RSVP for catering purposes to your Bankstown Hospital STN or Clare Jacobson on (02) 6201 901 or audiondesk@stnnsw.com.au for further information.

BATHURST

Meet on the first Tuesday of March, June, September & December at Daffodil Cottage Contact: Louise Linfoot (02) 6330 5767

BEAT BLADDER CANCER

Delta: Last Tuesday of every month
Time: 7.30pm to 9.30pm
Address: Macquarie University Hospital 3 Technology Place, Macquarie University Contact: Adam Lynch, President BEAT Bladder Cancer (02) 4261 616

BOWRAL STOMA SUPPORT GROUP

Time: 2.00pm to 3.00pm
Address: Bowral Bowling Club, 45 Shopland St, Bowral
Contact: La Wang & Eric Wagner Stoma Therapy, Liverpool Hospital – (02) 8739 4308 or Clare Jacobson (02) 6201 901 / audiondesk@stnnsw.com.au. Everyone is welcome! Please RSVP 1 week prior.

BROKEN HILL

Meet: Every 3rd week of each month. Venues Honorable John Dugan Hospital Contact: Sandra Taylor (02) 8861 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, please phone the Stoma Therapy Service on (02) 4320 3232

EUROBODALLA REGION

Meets First Sunday of Feb - Apr
- Aug - Oct - Dec at 1:15
Venue: Lauridsen Room, Merina Hospital.
Phone: Betty (02) 4406 2274

NATIONAL DIRECTORY OF OSTOMY SUPPORT GROUPS

National Directory of Ostomy Support Groups

Regional Directory of Ostomy Support Groups

*Due to Covid-19, make sure you check with your association about these support meetings before attending.

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QUEENSLAND

BEENLEIGH
Meets 10am - 12noon on the first Tuesday of every month from Mar to May, and from Jul - Sep. Contact: Katie Gallagher 0409 760 169.

BOWEN
Meets 2nd Tue. each month at 10am. Contact: Gayle Hill 0418 007 032.

LOGAN
Meets 2nd Wed. each month at 10am. Contact: Lynne McDonald 0407 620 572.

MACKAY
Meets 2nd Wed. each month at 10am. Contact: Deborah Caracciolo 0428 225 148.

SOUTH BURNETT
Meets 1st Wed. each month at 10am. Contact: Janelle Robinson 0409 762 457.

SUNSHINE COAST
Meet: 10am - 12 noon on the 2nd Wed. each month. Contact: Helen Grimwade 0409 786 466.

TOOWOOMBA
Meets 2nd Wed. each month at 10am. Contact: Janelle Robinson 0409 762 457.

WIDE BAY
Meets 2nd Wed. each month at 10am. Contact: Janelle Robinson 0409 762 457.

TASMANIA

‘SEMI COLONS’
Meets in Hobart on the 2nd Tuesday of every month from 10am to 12noon. Contact: Renata, Cancer Council Tasmania, (03) 6169 1900.

NORTHERN TERRITORY

DARWIN
Meet: 5.30 - 6.30pm on the 1st Thursday of every month. Contact: Caroline Balfour 08 8944 1800.

SOUTH AUSTRALIA

CENTRAL
Meet: 3rd Tuesday of Mar, May, July, Sep and Nov. Contact: Sue Williams 08 8368 2278.

FLEURIEU
Meet: 10.00am until 12 noon on Mondays 3 monthly at the Fleurieu Community Library. Contact: Val Macey 0419 839 869.

PORT AUGUSTA AND BEYOND
Meet: 10am - 12 noon on the 2nd Wed. each month. Contact: Janelle Robinson 0409 762 457.

PORT PIRIE
Meet: 10.00am until 12 noon on the 2nd Wed. each month. Contact: Janelle Robinson 0409 762 457.

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