

Ostomy

A U S T R A L I A

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National Directory of Stoma Associations

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

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

From The Editorial Desk

Another year gone forever, and another new year is well underway. Is it just me or does "time" just seem to get faster and faster every year? Perhaps it's the pull of gravity once you are "over the hill" and on the downward slope?

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

In this issue we again feature more stories from Ostomates. One such article is by Peter Dowling, who tells of his difficulties and successes in "*Ulcerative Colitis / Colectomy / J-Pouch Formation - A Personal Reflection*". Peter describes how a J-Pouch Formation enabled him to renew his sporting pursuits and active lifestyle with new vigour, freedom and good health. Another great story features Imogen Phillips in her "*A Problem Shared*" article, where she explains how she overcame Crohn's Disease as a teenager and how her life-saving treatment ultimately influenced her career choice. Similarly, Karen McKenzie tells us in her "*My Las Vegas Wedding*" article how her operation not only saved her life, but also enabled her to get married and have another child.

Courage and positive approach to life are large factors in the independence these Ostomates gained after their operations. Imogen's comment in particular summarises it well; "*Don't be a victim of your situation. Embrace the challenges ahead of you and come out the other side as a stronger person who can take on the world!*".

At the request of a reader, we have reprinted the "*Oh, the Horror!*" article from the March 2007 issue of *Ostomy AUSTRALIA*, which describes the ostomy technology available to Ostomates fifty years ago. Ostomy appliances available to Ostomates in 2013 under Australia's Stoma Appliance Scheme (SAS) are a vast improvement thanks to continual product evolution and improvement. However, Ostomates in some other countries do not fare as well. For example, most Ostomates in the Philippines do not have access to even the most basic ostomy appliances due to cost or lack of donated supplies. Instead, many have to improvise their ostomy equipment as Robert Hewson describes in his "*A Good True Story*" article. Fortunately, donated supplies made possible through ACSA's Australia Fund as well as people such as Robert do make a difference.

We welcome the new **South Gippsland Support Group** in Victoria, which is now listed in the National Directory of Support Groups page. Unfortunately, the **Launceston Support Group** has become inactive for want of a co-ordinator. If anyone is interested in starting it up again please contact the Secretary at Ostomy Tasmania.

Crohn's & Colitis Australia's (CCA) also advise that a new "**Can't Wait**" card is available to CCA members who have been formally diagnosed with Crohn's or ulcerative colitis. These cards request access to the closest toilet in times of urgency upon presentation of the card to an approved pharmacy.

Thank you again to those who responded to our "*Like to be on the front cover of this journal*" appeal by sending in their photographs and story. We received some great pictures but unfortunately could not use any on our front cover this issue as none scaled up with sufficient clarity, vibrancy and high-resolution. However, these photos are included within the various letters and stories throughout the journal. Please keep sending in your photos and story and we will feature any that are interesting, colourful and high-resolution.

Take care and stay healthy.

Kim Lyell EDITOR

Help!

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



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

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

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

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

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

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

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



Like to be on the front cover of this journal?

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

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

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

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

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

*"Fresh activity is the
only means of overcoming
adversity."*

Johann Wolfgang von Goethe

President's Message

The New Year is well and truly with us and, as usual, it brings with it its own set of challenges in one form or another to us all. This year especially, our country is living up to its description of being "a sunburnt country of droughts and flooding rains" (one wonders if "bushfires" should now be added to that description!). From Queensland to Tasmania, we have faced the extreme challenges of massive floods and tragic bushfires. And yet again we find that, as has been the case right throughout our history, these tragic and trying circumstances have brought out the best in the Australian people. While this may not be the right time to call Australia "the lucky country", we continue to have much to be thankful for. Not just for our many gifts of natural beauty and bountiful resources but also for our great spirit of community and support of each other through adversity.

The small town that I come from in Tasmania was almost totally destroyed by bushfires in 1967 and the spirit and togetherness that emanated from that disaster almost fifty years ago is still evident today. One of the primary lessons that we can learn from our natural disasters is that it is up to us all to pitch in and to work together to overcome the challenges faced. The sobering thought is that only we can preserve this lucky country and in doing so, show our resolve through our actions in refusing to accept any attempt to undermine the values we hold so dear as the Australian Way.

Just as large scale challenges such as recovering from natural disaster can seem daunting and, at times, insurmountable, so too can the challenges faced by a new Ostomate. Many new Ostomates are discharged from hospital after surgery with only a vague recollection of what they have been instructed to do and not to do when they return home. Although pre-surgical counselling is invaluable in preparing a person for ostomy surgery, the reality of waking up to find a stoma on your abdomen can be an incredibly overwhelming experience. In many cases these feelings are compounded by the slow realisation that this condition may be permanent and with you for life. It's important to recognise that these early days as an Ostomate require a lot of patience, understanding, and above all, constant adjustment to accommodate this new life style.

As a new Ostomate, you must not become indifferent to the many and varied issues surrounding the adjustments required for this new way of life. Some new Ostomates will adjust to their new lifestyle quickly while others,

who may also face additional challenges such as advanced age, associated health issues or non-acceptance of what will prove to be life-saving surgery, may take a little longer to come to terms with and to adjust to life with a stoma. Instead of becoming insular and withdrawn or self-conscious about the fact that you have a stoma, you should be applauded rather than stigmatised for having the courage to accept this life-saving surgery. So embrace the condition you find yourself in with open arms and don't just cope: live your life to the fullest! And remember, your best friends in the early days are your Stomal Therapist and Ostomy association. Your association is so much more than the supplier of your appliances and relevant pharmaceuticals: they can also provide you with stoma related information and support. Through them you will have the opportunity to meet other Ostomates and, perhaps when your health recovers, to do some voluntary work. You will also be able to find out about support groups that meet regularly for a comforting chat and coffee, and to organise social outings and functions. Remember these things won't just happen without some positive initiative on your part. As a new Ostomate, you can be your best friend or your worst enemy!

On the national scene, this year we will see the final implementation of the review into the Stoma Appliance Scheme. Premium priced products, support garments and pharmaceuticals will all come under the scrutiny of the Stoma Products Assessment Panel. The Stoma Appliance Scheme is widely recognised as equal to if not the best scheme of its type in the world. As Ostomates and users of the scheme, we all have a responsibility to preserve the efficiency of the scheme and can do so by adopting principles of responsible consumption which include only ordering what is required when it is required, keeping an adequate but not excessive stock in reserve, using products for which they are intended, rationalising use of ancillary products and not expecting the taxpayer to fund personal choice. If we all adopt these principles we will all be playing our part in the Scheme's future.

For now, keep well and be involved.

Peter McQueen PRESIDENT



Letters to the Editor

Dear Editor

Congratulations on our splendid journal which I find comforting due to all I have learnt over recent years - not only from the articles contained within but the many useful tips gleaned from readers' letters.

As the subject of warming the flange on a two-piece device comes up regularly, I thought it may be worth mentioning my method of using a rice-bag. Before my shower I toss the rice-bag into the microwave oven, in my case for one minute - time depends on size of bag being used - then it is off to the shower. Place the flange under the rice bag on the vanity unit, hop in and shower away. When you get out there is a nicely warmed and softened flange ready for fitting. This was not advice from outside but purely came about because we had a couple of the rice-bags in the house and I thought it was worth a try. It has served me very well during the six years that I have been blessed with this chore so I hope it just may do the same for others in the same situation.

Keep up the good work with our journal.

Dave Packham

Dear Editor

In the December 2012 edition of *Ostomy AUSTRALIA*, you had an article about Folliculitis and skin rashes caused by shaving the abdomen around the stoma site. As a retired pharmacist, I can vouch for the use of Sorbolene Cream to shave. It is extremely safe and is non-irritating. Most commercial shaving creams contain some perfume and may cause contact dermatitis to delicate skin.

I have used this successfully since my surgery in November 2011. At first I had both Ileostomy and Urostomy bags but now only the latter, as I had reversal surgery for the Ileostomy. I have never had any rash at all in that area. It is safe for use near the stoma and is very inexpensive to buy and is readily available at all pharmacies. I just use an ordinary safety razor. My wife, who has worked in pharmacy for more than fifty years, has recommended its use to many people. My wife changes the bag for me with me lying flat on the bed. This method seems to give good adhesion as I have never had any problems with leakage, even when I had both bags.

David Lewis, VIC

Dear Editor

My wife has a transverse colostomy and a digestion problem (malabsorption syndrome) which requires her to change her bag six times a day on average. Despite this she never has any difficulty with peristomal rash or adhesion difficulty.

We think this is because we never use soap on our skin. Decades ago I was advised by a doctor to stop using soap on my itchy anus (entirely successful) and I decided that if it was good enough for that it might be good enough for the rest of me, and I took to thorough showering with just water and a face washer.

A notable benefit from this has been the absence of *Staphylococcus aureus* on my skin (I have had tests to confirm that) which means that if I have a splinter in my skin it does not cause redness, tenderness, swelling and pus, and I have to dig it out instead of waiting for it to float to the surface in a blob of pus. My doctor assures me that I am not smelly for want of using soap.

My wife had followed me in abandoning soap long before her ostomy, and she has always been comfortable and rash-free despite her frequent bag changes.

There is a temptation to use lots of soap to get the skin clean when there is a yeast or folliculitis rash, but that's like trying to put out a fire with kerosene. I believe that soap causes a good proportion of the skin problems that we clean, modern people experience.

Dr Michael Grounds, VIC

Dear Editor

In the December issue somebody questioned membership fees. The Bendigo and District Ostomy Association's annual fees are \$60 and \$12 postage.

My son had an Ileostomy bag for nine months. At the beginning we didn't know how much to order, but after couple of months we got it right. After the reversal, we donated the left-over ostomy bags to the District Nurses and Stoma nurse at our local hospital. They know who have the stoma bags, and if anybody runs out for whatever reason, they can help them out. This might help some readers.

Nancy, VIC

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Better a Semicolon than a Full Stop!

Submitted by **Ben Selinger, NSW**

Love the journal. There is nothing more reassuring than reading the experience of others.

I was diagnosed with ulcerative colitis in my mid-twenties, suffered for a dozen years when none of the drugs, retention enemas, etc worked and ended up in hospital in the old Radcliffe Infirmary in Oxford, UK while on a trip. It was the sort of place that is filmed for period medical TV shows.

"You will need an operation."

"In the next year or so?"

"No, in the next week or so."

The staff were fabulous. I was introduced to a woman who, during the war, had been fitted with a small steel biscuit tin. I was going to be lucky as I would have a flexible, cleanable, re-useable rubber bag (inner tube).

"But don't lose the stopper down the toilet!"

The surgeon said I could live with the ileostomy or it could live with me. I chose the latter and "Clancy" (of the overflow) and I have had several accidents over almost forty years. Please keep up with the improving technology. Recycling definitely had its downsides.

Let's talk about SEX

Submitted by **John Lankester, QLD**

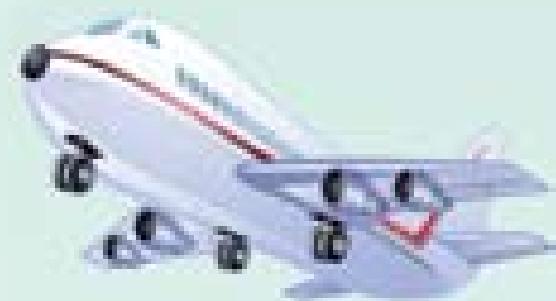
I suspect that most new Ostomates wrestle with the question of how their newly constructed and decorated anatomy will affect their sex lives and intimacy. It often comes up whenever I counsel about-to-be or new Ostomates. Even my happily married daughter who had the same surgery a few years ago confided these concerns to me. My GP, who mentors new male and female doctors, often asks me to explain to them what it means to live with an ostomy.

I am now in my 50th year with an ileostomy which took place when I was a randy 28-year-old (the last thing I can remember before waking up from emergency surgery was watching the funeral of President Kennedy). Since then I have been sexually active with a few different partners and I can affirm that my ostomy has never been an issue or a turn off. Even in the early days when appliances were made of smelly, heavy duty rubber with plastic clips and rubber bands to seal them and no vents to deflate them.

It is my experience that most people can deal extremely well with candour. Avoid surprises. If it appears likely that you could be heading for an intimate relationship find a time to say to your partner that you are a bit shy because you underwent serious surgery and

ended up having your plumbing rearranged. Then when you reassure them they generally become supportive and even curious. From that point on "no worries mate". Given the trend toward tattoos and body piercing you might even be in for a few surprises yourself. When my little friend interrupts a conversation with an unexpected gurgle (or worse) I just smile and say it is his way of telling me he is hungry. The situation will dictate whether you need to briefly fill in the details, matter-of-factly and with good humour.

Enjoy yourselves!!



Problems Obtaining Travel Insurance Cover

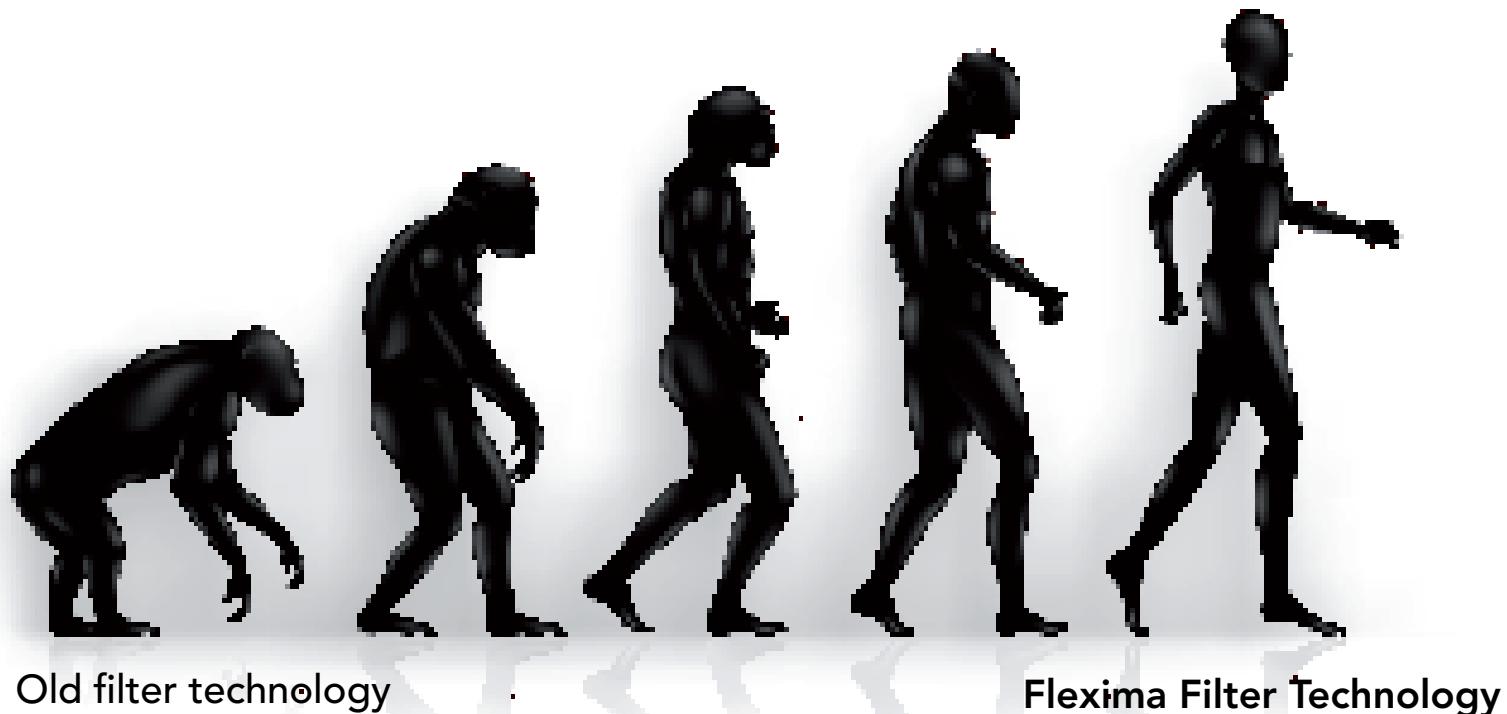
Submitted by **M.Y., QLD**

I wish to flag the problems some people with Crohn's Disease appear to be now having with obtaining travel health insurance that covers this condition. I have had the disease for over 35 years, have travelled overseas previously in the 1980s/1990s on multiple occasions, and obtained travel insurance (with an extra fee always paid for pre-existing illness cover). I have never been ill or had to make any claim when travelling on any occasion.

Now semi-retired, I am looking at resuming some overseas travel, but I have been unable to find any insurer to offer me the cover they previously would. One insurer told me it was because of the medications I was on (Infliximab), which one would think would actually lower the risk of a flare up of Crohn's and lower the risk to the insurer of any claim! I will be on that medication for the rest of my life, and thus, if they all take that position, I will never be able to obtain any travel health insurance that covers Crohn's.

Another insurer stated they would refuse cover because I had had a sub-acute gut obstruction about one year prior to travel. This is despite the fact that I explained that the obstruction was minor, resolved with no surgery required, and was the first one I had had for some ten years. Even if more time elapses between that episode and my application for any travel insurance, I got the impression from them that there are no guarantees they will ever provide any pre-existing medical insurance.

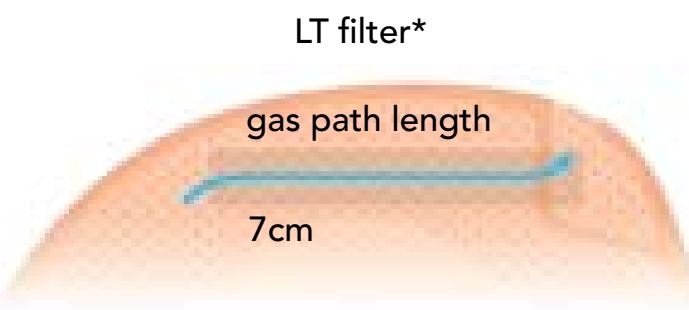
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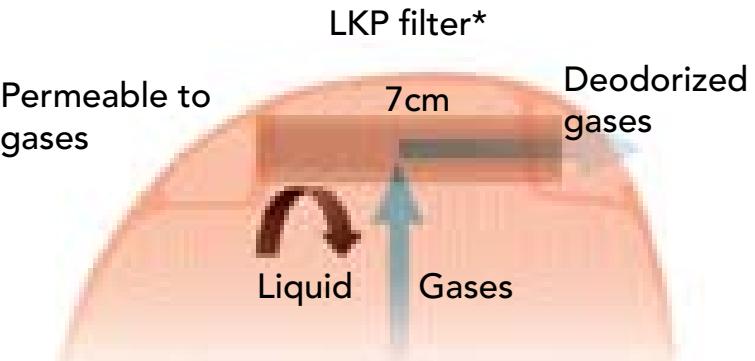
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It is interesting to note that many travel health insurance companies seem to now automatically insure a number of chronic medical conditions, including some conditions that can and do relapse suddenly and without warning such as diabetes and epilepsy, but they do not include Crohn's.

In the end, I travelled overseas for five weeks with a health insurance policy but without pre-existing illness cover, and didn't have any health problems.

I have always tried to be responsible and cautious whenever I travel, and I would have preferred to have paid extra just to have an insurance policy that would have covered me in the unlikely event of a flare up, as I had done many times in the past.

I am hoping to travel overseas again next year, and once again I have been searching on the internet to try to find travel insurance companies that would more broadly automatically accept Crohn's disease as a pre-existing condition, albeit with payment of an extra fee.

While I was unsuccessfully trying to find such an insurance company, I noticed similar problems to mine being experienced on one Crohn's forum, with one person from Australia commenting in the blog that some Crohn's patients are limiting their overseas trip to no further than New Zealand, so that in case of any relapse they can get back to Australia, as they cannot obtain pre-existing illness travel insurance to cover that risk.

It appears that in Australia it is becoming more and more difficult for people with Crohn's Disease to gain cover for their pre-existing condition in the travel health insurance products currently being offered by insurers.



My Ileostomy - Don't Put Your Life On Hold

Submitted by **Glenda Ellis, QLD**

Melbourne Cup Day in 1973 is for me a most important day. I not only backed Gala Supreme to win (which he did!) but I told my surgeon at the Royal Melbourne Hospital that I had no intention of

going home until I had a bag.

I was 34-years-old, with two children aged ten and twelve, and a husband whose military career was being severely impacted by my continued, if spasmotic, attacks of ulcerative colitis. Life had become quite problematic over the previous six years; it was difficult to plan holidays or even outings at times. I had been hospitalised more times than I can remember, my mother had travelled from Sydney so often to help out that it was becoming



most unfair on my father, neighbours had been wonderful stepping in to assist, and now I was sick again! Each time, medical staff had been their usual wonderful selves.

My doctor insisted that surgery was not necessary – yet. I knew that there was a good chance of me living a 'normal' life with ulcerative colitis, but by now I also knew that it was not happening for me. Ongoing medication, surgery for fistulas, plus a skin graft where a form of gangrene had permanently scarred my arm, and now sick once more ... I had had quite enough!

Looking back, I cannot understand why such a decision took so long. During the six years before surgery I managed to retain my part-time teaching job at the local high school (though I was never tempted to ask for full-time employment) and I did most of the domestic chores of a mother and wife without blinking. It did bother me that there seemed no cause for my illness. Indeed at times I wondered if it was psychological! Stress was not something that one suffered from in those days, so that did not enter my thinking. We all got on with life as best we could and at times the fact that I pulled out of activities on very short notice was accepted with little comment. I don't think this would be the case today.

Anyway, Gala Supreme won the Cup, I went in for surgery two days later, and not only did I have



ulcerative colitis, I also had Crohn's disease. As my surgeon said – 'it is all academic now' – because my large bowel was no more. I cried bitterly when I caught sight of myself in the bathroom mirror at the hospital. 'The bag' did nothing for my self-image! And it took quite some time for the wound to heal as the skin on my tummy would not mend. A permanent bag could not be attached for some weeks, but the nurses were supportive and gradually things improved.

I went home for Christmas 1973 and in the following May began teaching again. Not part time any more, but five days a week. Life became more or less predictable, my children knew that I would most likely be around for whatever activities were planned and my husband could now pursue his career. We could also visit grandparents, for a change.

Not only was I able to enjoy a rewarding career, I am able to travel extensively without checking out the availability of toilets (although those in some parts of Turkey and Asia have been challenging just the same). I am sorry that being an Ostomate does not seem to inspire the same degree of awe as surviving heart-surgery or some forms of cancer, and jokes about colostomy bags make me wince!

My ileostomy changed my life completely and allowed me to be in charge again. I enjoyed teaching for over thirty years, and have become totally comfortable with the various improvements to 'the bag' since then. I hope that no-one is trying to live with similar problems and putting off their operation, hoping for a 'cure'. Please don't put your life on hold for years as I unwittingly did.

You Can Achieve Anything If You Really Want It

Submitted by **Sue Mahon**, NSW

Having read the wonderful stories of fellow Ostomates, I admire the courage of everyone and the way they face every day.

I found myself facing cancer six years ago. After three



surgeries and a life threatening peritonectomy to remove everything they could possibly take, including most of my bowel, I thought life was going to be hard to face.

After eight weeks in hospital, I was scared I would never be able to swim or ski again, but just six months after my operation, and as soon as the water warmed up, I hit the water to prove a point to myself that you can achieve anything if you really want it.

I still have many blowouts and get very annoyed at times but I won't let this stop me from enjoying life. At fifty-two I am back water-skiing better than ever, probably due to the loss of thirty kilograms while in hospital.

I took myself off to Europe back in September on a scenic river cruise with three very wonderful and understanding friends. My first trip overseas. I was very scared but I was blessed with my stoma actually behaving itself most of the time. One of the big highlights was spending the day in the old Turkish baths of Budapest.

I have just found out that I will have to go through the whole peritonectomy thing again in a few weeks' time but I am going to enjoy the rest of summer with as much time on the water as I can and spoiling my new grandson before attacking the next chapter of life.

Cancer Patient Reaches for the Sunshine

Submitted by: **Norm Kelly**, Gold Coast Ostomy Association
Reprinted with permission: Article by Donna Mroz Turcic, Gold Coast / Tweed Seniors Newspaper - August edition, Page 39

Susan Keogh comes across as a carefree personality without a worry in the world. The attractive, vivacious fifty-year-old not only has a ready smile, but a husky laugh that fills the room. Interested in fashion, 'Susie' happily admits that she loves wearing bikinis on the beach. Life sounds good for this mother of two adult children.

In reality, Brisbane-born Gold Coast resident Susie suffers from serious on-going medical problems that affect her daily life in a variety of ways, *Continued page 12*



bringing good and bad days; highs and lows. Susie, however, makes every effort to focus on the positive; to reach for the sunshine.

A severe asthmatic since young, Susie explains that she also suffers from a genetic condition known as Lynch Syndrome or HNPCC (hereditary nonpolyposis colorectal cancer), which brings a high risk of different types of cancers.

Susie's children, aged 30 and 26, have also inherited HNPCC, putting further stress on Susie and her family.

Susie was first diagnosed with bowel cancer in 1998 at the age of thirty-six after persistent pain in her lower back and bowel. During a major 6½ hour operation (after which she had a severe asthma attack), surgeons removed three metres of Susie's small bowel, plus rectal muscle, resulting in the need for Susie to wear colostomy bags for the rest of her life. On life support for three days after the operation, Susie later endured chemotherapy and radiation for six weeks. "It was scary. I felt frightened and alone."

In 2007 the bowel cancer recurred, discovered through a colonoscopy. This time, most of the large bowel was removed through an operation where surgeons, "as per my instructions" she laughs, cut below the bikini-line.

Most scarring, and the opening (stoma) for the colostomy bag, remain below the bikini-line, cosmetically important for Susie. Though bowel cancer runs in Susie's family, with her father having the disease at fifty-five but due to celebrate seventy on his next birthday, and her grandfather dying from the cancer at forty-four, Susie urges everyone, especially men who tend to shy away from doctors, to have regular health checks from younger ages.

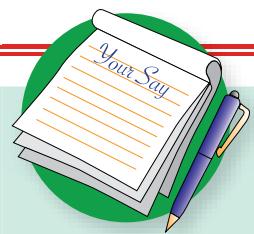
An unexpected disappointment for Susie has been the reaction from some family members and friends towards her medical issues (which include having a cancer cut from her ear at Christmas), with certain friends no longer in touch. "People seem to think that you're different and they don't want anything to do with you", she says with a tinge of sadness in her voice.

But life goes on for the amazing Susie, who hopes to travel to Hawaii one day. She has been an accredited AUSTSWIM teacher for some twenty-eight years and still teaches swimming two days a week to children (as young as six-months) through to adults, including people with disabilities.

Life is not easy for Susie but focusing on the positive, and reaching for the sunshine, makes it that much better.

Quality of Life is Important

Submitted by: **Keith Wilby, TAS**



I had had it in mind to write of my experiences regarding pain and the letter written by D.D. of Queensland published in the last issue of *Ostomy AUSTRALIA* further spurred me to do so.

In 2006 I was diagnosed with an unusual form of rectal cancer that was not treatable by chemo or radio-therapy but could be controlled by medication. Everything went well until about 2009 when an M.R.I. showed that the growth was enlarging and surgery was suggested.

The operation was performed in January 2010, leaving me with a colostomy. I learnt to manage this though not really liking it, and my quality of life remained static until 2012 when persistent urinary retentions lead to the installation of a Suprapubic Catheter (a urinary catheter inserted into the bladder through the abdominal wall).

It was at this stage that I experienced severe perineal pain; a feeling that the growth was forcing its way out. This lead to disagreements between surgeons as to the cause of my discomfort, with thoughts of prostate problems on one side to cancer medication not being affective on the other. A biopsy finally proved the latter was the case.

My GP had made many attempts at pain relief with limited success and I now put hard words on my oncologist for something to be done to provide better relief and was referred to a Palliative Medicine specialist. This gave me a bit of a shiver as many acquaintances who have been on their last legs had ended their days in palliative care. However, I should not have worried as the doctor I was seen by could not have been more reassuring and having taken a history and examining me, the doctor then concentrated on my pain and prescribed a number of analgesics. At this stage my cancer medication was also changed to a much newer version which is being effective now.

Palliative care is NOT confined to those about to drop off their perch but can also assist in many cases where quality of life is an issue.

From personal experience I can recommend that these excellent services could be of benefit to anyone suffering similar pain issues.

It is important to remember that quality of life is the main aim of the treatment and for me that is now certainly the case.

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Ulcerative Colitis / Colectomy / J-Pouch Formation A Personal Reflection

by Peter Dowling, VIC

My name is Peter Dowling and I was diagnosed with Ulcerative Colitis in 1988 at thirty-eight years of age. Initially I was surprised by the diagnosis and was in a bit of denial as I had never been ill before. Up till then my only experience with doctors and hospitals had been for sporting injuries and the like.

Over the next eighteen months I was closely monitored and treated by my Gastroenterologist, an excellent clinician. I was unable to be treated with sulphonamides as I had a previous childhood allergy to these drugs. I cycled on prednisolone during this time, with high doses during flare-ups of the disease, then tapering off as the symptoms were controlled.

My condition gradually worsened despite the best efforts of all the medical specialists. Severe abdominal pain and cramping, frequent rectal bleeds and constant diarrhoea. My clinician, as well as my colorectal surgeon, were suggesting a total colectomy and ileostomy formation. I resisted their initial advice believing I would somehow improve and surgery would be unnecessary.

The decision was taken out of my hands some two weeks later when I had a significant rectal bleed whilst driving home from work. I was admitted to the Royal Melbourne Hospital and underwent surgery. Due to the fact I had delayed having surgery I was quite unwell when I had my colectomy and ileostomy formation. My colorectal surgeon basically described it as a friable large bowel that broke up as it was resected. The surgery was difficult and I had to go back to surgery five days later as I was having an abdominal bleed. This was in April 1990.

Resulting from the surgery I became septic. Infection was systemic, with tachycardia, hypotension and raging fever. I was very unwell. Early intervention would have meant a



shorter hospital stay as I would have been in a more stable pre-operative state. I spent ten weeks in hospital.

Upon discharge, I focused on getting healthy, putting on weight and preparing myself for an ileostomy reversal and the construction of a J-pouch. All went smoothly, and it was great to have the freedom of not having an ileostomy. The J-pouch took a while to get used to and at first I would go to the toilet ten to twelve times a day. Things started to settle down after a few months and on average I would go to the toilet six to eight times a day. This was variable as my body

J-Pouch

This ileoanal reservoir procedure is a surgical treatment option for chronic ulcerative colitis, colon cancer and familial polyposis patients who need to have their large intestine (colon) removed.

An ileoanal reservoir (or pouch) is an internal pouch formed of small intestine. This pouch provides a storage place for stool in the absence of the large intestine. Anal sphincter muscles assist in holding in the stool. Stool is passed through the anus several times a day.

adjusted to diet and fluid intake of various types.

Overall the adjustment process went smoothly and I renewed my sporting pursuits and active lifestyle with new vigour. Surfing, swimming and snow skiing were enjoyed with new freedom and remarkable good health.

Over the next twenty years my health was fantastic and I undertook numerous challenges with much enthusiasm. I became a regular ocean swimmer and twelve times since 1995, swam the "Pier to Pub" event which is held each January in Lorne, Victoria. In so doing I became a "Lorne Shark Bait" member - for those swimming more than ten races. I also completed my ASPA (Australian Ski Patrol Association) qualifications and enjoyed seasons of great skiing fun. During this time I also undertook a career change and gained employment with Ambulance Victoria, returning to university at Monash to complete my ambulance qualifications. I am still working as an Advanced Life Support Paramedic.

Travel has also been high on our agenda as my wife and I have travelled widely since the J-pouch operation, with two visits each to Europe, Thailand and Bali plus single trips to Malaysia, Vietnam, Cambodia and Laos.



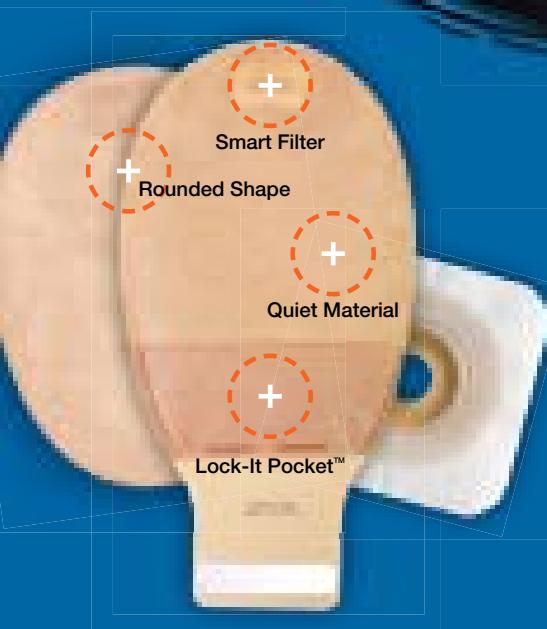
In 2008 I undertook a ten day "Battlefields Trek" along the Kokoda Track. The normal trek is ninety-six kilometres but this was a little bit longer. We covered one hundred and fifty five kilometres over the ten days across the Owen Stanley Ranges. Whilst it was extremely difficult trekking in very wet conditions, it was immensely satisfying.

My good health post the J-pouch

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has also meant I have been fortunate to enjoy seven beautiful grandchildren, with an eighth due in January this year.

However, after twenty years of remarkably good health I suffered a series of small bowel obstructions in 2010 and 2011. In August 2011 an exploratory operation was followed by nine hours of surgery to remove a malignant

adenocarcinoma in my ileum. This led to removal of my J-Pouch and an Ileostomy reinstated. I remain optimistic about the future.

In writing this article I want to express my love and gratitude to my beautiful and devoted wife Mary. If not for the love, kindness, support and courage displayed by Mary I feel I would not have survived this setback, let alone

the other mountains we have climbed over the years. As well, to our children, Katrina, Mark, Susie, Cameron, David and Melanie, I also say a big thank you.

Finally to my two main clinicians, I express my gratitude for your efforts, support and clinical excellence that has allowed me to do so much in my life. ●

Queensland Colostomy Association Celebrates World Ostomy Day

Submitted by **Paul Martin**, Queensland Colostomy Association

Queensland Colostomy Association (QCA) celebrated World Ostomy Day on 6th October 2012. The day was about making the public more aware of Ostomates and the work done by volunteers in the twenty-two Ostomy associations dotted around Australia.

Ostomy surgery saves lives and the World Ostomy Day theme this year (2012) was 'Wear Lilac for Life'. In keeping with that theme, QCA went one step further by painting the exterior of its Moorooka premises lilac, turning a great many heads, which was the whole purpose to draw public attention to the world of Ostomates.

The Queensland State Parliament sat in the week leading up to World Ostomy Day and as a mark of respect, all eighty-nine members of parliament each wore a lilac ribbon.

QCA's World Ostomy Day Co-ordinator, Paul Martin, arranged with the local Member of Parliament, Carl Judge, to make an address to State Parliament about World Ostomy Day and the work QCA and its Queensland sister Ostomy associations do within their local communities and the service they provide to each of their members.

Each Ostomy association was asked to stage an event on the day and nominate a charity to which all proceeds collected should go.

QCA chose to hold a Garage Sale to enable members and the public to come together on October 6th at the QCA premises. Members were asked to donate goods that we could sell onto the public and their response was great with items brought in by the car-load.

The day was an outstanding success. QCA raised a total of \$1,790.00 on the day for its nominated charity, Spina Bifida Hydrocephalus Queensland, which was well above our target.

October 6th also marked the 40th anniversary since the Queensland Colostomy Association was first founded. A tree was planted by Carl Judge MP and a plaque laid which pays tribute to all past and present volunteers who have contributed their time and effort over the years to make the success that Queensland Colostomy Association is today. ●

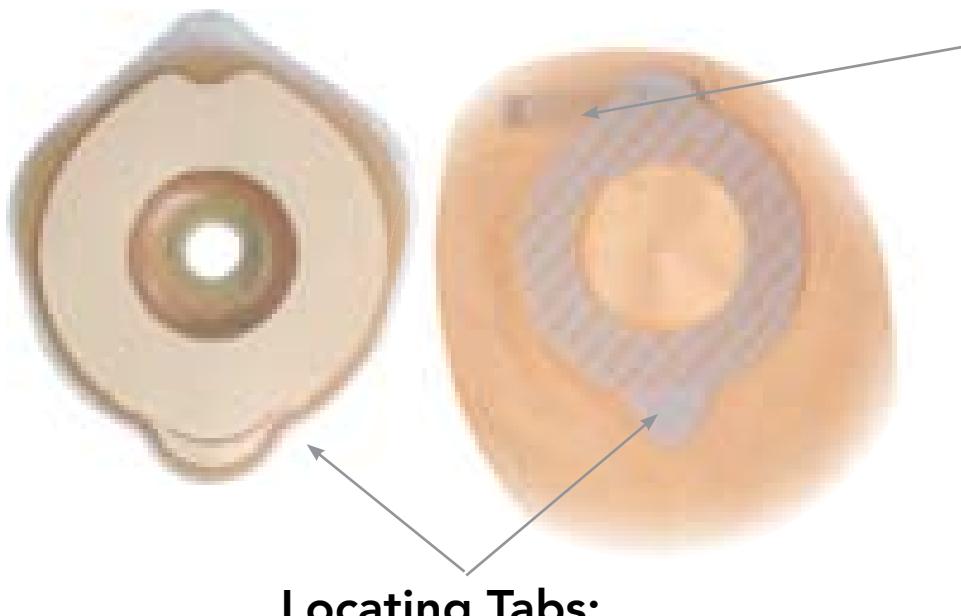


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A Problem Shared

By **Imogen Phillips, SA**

- Imogen's Story

In the past few issues of *Ostomy AUSTRALIA*, I have noticed more and more stories from strong young women who are going through life with a stoma. I have often thought about sharing my personal story about life with an ileostomy and reading these women's stories has been the inspiration for me to do so. So, from the beginning, here is my story.

I have Crohn's disease. The symptoms of this disease started for me when I was about twelve years old, just after I started high school at a boarding school about six hundred kilometres away from where my family lived. This was a strange and new environment, which I was not completely comfortable with at the best of times.

I then started to get sick. Initially with stomach upsets, loss of appetite, and many bathroom trips every day. As a twelve-year-old who was already trying hard to adapt and fit into a new environment, I ignored the symptoms and somehow managed to block them out, to a certain degree.

Thoughts of 'I'm sure it will resolve itself soon' and 'there is no way I'm telling anyone about this, it's embarrassing' dominated my daily thinking. So I kept going to my classes and subscribing to 'normal school life', all the while carrying this burden around with me.

At the very beginning I held onto the idea that I had probably just picked up some sort of stomach bug. The notion that this would be a chronic problem didn't really cross my mind (or maybe it did and I refused to accept it). I'm not really sure now, how I processed what I was going through then.

And so I went on like this. The longer I kept my secret from everybody (including my family), the more difficult it became to talk to anyone about it. Constantly ill, but never letting it show to anyone.

The thing about Crohn's is that you cannot hide the symptoms forever. When I was fifteen and while at home with my family for the Christmas holidays, I started to lose a lot of weight and was having trouble eating food. I was using the bathroom fifteen to twenty times



throughout a 24-hour period.

My mum, looking at how much I had changed since she last saw me, immediately knew something was wrong. She questioned me about it and I told her everything. The catharsis of releasing this information to someone was immense. I had been holding on to this secret for three years at this stage, and it was an incredible relief to finally tell someone about it, to give away a bit of the responsibility that I had been shouldering.

However, I was still sick. Anyone who has had a Crohn's diagnosis would be aware of the barrage of unpleasant tests and misdiagnoses that comes before a definitive diagnosis, so I won't go into the details here. Needless to say I was underweight, lethargic, unhappy, in pain, and subjected to every probing diagnostic tool under the sun.

I was fifteen years old and was supposed to be enjoying my high school years. I was supposed to be studying, learning and socialising my way through those definitive teenage years. Instead I was trapped, miserable and tired, in a situation that I couldn't control. My body had turned against me, attacking my whole large intestine as if it was a foreign body that was not supposed to be there.

After diagnosis, my specialist began treatment with various medical therapies. Over the course of the next seven months I was prescribed every medical treatment available at the time for Crohn's Disease. Each medication I tried was as ineffective as the last and with each new medication came a collection of side-effects of increasing threat to other healthy areas of my body.

As I was not responding to any of the prescribed medical treatments, my specialist decided that I should be admitted to hospital for a seven-day course of IV hydrocortisone. I was still at boarding school during this time and my mum asked me if I wanted her to stay in town while I was in hospital. I told her no, I would be fine. I was just going to be bored for a week in hospital and that there was no need to worry about me. I had turned sixteen by this stage and although my teenage years had been quite different

from most others, I had still developed that independent streak that most sixteen year olds have about not needing their parents.

The doctors in the hospital carried out another set of tests (including the ever-dreaded colonoscopy) and on the third day of my admission, a surgeon walked into my room in the morning wanting to speak to me. Up until this point in time, I had spoken to GPs, gastroenterologists and nurses. Surgeons, and indeed surgery, were not something that had been mentioned or discussed with me during the course of my diagnosis and treatment.

So, you may be able to imagine how I felt when the surgeon sat down next to my hospital bed, introduced himself as a colorectal surgical consultant and matter-of-factly told me that the damage to my large intestine was beyond what was treatable with medication. His next words were to tell me that the best course of action was to remove my large intestine and to create an Ileostomy. A permanent Ileostomy.

This is when I broke. My world fell apart. This couldn't possibly be happening to me. What had I done to deserve this? Aren't stomas something that only elderly people have? How can I ever go back to school? My friends won't want anything to do with me. These were just some of the many thoughts that were going through my head.

From somewhere I mustered some strength and politely thanked the surgeon for his opinion, but told him I wasn't interested. There was no way that I would be having that surgery. He politely told me that as I was 177.8cm (five-foot ten-inches) tall and weighed only forty kilograms, my body was starting to fail and surgery was my only option.

He left me with that thought, and I did what any other teenager would do in this situation. I called my mum.

I explained to her what the surgeon had told me, which came as much of a surprise to her as it did to me. She had been there every step of the way through my diagnosis and treatment so far and the idea of surgery had not been mentioned once.

My parents made the six-hundred kilometre journey to the hospital that day, and after a family meeting with my new team of doctors, it was decided that I would have the operation in two days' time. I became a spectator to my situation and don't remember much about the couple of days leading up to the surgery. My conscious awareness seemed to leave me at this time, I suppose as a way of coping with what I was going through. I remember crying a lot, but it was as though my body was grieving. My mind was blank.

The only clear memory that I have from the days leading up to the surgery was being in the recovery room before the operation. One of the theatre nurses came over to my bed, grabbed my hand, and told me it would be all right. This simple gesture of kindness provided me with more

comfort than I had felt in a long time. I didn't quite believe her, but it helped none the less.

After being wheeled into the operating theatre, I remember being surprised by the fact that there were about fifteen health professionals in there. And they were all there to help me. This too was a comforting thought. Then came the 'jungle juice', a hypnotic sedative they give you before a general anaesthetic. I remember feeling woozy and nice, and then, nothing.

I was taken to the high dependency unit after the operation. I only remember glimpses of the next four days, little moments like holding my mum's hand, or being told to wriggle my toes because my heart-rate kept dropping. The large amounts of pain-relief that I was receiving stopped me from consciously experiencing those first few days.

The real struggle started after I was moved up to the colorectal surgical ward. I had developed a paralytic ileus, which is a way of saying that my digestive system had not started to work again after the operation. My stomach was producing all of the things that it should, but my small bowel was not moving.

So I started to vomit about every fifteen minutes. Vomiting is an unpleasant thing to do at any time, but when you are vomiting small amounts of bitter bile, as frequently as I was, with a twelve-inch surgical incision running through my core stomach muscles, needless to say this was an extremely painful experience. They inserted a nasogastric tube to relieve some of the pressure, but it didn't help. Thankfully, my bowel started to work about ten days post-operation and it was only then that I started my recovery.

The Stomal Therapist at the hospital came to see me every day. She began to teach me about the bag, and what I would have to do to maintain it. This must have been a difficult job to do, as I was a very reluctant student. I didn't really want anything to do with the bag. I was angry and resentful at my situation and acceptance of having an Ileostomy was the last thing on my mind. I was sure that I wouldn't be able to cope with changing it. I was sure that my life was pretty much over.

The Stomal Therapist changed the bag for me daily, all the while educating me and giving me tips for managing it. Every day that she came in I told her I wasn't yet ready to change it myself. She patiently accepted my reluctance.

It's funny how life just sometimes makes you learn the lessons that you need to learn, no matter how hard you fight against it. One night, about one o'clock in the morning, I noticed that the wafer had started to become unstuck. I was stuck in a helpless moment where I knew the bag had to be changed but the Stomal Therapist was not there to do it for me.

I could have pressed the call-button, and have a nurse come into my room to help me, but I was sick of being so reliant on other people. I was sick of not being in control of my

Continued page 20

own situation. I have always been a fiercely independent person and although I thought I had completely lost the ability to look after myself, I decided that I would just have to get up, get to the bathroom, and change it myself.

And so I did.

That was a turning point for me. I had done it by myself. I had taken responsibility for something that I had been so desperately avoiding. Refusing to change the bag myself gave me the illusion that it wasn't happening to me. But that was over now. It was real, I had done it on my own and I was actually very proud of myself.

Of course I still had immense doubts about how people would perceive me if they knew I had the bag. I still had doubts about going back to school and about seeing my friends again. I had doubts about whether or not I would actually be able to enjoy life, but I had won this little battle. It was monumental in not only my physical recovery, but also my emotional recovery.

I spent the next two months in hospital, slowly regaining my strength, my health, and my independence. I should note, that although I was in a lot of pain after my surgery, could hardly move and walking was a struggle, I felt healthy again.

I had completely forgotten what healthy felt like. All of the energy that my body was producing had been going into feeding and fighting the Crohn's Disease until that point. Once the diseased bowel was removed, that energy started to once again fuel the rest of my body. It's a difficult sensation to put into words, but I'm sure that anyone who has had a similar surgery will understand what I'm talking about.

After discharge from hospital, I went home with my parents to recover. I spent the next few months there, feeling depressed about having the bag and knowing that I would have it forever.

I was recovering physically, but I still couldn't get over the fact that I had to try and lead a normal life with an Ileostomy. I was reluctant to go back to school. I had been doing my school work via correspondence during this time so that I wouldn't fall too far behind, but the idea of actually returning to school was terrifying. My parents had been supportive of my choices and didn't force the issue.

After a few months in a small country town, boredom eventually overtook my feeling sorry for myself, so I decided to go back to boarding school to complete my final year of high school education. I had kept up with my Year 11 subjects while I was recovering at home, so was allowed to start Year 12 with the rest of my peer group.

I decided to be brave. Everyone at school knew that I had been sick, but no one knew about the bag. I told a couple of my close friends, and they had nothing but complete acceptance of it. They loved me as a person,

and something as little as the bag didn't matter.

I realised that most of my fears were completely in my own head. There was actually nothing to be ashamed of, or scared about. My friends who supported me through this time made me realise that "those who matter don't mind, and those that mind don't matter".

So finally, after all this time, I had my life back and was having fun again. I was once again an active participant in life and I was healthy, so could actually enjoy it.

I finished Year 12, and after a couple of years off (to catch up on all the socialising that I had missed!) I went to University. I am very open and honest with the friends that I have met along the way about having an Ileostomy. I have not come across one single person who has had a problem with it.

I am now twenty-four years old, have just finished my Nursing degree and I am absolutely in love with my life. I am an active person who loves travelling and having new experiences. I went through a very difficult time, but it has shaped who I am today. I believe that you can take a positive lesson from almost any negative experience. Having to have an Ileostomy, although not ideal, has given me the opportunity to show just how strong I really am.

I'm not going to lie. I spent the best part of two years after the surgery being angry, feeling sorry for myself, and hating my situation. It was a long, hard journey. But the older I get, the more I realise how much that experience has positively influenced the person that I have become. It has even influenced my career choice; I'm now a Registered Nurse who gets to help people through their own difficult times.

I mentioned the theatre nurse earlier in this story who held my hand and told me things would be okay. I now get to be that person for someone else, and I can say and really mean it because I have been there. I have used what was a very negative experience, and made it into something positive. By telling this story, I hope that those reading it can do the same.

Having a chronic illness is hard. It can be soul destroying at times, but you can get through it if you try hard. You can even turn it into something positive. This story spans a journey over nine years. It certainly wasn't an overnight process, but now I'm back. I am now more comfortable in my own skin than I ever have been.

Don't be a victim of your situation. Embrace the challenges ahead of you and come out the other side as a stronger person who can take on the world!

I especially want to direct my story to young people. I felt like I was the only young person in the world going through something like this. I now know better, but at the time I felt all alone. Hopefully some other young people battling with similar issues will read this and feel a little bit stronger for having done so.

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Trekking in Nepal ~ Living Bigger with

As we leave summer behind in Australia with all the quirkiness of our Aussie weather with bushfires and floods, cyclones and some incredible heat, spare a thought for the conditions in other parts of the world. Also let us consider the conditions under which Ostomates in other parts of the world live with their stoma.

As we go to print with this article one very brave Ostomate is testing the bounds of "Living Bigger with Colostomy".

Canadian hockey player, Paul Riome, has been trekking through Nepal since World Ostomy Day 2012 (October 2012), at sixty-two years of age a remarkable undertaking. Paul became an Ostomate in 2009 due to bowel cancer; like many he had ignored rectal bleeding for over two years and is therefore very lucky to be in the position he is in now.

In 2011 he travelled to Nepal and thus began his dream to trek to Everest Base Camp.

Along the route, Paul and his team distributed toothbrushes to the local children: 444 in all to families who, with an average annual family income of \$450, generally share one toothbrush for the whole family. These children also had the joy of being introduced to a particular member of the party - Hogus - a Gastronaut puppet, who joined Paul for the complete trip.

So begins his story which has been prepared, with his permission, utilising his web based blog www.livingbiggerwithcolostomy.com

The first ten days of this journey is "the road less travelled" and takes us back into the home villages of our local guides and porters. After a day of acclimatisation (to high altitude and low oxygen content) in Namche, we will trek 244kms from Tumlingtar to near Mount Everest Basecamp and climb Gokyo Ri, Kala Patthar and Island Peak. In doing so we will climb a total vertical of 25kms – the equivalent of 31 trips up the tallest building on the planet or the equivalent of 7 trips from Everest Basecamp to Everest Summit. We (the three climbers) will further challenge ourselves by attempting the approach and summit of Imja Tse (Island Peak). Our plan is to overnight at Imja Tse basecamp (5,087m), then climb and sleep overnight on the mountain at High Camp (5,700m). Next day we will attempt to summit Imja Tse (6,189m) and return safely to base-camp to sleep and to rest our exhausted bodies.

Most days we are unaware of our Ostomy, except for a 3-minute bag change. But flange failures without clean-up facilities, while living in sub-zero temperatures 24-hours-a-day, can certainly consume some mindshare. I had solved heat-induced Ostomy challenges earlier in this journey and was thinking I was better-built for cold conditions. Apparently cold also offers challenges. I use flanges (normally good for six days) with closed-end pouches.

This is a log of my cold-induced Ostomy experiences while trekking and climbing in Nepal (my terminology):

- Seal Failure - stool seepage past the seal and into the tape adhesive.
- Tape Failure - stool seepage outside the tape adhesive, and stool now exposed.
- Total Flange Failure - more than 50% of the flange is not attached to the skin, and stool spreads well beyond the flange area.

The temperature is well below freezing

every night, and we sleep in unheated lodges or tents. As we continue to gain elevation, it gets progressively colder each night and the 'accommodation' gets progressively rougher.

It is Day 4 for my flange, and I prefer to avoid changing a flange in a very cold tent or while climbing. So I decide to change flanges early and have a 'new flange' in place for the Island Peak adventure. In a sub-zero temperature lodge, I wash with cold water and place a cold flange on cold skin with cold hands.

Next day, while trekking from Dingboche to Island Peak basecamp I had seal failure by noon. With no clean-up facilities, it was impractical to change flanges, so I just added a band of micro-pore tape around the perimeter of the flange, hoped it would last until we arrived at basecamp that night, and continued trekking. I had tape failure during the afternoon, so a clean-up was due by the time we reached basecamp that night. The temperature in my tent was -15C. At home I would have a hot shower, then place a hot flange on hot skin with hot hands... but of course that wasn't practical here. Heat would be nice, but it's not available. There is also the dilemma of my clothes (wearing multi layers of bulky warm clothes). If I take off my clothes I will be very cold, very quickly and the flange won't stick when cold. But if I leave my clothes on ... well I already have a mess to clean up, and I know that dealing with a failed flange will mean output smears on my clothes. So I compromise, leaving most of my clothes on, and open up the midsection enough that I can see what I am doing. Then I wipe the smears with a damp sock, knowing I will have a cold night drying damp long-johns and socks with body heat. I rigorously slap the area around my stoma, bringing heat to both my hands and the stoma area. I heat the flange under an armpit. The flange-change seems good, so I zip up all my clothes and get into my sleeping bag to warm up.

Colostomy

Submitted by Ruth Horne, SA

While on Island Peak Mountain, I had a challenging total flange failure under extreme conditions, and descended five hours with extreme exertion without Ostomy gear. I was totally exhausted after sixteen strenuous hours on the mountain, consuming just one litre of water and three Mars Bars, living on 50% oxygen, and physically drained from the effort. All I wanted to do was sleep. But I had a serious clean-up to do, and a cold-induced Ostomy problem to solve. I had output and smears from belly-button down to mid-thighs and everything in between. Fortunately, and common at high altitudes, appetite and stool production declines, and stool thickens, so the five hours without Ostomy gear was not as bad as it could have been. I laid out my clean-up and Ostomy gear and pre-thought how I would get this job done without exposing too much skin for too long to the below-freezing temperature, and without leaving my clothes wet as I would have to dry them with body heat. At home I would just toss the dirty clothes in the laundry, have a hot shower, and put on clean dry new clothes, but of course none of this exists here. I again used flat stones as scrapers, and semi-cleaned my skin and long-johns.

I have a valuable litre of boiling water from our cook, which I first use with a damp sock to wash my skin and "reasonably" clean my clothes, inside and out. Then I wrap a new flange around the water bottle and hold the water bottle on and around my stoma ... heating my skin, my hands, and the flange. When all is hot (and uncomfortably burning my skin) I place the new flange and add a pouch.

Then I slip back into my sleeping bag, holding the hot water bottle over my stoma to heat-seal the new flange in place. The hot water bottle heated

the inside of my sleeping bag and I immediately fell asleep, pleased I had solved my cold-induced Ostomy gear challenges.

Some will imagine this to be an awful or humiliating experience. But it wasn't. This entire journey has been about challenges, adaptability, acceptance, and grit.



As we sometimes struggle to cope day to day with our stomas let us consider what Paul has endured but achieved. More importantly let us consider what some of our third-world Ostomates have to deal with, many of whom do not even have the benefit of purpose built Ostomy products. Article authorised by Paul Riome – check out his full blog and some wonderful photos of Nepal at www.livingbiggerwithcolostomy.com For Gastronaut puppet information visit www.thebowelmovement.co.uk or ACSA www.australianstoma.com.au

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1. *The skin around my stoma is quite pitted and so my Stomal Therapist recommended that I use both large and small Eakin Seals under my base plate. However, my association has told me that I need to have my Stomal Therapist submit an Application for Additional Stoma Supplies so that I can have thirty of each seal each month. Can you please explain why this is necessary as I have checked the Stoma Appliance Scheme schedule and it states that the monthly allowance of each product is thirty per month.*

This is a very good question! Our member associations report that Stoma Appliance Scheme allowances continue to be the source of much confusion amongst scheme registrants, particularly when the registrant is ordering more than one product from within the same scheme sub group.

Clause 6.5.2 of the Operational Guidelines for Stoma Associations (Department of Health and Ageing, May 2009), provide that:

"When supplies are requested from within one sub-group listed on the schedule, and the products are intended for the same purpose, then the supplied amount is restricted to the maximum limit for that type of product".

In your case, because the large Eakin Seals and the small Eakin Seals are "intended for the same purpose" ie: to provide a seal under the base plate, a maximum combined limit of thirty seals per month applies. In fact, the maximum combined limit of any product appearing in Group 9I (Accessories) of the Stoma Appliance Scheme schedule is thirty per month, regardless of the size of the seal or its manufacturer.

2. *I used to belong to a Victorian-based Stoma Association which was more than happy to accept my orders for product over the telephone. However, I have recently moved to Queensland and find that my new association will only accept orders that are in writing and either faxed, emailed or delivered to the association by person or post. I find this to be very inconvenient. Why aren't the rules consistent across all associations?*

Although all twenty-two of our member associations have the same role with respect to delivering product on behalf of the Commonwealth Government through the Stoma Appliance Scheme, each association is an independent organisation with its own governing body and set of rules. Consequently, policies and procedures with respect to order placement have been developed by each association in consideration of individual association management efficiencies and service to members.

It is the policy of some member associations to accept telephone orders for operational convenience. Similarly, many other associations have developed a policy not to accept telephone orders but rather to request that all orders be placed in writing so that a written record can be produced to support an association's claim for reimbursement from Medicare, or in instances where a supplied product or quantity is in dispute by the member Ostomate.

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

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

AASTN President's Report

Submitted by **Elaine Lambie** - President AASTN - (Australian Association of Stomal Therapy Nurses)

As I write this, I have just returned home to the Gold Coast after being caught up in road closures due to flooding in the Lockyer Valley. My thoughts and prayers go to all around the country who have been affected by floods or bushfires.

My term as President of the AASTN is almost over and I will hand over to the incoming President at the Hobart Conference in March. It has been a privilege to be National President of the AASTN. It has been a great experience with many challenges.

The connection between the AASTN and ACSA continues to be very important and necessary. To this end, the National Executive has asked the AASTN State Representatives to liaise more closely with the Ostomy groups in their areas and state, to improve the distribution of information and promote

the continued growth of the relationship between our associations. It is essential in our continued support of issues and SPAP.



The AASTN Executive and Educational and Professional Development Sub-committee, have asked STNs to participate in a web-based survey to assist in correlating benchmarks and needs of Stomal Therapy Nurses. We are hopeful to have early feedback by the conference.

In 2015, in Melbourne, the AASTN will be part of a co-joined conference, with the Colorectal Surgeons Society of Australia and New Zealand, (CSSANZ). Organisation of this will be well and truly underway from April this year.

I wish you all the very best for 2013.

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Dear Carmen

In the December 2012 issue of *Ostomy AUSTRALIA* (Page 28, Volume 21, No. 3) you have a letter from a D.D. Innisfail Qld.

I am a sixty-seven-year-old male from South Australia and have had a colostomy since 1979. The operation back then was eventually a success but due to the fact I have had thirty-nine bowel surgeries I was also plagued with the type of pain D.D. describes. That was until October 2011 when I happened upon another doctor who is a Musculoskeletal, Rehabilitation and Pain Management specialist.

Until then I had been using a T.E.N.S. unit externally for approximately six years. Apparently my repeated operations kept waking up nerves that should have been inactive as they were no longer needed, as the area they serviced was no longer in my body.

Anyway, last October the specialist doctor implanted a Bilateral Peripheral Perineal Nerve Block Stimulator (that's a B.P.P.N.B.S.)

into my left buttock just below the waist-line. Since the actual moment I woke from that surgery I have had no pain. Imagine, after over thirty years, NO PAIN.

Both my Grandfathers died early in life of Bowel Cancer and a number of cousins. Two siblings have also died as a result of Cancer. I have had fifty-three major operations overall but only thirty-nine for bowel surgery and refashioning, etc. But I still soldier on.

Regards Lindsay W, SA

Dear Lindsay

Thank you for your wonderful letter and the information within it.

This BPPNBS sounds miraculous. If this perineal nerve stimulator is available within Australia and has the success that you have experienced I think many of our members will be having this procedure.

OUR Stomal Therapy Nurse



I will try and find out more about it and maybe we can get an article for this journal.

Thank you again. Keep soldiering on.

Regards, Carmen



Perineal Nerve

From Wikipedia, the free encyclopedia.

Not to be confused with peroneal nerve. The perineal nerve is a nerve arising from the pudendal nerve that supplies the perineum.

The perineal nerve is the inferior and larger of the two terminal branches of the pudendal nerve, situated below the internal pudendal artery.

It accompanies the perineal artery and divides into two branches:

1. Superficial perineal nerves, becoming posterior scrotal nerves in men and posterior labial nerves in women.
2. Deep branch of the perineal nerve (also known as "muscular").

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.

Bulletin Board

Ostomy Support Group Changes

LAUNCESTON SUPPORT GROUP

Volunteer Required

The Launceston Support Group has become inactive for want of a co-ordinator. If anyone is interested in starting it up again please contact the Secretary at Ostomy Tasmania Incorporated on (03) 6228 0799.

In the meantime, the "Semi Colons" support group for men and women impacted by Colorectal cancer meet in Hobart on the third Thursday of every month, from 3.00 pm to 4.15 pm. Please contact Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on (03) 6233 2072 for more information.

MACKAY OSTOMY SUPPORT GROUP

Change of Venue

Gordon White Library. Philip Street, Mt. Pleasant. 4740.

SOUTH GIPPSLAND SUPPORT GROUP

New Support Group

We now have a support group in South Gippsland, Victoria. Meetings are held on the first Tuesday of each month at 2:00 pm. Please contact Thea on (03) 5655 2628 if you would like more information.

YOUNG OSTOMATES UNITED (YOU)

New Web Address

www.youinc.org.au

BAIRNSDALE & DISTRICT

Meetings Suspended

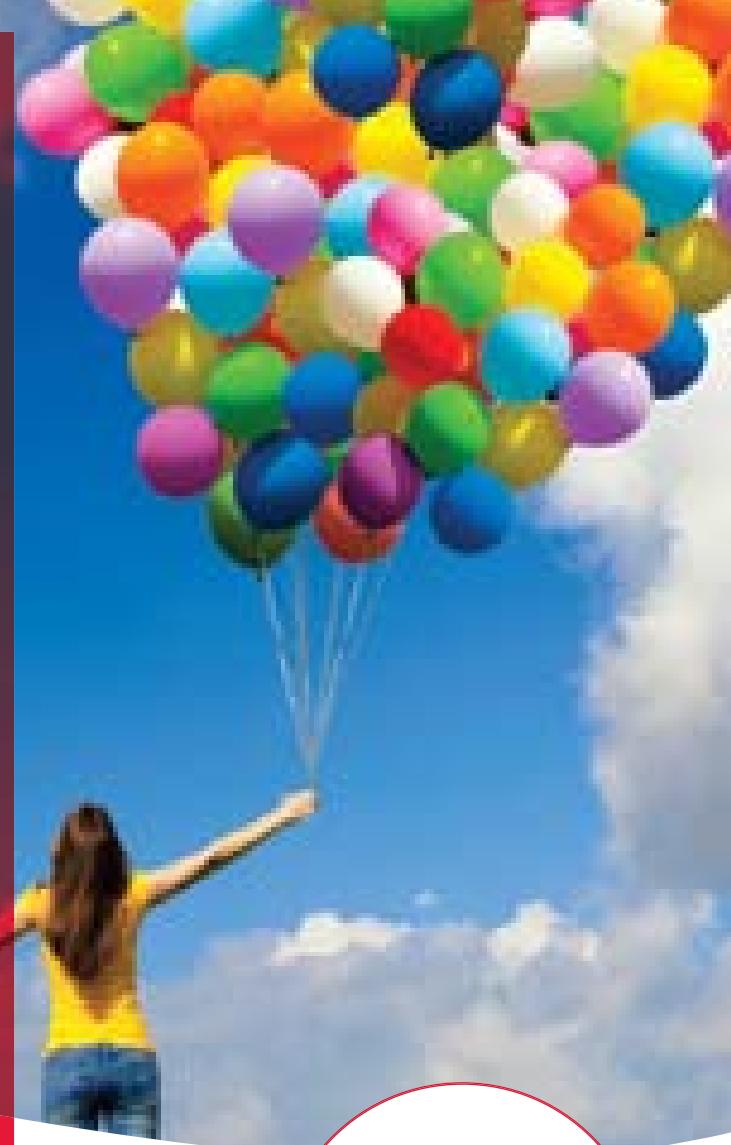
Due to lack of numbers our meetings have been suspended, though we are still available for people to talk to and for home visits in the local area.

Contacts:

Janine: 0418 854 562 and

Derelle: 0448 458 997

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STN

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* Evaluation of the New Hollister High Performance Filter 2008. Feedback from Australian STN's and Ostomates

Avoiding Medicine Mishaps After a Stay in Hospital

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National Prescribing Service Ltd,
MedicinesTalk, December 2012

Unfortunately, a hospital stay can make it more likely that you might experience a problem with your medicines when you return home. However, there are some things you can do to reduce the likelihood of such problems.

Medicine mishaps can occur following a stay in hospital or a respite facility such as a nursing home, because people do not realise that their medicines were changed during their stay. For example:

- you may accidentally take a double dose of a medicine, because you end up with two different brands of the same medicine, or
- you may not be aware that you should stop a medicine that you were taking before your hospital stay.

This could cause unexpected side effects, or even make you ill enough to put you back in hospital. However, there are some things you can do to reduce the likelihood of such problems.

Ask for a discharge meeting

The arrangements for leaving hospital - your discharge - can often be rushed, as hospitals are busy places and most people are keen to get home.

However, before you leave hospital, it's really important that you understand any changes that were made to your medicines during your stay. When you're told you can go home, it's a good idea to check with the nursing staff whether someone will explain your medicines to you before you're discharged. If not, you can request such a meeting.

Arranging a meeting in advance is especially important if you or a person you're caring for speaks a language other than English, because the hospital needs time to organise an interpreter.

You might also like to arrange for a friend or family member to be with you for the meeting. You're unlikely to be feeling your best, and may find it harder to recall things that were said. This person may also be able to support you with any decisions you might need to make.

Once you know when the meeting is likely to be, you can prepare any questions you would like to ask. Don't be shy about asking questions or asking for anything to be repeated: it's important for you to have the correct information. The information you need to ask about includes:

- Have I been given any new medicines?
- Have any of my old medicines been stopped?
- Has the strength of any of my medicines been changed?
- Have any of the brands of my medicines been changed?
It's important that you don't double up on the active ingredient of any of your medicines.
- Are any of the medicines short term - such as those for pain relief?



- When do I need to see a doctor or visit the hospital for a check-up?

It's also helpful to keep an up-to-date medicines list, and to ask the hospital staff to update it to reflect any changes made while you were in hospital.

After you leave hospital

The hospital may give you a supply of medicine to take home or a prescription to fill or both. The amount of medicine you are given will depend on the hospital and the State or Territory where you were treated.

You may also be given a document known as a 'discharge summary'. This includes a summary of your treatment in hospital, as well as a list of your medicines and how they should be taken.

Once you leave hospital, it's important that your regular doctor knows that you have been in hospital and is aware of any changes that may have been made to your medicines. This is especially important if you were unable to have a discharge meeting or were unsure of anything that was discussed. Take a copy of your discharge summary and your medicines list with you to your appointment.

What To Do With Your Unused Medicines

Reproduced with permission. National Prescribing Service Ltd,
MedicinesTalk, September 2011

While it may seem wasteful to dispose of unused medicines, saving them 'just in case' can be dangerous. Most medicines deteriorate with time, which can lead to changes in their chemical composition. These changes can result in them becoming toxic or less effective if they are used after their expiry date.

Dispose of them safely

The Return Unwanted Medicines project is a free Australia-wide service. Local pharmacies collect out-of-date, unwanted and leftover medicines, and then arrange for them to be disposed of safely in high temperature incinerators.

In the past, people often flushed unwanted medicines down the sink or toilet, or put them in the rubbish to be taken to the tip. Disposing of medicines in these ways can damage the environment, particularly streams and soils.

Using the Return Unwanted Medicines scheme ensures that your unwanted medicines are disposed of safely without harming the environment, people or pets. It also helps to make your home safer.

Check first then dispose

You can take your unwanted and expired medicines back to a pharmacy at any time. So it's a good idea, every so often, to gather all the medicines in your home, and:

- remove any that have passed their expiry date
- go through the remaining medicines and check whether you really need them, and remove any that you no longer need
- take all the expired and no-longer needed medicines to a pharmacy.

Further information

If you would like more information, talk to your pharmacist.

Can I Mix Medicines and Alcohol?

Reproduced with permission. National Prescribing Service Ltd,
MedicinesTalk, December 2012

A question that might run through your mind when you're given a new medicine is, 'Can I still have a drink?'

Much of the time, the answer will be, 'Yes', but it is worth checking. Sometimes, you may have to avoid alcohol completely. While at other times, you may need to limit your alcohol intake in line with the advice of your doctor or pharmacist to avoid interactions between the two.

Interactions don't just occur if you consume alcohol and the medicine at the same time. Alcohol can take several hours to be removed from the body, so an interaction may occur at any time there is alcohol in your body.

Not only prescription medicines

Interactions with alcohol can occur with many prescription and non-prescription medicines, for example:

- sleeping, anti-anxiety and antidepressant medicines
- cough, cold, allergy and travel sickness medicines
- most opioid pain medicines, such as morphine (e.g. MS Contin) and oxycodone (e.g. OxyContin), patches like fentanyl (e.g. Durogesic), and even codeine (which is found in some pain medicines such as Panadeine).

These medicines can interact with alcohol to cause increased drowsiness and dizziness, which can make it harder for you to think clearly and may diminish your physical coordination. This, in turn, may make you more prone to falling and impair your ability to do things like driving a car.

In addition, some common anti-inflammatory medicines, such as aspirin (e.g. Disprin), celecoxib (Celebrex), ibuprofen (e.g. Nurofen) and naproxen (e.g. Naprosyn) can interact with alcohol to cause stomach upsets, stomach bleeding and ulcers. In general, the occasional drink or two while taking these medicines is less likely to cause problems, but heavy drinking may increase your risk of problems.

Interactions between certain



medicines and alcohol may occur at any time there is alcohol in your body.

Preventing problems

- When starting a new medicine, find out about drinking alcohol while taking it. Ask your doctor or pharmacist or ring NPS Medicines Line on 1300 MEDICINE (1300 633 424) for information about drinking alcohol while taking medicines.
- Read the medicine's consumer medicine information (CMI) leaflet for information on whether to avoid alcohol. Download the CMI for your medicine from the NPS Medicine Finder.
- Check the label or packaging. Prescription medicines that can interact with alcohol will usually have a warning sticker put on by the pharmacist. Non-prescription medicines will have a warning notice on the packaging.
- Take care if you're told your medicine may interact with alcohol to cause drowsiness or dizziness. Follow any advice about driving or using heavy machinery.

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A Good True Story

By Robert Hewson, QLD



Early in 2011 the Australia Fund was approached to see if they could help a lady in the Philippines get a reversal. She had been receiving donated supplies made possible through the Australia Fund. After hearing her story several association committee members and their partners put their hand in their pockets and the \$550 necessary for her operation was raised. We arranged for her to see the doctor who would operate but unfortunately she had developed heart problems and diabetes making the reversal no longer a possibility.

A short time later, Steve, the father of a ten-year-old boy named Owen, approached the Davao Ostomy Association asking for appliances after Owen had fallen from a friend's bike and ruptured his colon. Because it was a life threatening situation he was operated on without any payment. His father needed to appeal to the Mayor of Davao to successfully get the payment waived. He was supplied with suitable appliances that had been donated by the Australia Fund and he then no longer needed to use the plastic coffee bottle lid, with a hole for his stoma, tied to his side and a plastic bag tied to that. Even though he only had his colostomy for a few months he had suffered physical and verbal abuse and was given a very hard time from his school friends, partly due to the smell, partly because he pooped in a bag, but mainly because his stoma was about 150mm long and was very obvious.

He was able to return to school once he started to use the appliances and the smell was no longer a problem. He was still given a hard time but it was much better for him. It was decided to again approach the Australia Fund but this time to see if the funds that were made available for the other lady could instead be used for this young boy. The original donors discussed this while at the annual ACSA meeting held in Perth and even more money was made available to help Owen. An operation was soon planned. He was in the hospital waiting for his reversal when his doctor cancelled the operation as he said he needed to go to Manila for a few days. While he was away, Owen got a very bad infection and if he had not already been in hospital and able to get urgent attention, he could easily have died. After he recovered the reversal was planned for



the following week and it went ahead as scheduled without any further problems.

Owen has now recovered, returned to school and is so very thankful to the Australia Fund and all the individuals that gave so very generously so that he could become, as he called it, "Normal". The whole operation, with the tests and medications he needed before and after the procedure, cost less than AU\$1,400. This total amount was met by donations, mostly from Australian ostomy association committee members and partners, and the remainder from other private donations. In fact this amount included all the medication, tests, transportation to and from the hospital, and food for those that needed to be with him during all the tests, operation and recovery. He is only one boy, and there could be many more like him but at least now he has a normal life because others cared about his situation. Thank you to all those that helped making this wonderful story possible.

In the Philippines, most Ostomates do not have access to appliances due to cost or lack of donated appliances. They are instead taught by a nurse to cut a hole in a plastic lid of a coffee jar to suit the stoma, which is then tied around the waste with string or light rope and toilet paper used to pad the space between the lid and the skin. A normal plastic bag is then tied with string or elastic bands to this lid but an air gap is allowed at the top to permit the gasses to escape. While effective to a degree, the result is a working system that will keep all others at least five meters away due to the smell.

As a founding member of the Davao Stoma Association in the Philippines, I have witnessed this method on two Ostomates and I know that it has been employed by many others before they were supplied with donated appliances from Australia. In the USA many people without a good health insurance also struggle to pay for their ostomy appliances. We in Australia should be very thankful for what our Commonwealth Government supplies us, which in most cases is free of charge. Things are very much better here and we are really blessed to live in this beautiful country.

Editor's Note: Bob Hewson was the driving force in setting up the ostomy association in Davao, Philippines and arranging for Australia Fund support. He also put forward the request for assistance for Owen as well as arranging extra funds for Owen's operation.

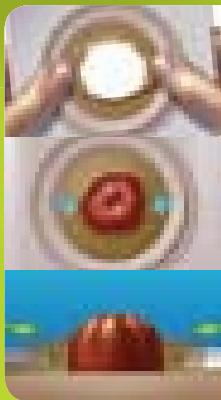
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¹ Scott V, Raasch D, Kennedy G, Heise C. Prospective assessment and classification of stoma related skin disorders. Poster presented at: 41st Annual Wound Ostomy and Continence Nurses Society Conference; June 6-10, 2009; Orlando, Florida.

² Hoeflok J, Guy D, Allen S, St-Cry D. A prospective multicenter evaluation of a moldable stoma skin barrier. *Ostomy Wound Manage*. 2009;55(5):62-69.

* U.S. Patent No. 6,840,924 B2

Oh, the Horror!

THE EVOLUTION OF OUR APPLIANCES

*Reprinted from the March 2007 issue of Ostomy AUSTRALIA.
Originally from the Ostomy Canada Magazine, Spring 2006 - Vol. 14, No. 1
Author: Roger Ivol*

Use your imagination.

Let's go back in time to a period about fifty years ago. Imagine a laboratory with a bespectacled scientist wearing a stained lab coat, surrounded by beakers, test tubes and containers percolating with gooey, smelly substances. There's a distinct sound of something boiling somewhere. He shuffles toward the boiling pot and begins stirring a dark, almost black, concoction with a small metal spatula. His eyes open wide and a broad grin begins to move across his face. At last! He's found what he's been looking for. After years of searching, here it is at last. But does he shout "Eureka!"? No. He shouts "Karaya! Karaya,! Karaya!" A new adhesive. Well, so much for this fantasy. But, how Karaya came to be, is immaterial here. This was the special glue that you may remember as your lifesaver.

Karaya was perhaps the first skin-friendly adhesive to be used in ostomy appliances to keep pouches firmly attached to the abdomen. It was the glue that gave us the freedom to wear a pouch without a belt. Sure, the pouches didn't always behave the way we expected. Sometimes, especially during very hot spells or during strenuous activity, the Karaya seal on the pouch would let go. "Accidents" were to be expected. Those who didn't like these accidents, always wore a belt!

Today's modern appliances have excellent adhesives, and only a few of us need a belt for added security. Although pouches with Karaya are still available, there are literally hundreds of high quality appliances made with space-age materials in Canada alone, never mind the rest of the world. These appliances are waterproof, leak-proof, odour-proof and almost fool-proof. And they

stick! No belt required. Technology has certainly come a long way!

Let's go back even further in time - when rubber was still the best material available - a time when plastics like nylon and vinyl were considered 'new discoveries' and still in their infancy.

In the archives of the Hamilton & District Ostomy Association, there are a number of examples of ostomy equipment from forty to sixty years ago. They're new, but very old! Someone, perhaps one of the long departed members, had collected them from far and wide. The items were discovered in boxes in a dusty corner of the chapter's meeting room. These are treasures, not trash. With the help and friendly advice given by Ostomy Toronto member Dianne Garde, ET, the approximate date, manufacturer and purpose of each appliance was determined. The origin of some are still a mystery.

My wife, Ann, the chapter librarian and archivist, is a lover of anything historical. She has done some research on the items, has labelled each with a yellow tag, and puts these old appliances on display once or twice a year at meetings. They always become items of great interest when displayed at chapter meetings, especially when they are displayed during appliance fairs when the reps of ostomy manufacturers show off their newest appliances. When the reps and visitors see the old appliances, there's often a look of horror on their faces, especially the younger members. Many remark that they're fortunate to have had their surgery after 'modern' appliances were invented. Then there are some who will mention that they remember a relative that had 'one of those things' I recall someone saying, "They look like



Gum Karaya is a vegetable gum produced as an exudate by trees of the genus Sterculia. Chemically, gum karaya is an acid polysaccharide composed of the sugars galactose, rhamnose and galacturonic acid. It is used as a thickener and emulsifier in foods, as a laxative, and as a denture adhesive. It is also used to adulterate Gum Tragacanth due to their similar physical characteristics. As a food additive it has E number E416.

medieval instruments of torture."

Back up a bit. The items in the archives were 'modern' at one time in history. Now they're antiques, but a lot of time and money, research and development went into them. They were the best you could get way back then. The first pouch similar to today's plastic bags only appeared after World War II had ended. And, there was no guarantee that these 'new' plastic pouches would be odour-proof anyway, so, because these plastic bags looked so flimsy, it took a while before Ostomates considered them as alternatives to rubber pouching systems. Plastic would soon be here to stay and become an absolute necessity for Ostomates.

Here are a few of those long-forgotten ostomy appliances. Most of these antiques were very pricey, bulky, heavy and complicated to use. Some were well designed with the Ostomate's well-being in mind. But all the appliances in these photos needed a belt to stay put as Karaya was still in the laboratory!

Let's start with an inexpensive model.

This artifact is probably one of the more 'modern' pouching systems of the time. A colostomy pouch, consisting of four parts - a nylon

'frame', a clear plastic bag fastened to the frame by a 'gum rubber' ring and a fabric belt that kept the whole thing from falling off the patient's

abdomen- was in use from the 1950s to 1960s. The size of the opening is so huge that my fist fits through it! One can only imagine the itching and burning of the skin around the stoma.

This next device, also from the '50s and '60s, is the 'ABC' colostomy appliance made by the Canadian company of J.F.Hartz. It was a six



piece model! The two photos show the separate pieces. First, there is of course, the belt and bag. The main piece is a very large and very rigid oval $5\frac{3}{4} \times 4\frac{1}{4}$ inch nylon flange with a two inch diameter opening in the middle. Then we have a spring wire belt harness twisted to make four loops for attaching a belt. A clear plastic ring with a short spring is used to keep the bag tightly in place (two small screws keep the short spring in place!) Then there's another smaller clear ring (also held on by two small screws) between the flange and the outer ring. I have no idea why this smaller ring was needed anyway. I think one would have had to be a mechanic to have used this very heavy, bulky and

complicated device successfully. As simple as ABC? Not very likely.

This next appliance by United Surgical Company in New York state, available in the '50s and '60s,



was very thin and light-weight by comparison. This was a four piece model, not counting the two metal belt-fastening teeth. The faceplate was made of hard plastic but the whole thing appears to have been more discreet, a lot less bulky, and would probably have been less expensive.

Now we come to a 'deluxe' model - for athletes, I should think.

This four piece system was in some ways similar in appearance to modern day appliances with one



big difference. It actually had a removable stoma protector (or maybe it had to stay on all the time?) The other striking difference is that the pouch had a small elastic band embedded in the plastic where it attached to the flange.

An interesting concept but was the elastic strong enough to withstand the movements of an athlete?

And finally we come to "The Rubber Family". Some of our members who are, shall we say, long in the tooth, will remember these, I'm sure.

These are things nightmares are made of.

We're going back in time. To the '30s. Davol was the big name in ostomy appliances, and gum rubber was king.



This first item is a round pouch - how it attached to the flange and what the flange looked like is a mystery. This was made by Davol and was not drainable.

Another Davol product was perhaps the first one-piece drainable pouch that was in common use. Emptying and cleaning the pouch would probably have been a fussy procedure as the flange portion, which was incorporated in the one-piece design, had nooks and crannies that were difficult to clean.

These pouches were intended to be re-usable. No throw-aways. I would imagine that one would need at least two other pouches on standby each and every day. How did one close the bottom of the pouch? Guess what? No clip or fastener.

You simply had to insert the bottom end of the pouch into two rubber belt loops. I would imagine that leaks were a very common occurrence. And by the way, do you know that rubber absorbs odours? These became very stinky after only a few days wear and had to be washed, soaked, disinfected and deodorized every day. In those days, did anybody even think of allergic reactions to gum rubber? And there weren't even any ETs to talk to. They hadn't been invented either!

Continued page 36

Continued from page 35



Now here's a deluxe colostomy pouch with comfort as its goal. This was a one-piece non-drainable system. A Rolls-Royce if you will, complete with its own spare tire! As you can see from the photo, it has an inflatable 'doughnut' that you can adjust to your comfort level. The only snag was, that if the doughnut deflated, you had to find a gas station or bicycle pump to fix the flat! (Maybe it came with its own mini pump!) Believe it or not, this and other Davol appliances were used even into the 1960s.

I know I've been poking fun at these old appliances. I surely hope that the inventors won't read this article, and if they're still around, that I mean them no harm. It's not the inventor - it's the product. Yet, if I had become an Ostomate in the 1930s or '40s, I would probably have been very happy to have a rubber pouch. Fortunately, when I got my ostomy, plastic had already been invented!

And finally, for those readers who are colostomates and irrigate daily, here is a bit of a history lesson for you.

Dr. Bowman, MB, FRCP, was born in Dundas, Ontario, in 1883. He graduated from the University of Toronto in 1906 and for the next two years trained in pathology at John Hopkins Hospital in Baltimore, Maryland. In 1912, He began his medical career at the Hamilton General Hospital, Hamilton, Ontario. In 1919, after serving

in the Canadian Army Medical Corps during WW I, he returned to Hamilton where he specialised in proctology, internal medicine and diabetes. Dr. Bowman's contribution is that he believed in 'irrigation' for colostomates and designed and developed his own irrigation system called "The Bowman Improved Colostomy Apparatus."

The photos here show the entire kit.



The simple concept was: fill the stainless steel jug with warm water and hang the jug two feet above the toilet. After sitting on the toilet, attach the irrigation cup over your stoma using the belt provided (a rubber catheter allowed the water to enter the stoma), and irrigate until you start to feel cramps. Allow the bowel to empty back into the cup and down the toilet by way of a large diameter rubber hose attached below the cup. The patient is warned to repeat the process until the drainage water becomes clear. The instructions on the box cautioned: "A thorough colostomy irrigation can seldom be done in less than forty minutes."



When the irrigation was complete, an aluminum stoma protector (part of the entire kit but smaller

in size than the irrigation cup) was placed over the stoma and held in place using an attached belt. The neat thing is that the belt could be removed from the cup by unsnapping two dome studs. Once unsnapped, the resulting small holes were "for releasing any gas which may accumulate." The stoma protector was really a colostomy appliance without the pouch. But the cup would certainly have showed beneath clothing.

Can you imagine how airport security would react today if someone went through metal detectors or bomb-sniffing machines wearing one of these relics? Metal and explosives detectors might interpret the metal, rubber, buckles and belts as terrorism! The whole airport would be on high alert. Even the bomb-sniffing dogs would go berserk!

On a serious note, there is no doubt that anyone who has experienced wearing these artifacts also experienced a great deal of turmoil in their lives. They became victims twice - once for the disease that resulted in an ostomy - and secondly, society's lack of understanding and intolerance that caused some Ostomates to hide from view and lose self-respect. This to me is the real horror.

Appliance manufacturers have always been at work developing high quality appliances for the sake of Ostomates. New research is going on every day for better and safer designs. Although the horrors of the past have not yet completely gone, we now live in a 'plastic society' that changes by the second. We also live in an age of Spandex, high fashion and form-fitting clothes and we strive for freedom and good physical health, so ostomy appliances have to be lightweight, discreet, and not one-size-fits-all, unlike those from the past.

I thank my lucky stars that I live in the 21st century!

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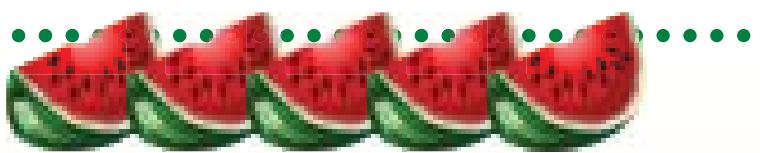
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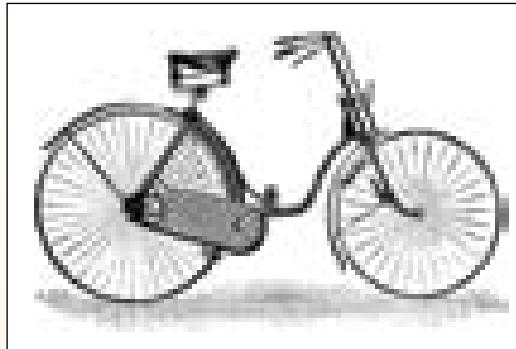
Submitted by **Harry Ashton, NSW**

When I was a child at school our teacher told us that we were living in a recession and that it was usual for such bad times to last about seven years, followed by good times which in turn also lasted about seven years. How wrong he was because at that very time we were going through the Great Depression, which started in about 1929 and continued for ten years, only ending when the Second World War suddenly made people very busy. In our class was a very thin boy who came to school in bare feet during both summer and winter, wearing clothes that he had long since really outgrown. At lunch time he would come among us seeking an orange peel or apple core, or if he was lucky, perhaps some unwanted crusts. To this very day I am ashamed of myself because, like all the other kids, I never gave a thought to offering him half a sandwich.

Tom, a coalminer in England, lost his job due to the depression. Under an "assisted" boat passage, he brought his wife, Maddy, and two sons to try his luck in Australia. By good fortune he managed to find himself a job in a factory but was sacked by the foreman after being there only three weeks because he was about to take a couple of unused boxes home for firewood. Someone later remarked that the foreman wanted the boxes for the same reason as Tom!

He was unable to find another job so could no longer pay the rent. His rather wealthy sister-in-law (who had accompanied them simply for a holiday) bought a block of land in Panania, about fifteen miles from Sydney city. Here she had a builder create a house which was actually just one room but without water or gas, and of course no electricity. Cooking had to be done out in the yard. Tom built a bedroom for the boys against one wall of the house, the roof being made of a couple of flat iron sheets that he found with holes that he filled, while the walls were made of tea-tree scrub.

Unlike some more fortunate men around him, Tom did not have the water "laid on" with which to grow vegetables but he managed to clear an area and tried growing watermelons. Even they needed SOME water so Tom would walk to the horse trough about fifteen minutes away and come back with a branch across his shoulder, carrying a kerosene-tin full of water on each end.



Tom earned a little money by assisting some of the vegetable growers nearby and one Saturday, when it was his wife's birthday, he decided to get a little more money and buy her a frying pan. He took one of his largest watermelons and borrowed a pushbike from the man next door. He then cycled towards Picnic Point where he felt

he would be able to sell that watermelon to some picnickers. When he was nearly there he hit a rut and fell off the bike. The watermelon hit the ground bursting into quite a few pieces.

He picked up the bike and the watermelon pieces, then borrowing a knife from one of the picnickers, cut the melon and sold it slice by slice! One man who had been fishing, came along and generously offered him two fish for one nice slice of watermelon.

Tom sold all of his watermelon and was soon on his way to the little shop in Tower Street in Panania, which was operated by two sisters - one who looked after the shop and the other one who made deliveries by horse and cart. They had everything from mouse-traps to horse food in stock, so Tom was able to get his frying pan.

That night around the cooking fire was the happiest birthday that Tom's wife had enjoyed in a long time. When the good times returned they were able to buy a proper house where the family lived for many years.

If you are ever in Panania, that little shop is still in Tower Street although its doors have been closed for almost fifty years.



Crohn's & Colitis Australia - Update

Adapted from information provided by **Maxine Wade, NSW**

About Crohn's & Colitis Australia

Crohn's & Colitis Australia (CCA) is the national peak body for people living with Crohn's disease and ulcerative colitis. Our mission is simple: **'Support for Today, a Cure for Tomorrow'**.

These two chronic conditions, commonly known as Inflammatory Bowel Disease (IBD), affect over 70,000 Australians and are more common than multiple sclerosis (MS), epilepsy or rheumatoid arthritis.

Generally diagnosed between the ages of fifteen and thirty-five, there is no demographic boundary. Many employers would identify with this age group as possibly the average age of their own employees.

The physical symptoms of IBD can leave a person requiring access to a toilet urgently and without warning. It is a very rare occasion that a person with this illness finds themselves in a dire situation to go to the toilet. However, removing the stress of 'if' it is going to happen, and 'where' am I going to go, allows an immeasurable improved quality of life.

New "Can't Wait" Card

A "Can't Wait" card is now available to members of CCA who have been formally diagnosed with Crohn's or ulcerative colitis. Upon presentation to an approved pharmacy, these cards request access to the closest toilet in times of urgency.

Many pharmacies have been approached and, due to the "no financial commitment", many are willing to support the program and their local community in this most basic of human rights.

All cards are registered with CCA, and the member's name and their CCA ID number is printed on the front of the card. The pharmacy may record this information and contact CCA if there are questions or concerns.

An ongoing awareness campaign, called the 'Can't Wait' Card Program, is being run by CCA with the aim of improving national recognition of the urgency of these conditions.

For more information call **Crohn's & Colitis Australia** on **1800 138 039** and ask for **Lauren**, or visit www.cantwait.net.au



Maxine Wade (arm in sling) and Keri Skeggs - volunteers at the Crohn's & Colitis Australia's stand (Pharmacy Expo, May 2012 - Hordern Pavilion, Sydney)



Stomal Therapy Nurse Scholarship Award 2012



Christine Clausen presents Frances Day with her 2012 Scholarship Award.

Submitted by **Warren Nalty, NSW**

Since 2009, Ostomy NSW Limited (ONL) in conjunction with the Australian Association of Stomal Therapy Nurses (AASTN), NSW Branch has awarded scholarships to assist student nurses with the cost of their study.

The Scholarships have been funded by donations from ONL members; the Sydney Fruit and Vegetable Markets, and for 2011 and 2012 the Narwee Baptist Creative Craft Group.

The Scholarships are awarded to nurses who would otherwise pay all their course fees and expenses. The Scholarships are

aimed at encouraging and enabling more nurses to undertake this course of study. As the number of Ostomates increases more nurses are needed to provide the invaluable service that is essential to Ostomates.

For 2012, ONL received six applications, but five had not yet progressed sufficiently in their studies and will again apply in 2013.

The 2012 Award was made to Frances Louisa Day for an amount sufficient to cover her study costs.

Congratulations Frances and we wish you success in completion of your studies and in your career as an STN.



Christine Clausen receiving a Certificate of Appreciation on behalf of Narwee Creative Craft Group from Heather Hill (ONL) and Jenny Rex (AASTN, NSW Branch).



Robert Newman and Heather Hill from ONL addressing the Narwee Baptist Creative Craft Group.

It was my 29th birthday. I was sick with a chest infection and seven months pregnant with my second son. My boyfriend Kris, took my son, Phoenix, and I for a drive to Lorne to my family fishing spot. It is my favourite place and was what I really wanted to do that day.

We went down to the beach area and walked around. Kris looked at me, put his hand into his pocket and pulled out a jewellery box, but he fumbled and dropped it into the ocean. I was horrified thinking that a piece of beautiful jewellery was gone and couldn't believe he did it. Then he took out another box, opened it and it was empty. Again I was shocked and unsure what was going on. He is a joker so I knew something was going to happen soon. Then he pulled out a ring from his pocket. It was hiding there the entire time. He proposed at the place I loved most, with my son there and my unborn son kicking away from all the emotion I was feeling. Of course I said "Yes" and there it was, we were engaged.

During the wedding planning, my mum Carolyn thought of the idea of us eloping to Las Vegas. Kris and I had never had a first date, let alone time to ourselves because we both already had one child each when we met. We loved the idea. We planned it so our youngest, Chester, was old enough to be looked after by my mum and Phoenix loved going to Nana's. We booked our wedding for 1:00 pm on 31st October 2012 at the Little White Wedding Chapel, which is the chapel where Britney Spears and many other people got married.

With my ileostomy, I was nervous enough wearing a champagne-coloured wedding dress, fearing there might be a malfunction, but my main worry was flying for fourteen hours. I had never been on a plane for so long with a stoma. I was even worried about going through the body-scanners in Los Angeles, wondering if they could see my appliance on the scan! It was all new to me.

On the plane my stoma functioned a lot more than normal. I had organised my seat to be close to the toilet so I was able to get up when I needed without disturbing anyone. I did eat on the plane and was careful not to let my bag get too full before I emptied it, but overall the flights were easy to deal with.

At the airport, I only had to go through the body-

scanners once. I was very nervous about it as I didn't want to be pulled aside. When I went through the scanners, I asked the security lady if she saw anything on the scan, but she said "no" and asked me "why?". I said it was because I had an ileostomy and I was unsure if she could see it on the scan and wondered what they did if they needed to check it. She informed me that they would never ask to see it, just scan your outer clothes for any substance that might be illegal. I was amazed that they knew what I was speaking about and that they did not question me at all. It was reassuring to see that such medical situations were well known to them.

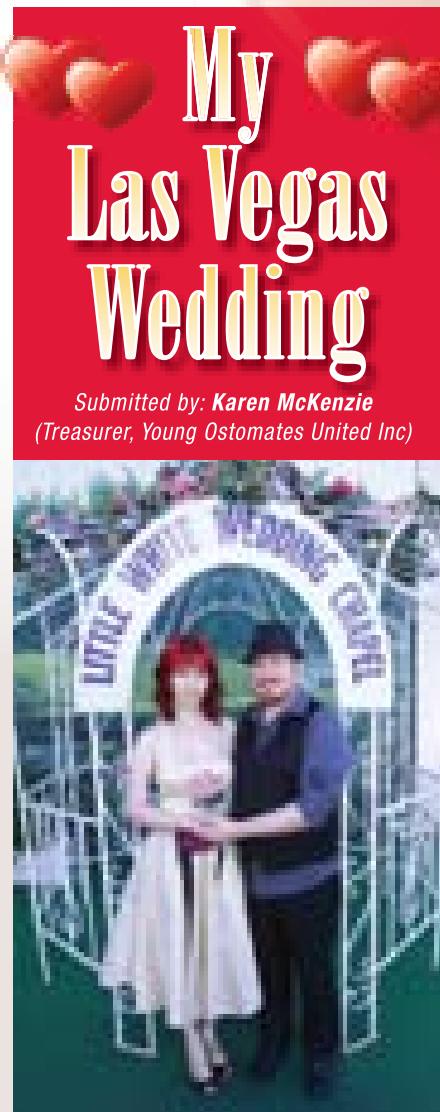
Our wedding was beautiful. We were the only ones there, as everyone else was still back home in Australia. We posted our wedding on the internet via webcam so our family and friends could watch it. Back home, my mum dressed up as any mother of the bride would for her daughter's wedding, and dressed the boys so they could watch and feel like they were with us.

As Kris and I had never had a date or even gone to dinner together as just a couple, our first ever restaurant dinner was the night of our wedding. We were shocked at the fact it took us two years to get

this first date but it was nice that we got it on the night of our special day.

The whole trip took eight days, with two of the days taken up by travel and three days each in Los Angeles and Las Vegas. It was a dream come true to go there and get married to the man of my dreams. We met when I already had a stoma and he has always been supportive of me and my health. I cried when Kris said in his vows "in sickness and in health," as he said it with a tone that let me know how serious he was about it and to know he is always there through it all. It took a long time for me to agree to have a permanent stoma but I can say it definitely saved my life and enabled me to have another child, my now husband and the ability to look after my eldest son.

With the support of my husband and children, I am now the Treasurer of the Young Ostomates United Inc. I love being a part of a group that supports others with a stoma and provides others with the care and information they need to have a healthy and happy life.



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Inflammatory Bowel Disease (IBD)

Submitted by: **Lilian Leonard, YOUNG**

This is a short summary of the talk by our esteemed keynote speaker, **Professor Tony Catto-Smith**, Chief of the Gastroenterology Department at the Royal Children's Hospital in Melbourne, for the Young Ostomates United Inc. Information Day held on 20th October 2012. A donation to the Gutsy Group was sent on his behalf.



Inflammatory Bowel Disease (IBD) encompasses both Ulcerative Colitis and Crohn's Disease. It is important to remember that IBD is treatable but not curable.

In the past these two diseases were treated very separately but it is now clear that they may be related more closely than we had previously thought.

The worldwide incidence of IBD in children has exploded in the last twenty years. Two published studies on Victorian children

ranging over a sixty-year study have shown a fifteen to twenty-fold increase of IBD in children, predominantly since the late 1980's. Similar increases have also been noted overseas and even in developing countries such as China, Thailand and India.

Possible Causes

Environmental: everyone has bugs in their gut and the majority of these are in the large bowel. It is believed that something to do with the bacteria in the bowel is responsible for IBD. One suggestion is that a new bacteria has arisen whilst others believe that the cleanliness of our environment has prevented us "learning" how to deal with normal gut bacteria, resulting in uncontrolled inflammation.

Genetics: every person has a different immune system make-up. A number of genetic mutations have been identified in patients with IBD, and virtually all of these are to do with how the body defends itself against bacteria.

Treatment Goal: is to induce and maintain remission as there is no medical or surgical cure for IBD. We need to weigh up the risks and benefits of therapies, consider quality of life, heal fistula and aim for normal growth and development.

Treatment: is intended to either induce a remission (get you better), or to maintain a remission (keep you better). Most treatments work by calming down the immune system.

Surgery / Medication Options

1. **"A.S.A."** Drugs (Sulfasalazine/Mesalamine) – controlled release.
2. **Steroids:** very effective drugs for inducing a remission but have significant side-effects if continued overly

long. Doses are usually tapered over six to twelve weeks. Most patients (92%) feel much improved (clinical remission) after seven weeks, but only 29% have achieved mucosal (lining of the bowel) remission. Treatment with these medications needs to consider the side-effects and potential for infection.

3. **Immunosuppressants** (Methotrexate / Thiopurines) – these result in fistula healing in about 55% of occasions but also produce mucosal healing. Side effects occur in about 10% of patients.
4. **Infliximab (IFX):** wonderful results have been achieved very rapidly with these new treatment drugs. However, they are very expensive (e.g. approximately \$3,000 for a two-month treatment). IFX was made available at the Royal Children's Hospital in 2004 by the Victorian Government's New Technology Scheme. In 2007, IFX was made available on the PBS for adults and children (down to the age of six-years) with Crohn's disease. The biggest problem faced by patients is the possibility that it stops working, most likely due to antibodies produced by the patient against the medication. Sometimes it may be appropriate to stop the IFX treatment because of an infection, infusion reactions, loss of response and uncertain risks regarding fertility and pregnancy.
5. **Enteral Nutrition:** This is used especially for Crohn's disease and is as effective as steroids but much better at achieving mucosal healing. A ten-week trial of Enteral Nutrition (EN) versus Prednisolone steroid showed a higher clinical remission rate (EN 79%, Steroids 67%) and mucosal healing rate (EN 74%, Steroids 33%). Complete rest of the gut and NO fibre can reduce the symptoms.



IBD Research

1. **Gutsy Group:**
 - A Barwon Study showing a high incidence of IBD
 - Prevention of postoperative recurrence in CD
 - Trial of causes using animals at St Vincent's Hospital
 - New immunosuppressants (Thioguanine).
2. **IBD Research Group at Royal Children's Hospital and the Murdoch Centre for Research Institute:**
 - Microbiological causes of inflammatory bowel disease



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

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

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*Coloplast market research 2010

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A BEND IN THE ROAD (Coping with an Ostomy)

Reprinted from the February 2002 issue of Ostomy AUSTRALIA. By Rochelle Manor-Bullock, Ph.D. licensed Psychologist



**"A bend in the road
is not the end of the
road, if you remember
to take the turn."**

This phrase, and title of Joan Lunden's book of principles for dealing with change, characterises what it takes to adapt to change: a new perspective.

Having an ostomy requires not just a new lifestyle that incorporates changing an appliance or chewing food more carefully. It requires a new perspective of ourselves and the concept of wholeness.

Assumptions about Life

Our culture teaches us that we are entitled to certain things; health, wealth, beauty, fitness, comfort, pleasure and power. Some people learn early that, because of their skin colour, religious heritage, place of birth, or physical deformities or handicaps that they are not as privileged. But for many, we grow up with these assumptions that we are OK and nothing bad will happen to us.

When tragedy strikes for the first time, it brings all the trauma of a world-view shattered.

Suddenly, all that we had grown to trust and assume is challenged. Perhaps I am vulnerable to pain, loss and discrimination. Grief is a multi-stage, multi-dimensional process that brings intense feelings and questions:

Shock: Numbness. Why me?

Denial: It's not me. This is not happening.

Bargaining: I'll try anything.

Anger: If only the doctor was better. Blame family/job.

Depression: I'm damaged goods. Nothing will be OK again.

Acceptance: I'll do the best I can. Self-care.

For people facing an ostomy, most have addressed these questions related to the illness that brought them to the point of surgery. Whether it was Crohn's, colitis, cancer or accident, something challenged the assumption of health and fitness. Living with illness reveals our vulnerability, facing possible death, dealing with loss of ability.

From a medical perspective, it is easy to say that an ostomy will help you to feel better and improve quality of life. For most people this is true. The pain

and inconvenience of the disease will be gone. But while an ostomy can restore health and wellness to the physical body, how we cope psychologically will determine how well we recover from the trauma / illness / surgery / change.

Facing the fears

An ostomy is a mixed blessing. It is a medical miracle that offers restored health and wellness, energy, activities. But it leaves a permanent scar and reminder of damage.

When someone (or a loved one) first faces ostomy surgery, there are medical fears and questions:

"How bad will the pain be?"

"What are the possible complications?"

"How will I learn to use and change the appliance?"

"How do I find a good surgeon?"



Fortunately, these questions can be easily answered by a Stomal Therapy Nurse. It is the emotionally based fears and questions that endure long after leaving the hospital.

Common Emotionally-based Fears

- Fear that others will not accept the ostomy
- Being seen as damaged or defective
- Losing sexuality (not attractive)
- Fear of being "found out" (odour, accident)
- Fear of having to change (clothing style, job, activities)
- Fear of being out of control

It is interesting to note that most of these emotional fears are really about how others will treat us.

The Key is in Your Attitude

"When we can no longer change a situation, we are challenged to change ourselves." Victor Frankel

How people face change and fear is somewhat determined by their personalities. It is extremely difficult, if not impossible, to go from a cantankerous, bitter, grumpy person to one who easily copes with pain and change with a positive spirit. But the more we know about ourselves and the more we are

willing to be open to change, the better our resiliency and coping will be.

"The good news is that the bad news can be turned into good news when you change your attitude."

Robert Schuller

Psychologists have developed numerous theories to describe how our thoughts / emotions / actions are interrelated to one another. A change in any part of the system automatically influences change in other areas. If one focuses on the emotionally based fears listed above, life will be a miserable experience. But, if we can think positively and take care of ourselves positively, the positive emotions of acceptance will come.

We all know that a positive attitude is a good thing. But in times of change and transition, it can be critical. Emotional and physical healing is enhanced when one thinks positively. Research on brain chemicals and cognition levels reveals that positive thoughts release endorphins (like those released during a "runner's high") while negative thoughts release the chemicals seen during major depressive episodes.

Positive thinking alone can't pull someone out of a major depressive episode, but for many, a daily dose of positive thinking can get us through a lot of stress.

"Every adversity, every failure, and every heartbreak carries with it the seed of an equivalent or greater benefit." Napoleon Hill

The trick is finding the seed, the truth of potential benefit in the midst of the pain. Here are some truths to focus on:

1. An ostomy is part of you. Like having brown hair. It is part of your body. Not an illness, not a condition. It is part of your state of being. It may have resulted from illness or disease, but it is now a physical part of you.
2. You have control over what you tell and how. This process will allow you to tell others, as you feel comfortable. You must figure out how to handle people who can't accept you now.
3. No one wants to face "an infirmity" and having an ostomy is a visible, yet hidden one. Your body is no longer intact. If you think of yourself this way, others will, too. But if you see yourself as a whole person, others will see you that way.
4. You can't change others. Whether they accept your ostomy or deny that you have a problem at all, you can't change them. Learning to accept yourself is the key.

"No one can make You Feel Inferior Without Your Consent". Eleanor Roosevelt

Look Through the Eyes of Others

We have the tendency to think all eyes are on us. In reality, people don't notice that much. Surprisingly, we are usually much more tolerant of others than we think they are of us.

A little selfishness is OK. You can't take care of everyone else's emotions. You are the one doing the most adjusting. You must determine what you need, ask for it, and find ways to get your needs met.

Don't Take Blame

Others who might not understand may think you could have done something to prevent your condition. "If you had eaten right, gone to the doctor sooner, taken better care of yourself . . ."

Inspiring Words

Allowing ourselves to face the emotional/psychological aspects of coping with an ostomy is critical to a healthy adjustment. It is more than just a surgical procedure to change the plumbing. Each person experiences a range of fears, concerns, even panic about how this surgery will affect their relationships with others.

Sometimes, other people will not be able to join us in accepting the change. The reality is that some marriages have broken up, relationships become strained, friendships change after an ostomy surgery. But your ability to set a positive tone may help them to cope more positively as well.

Search for strength and inspiration wherever you can. If your friends and family can't provide it, search elsewhere. But find the positive energy that can help you heal.

I hope these words may encourage you.

"Don't give up. Keep going. There is always a chance that you will stumble into something terrific.

I have never heard of anyone stumbling over anything while he was sitting down." Ann Landers

"Nothing can stop a man with the right mental attitude from achieving his goal: nothing on earth can help the man with the wrong mental attitude."

Thomas Jefferson (This goes for women as well).

"You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You must do the things you think you cannot do." Eleanor Roosevelt

"All things are possible when you make them so."

Goethe

References:

- Lunden, Joan & Cagan, Andrea (1998). *A Bend in the Road is Not the End of the Road: 10 Positive Principles for Dealing with Change*. William Morrow & Co. New York. NY.
- Phillips, Robert. (1996). *Coping With an Ostomy*. Avery Publishing. Wayne. NJ.

National Directory of Ostomy Support Groups

NEW SOUTH WALES

BATHURST

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

BROKEN HILL

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

CENTRAL COAST

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

COFFS HARBOUR

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

EUROBODALLA REGION

Meet first Sunday in Feb, April, June, Aug, Oct, Dec. 11am
Venue: Laughter Room, Moruya Hospital.
Phone: Betty (02) 4476 2746

FAR NORTH COAST

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

FAR SOUTH COAST

Bega & Surrounding Areas
Meets second Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11.00am at a different venue each time.
Flyers are sent to Ostomates 10 days beforehand.
Inquiries:
Eileen. Phone: (02) 6492 2530
Geraldine. Phone: (02) 6492 2366

GRAFTON

Meet: first Thursday of each month from 9.00am to 11.30am
Venue: Community Health Centre, 175 Queen Street, Grafton.
Contact: Anne: (02) 6641 8200

GRIFFITH & DISTRICT

Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)

Enquiries: Barry 02 69635267 or 0429 635 267
email: ann.bar@bigpond.com
Karan: 0434 785 309

HASTINGS MACLEAY

Meet: The Old Hospital in Room 4 at 10am to 12noon on Wed.
20th Feb - 17th Apr - 19th Jun - 21st Aug - 16th Oct - 18th Dec
Inquiries: Keith (President) (02) 6583 3970 or Barbara (Secretary) (02) 65824206

ILLAWARRA

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

MANNING/GREAT LAKES

Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Venue: Skills for Life Building, 5-9 Elizabeth Ave. Taree NSW (wheelchair accessible)
Website: www.mglostomy.co.cc
Contact: Karla MacTaggart on (02) 6592 9469

NEWCASTLE DISTRICT

Meet at 1.30pm on last Saturday in Feb - May - Aug (AGM) - Nov.
Venue: Hamilton Wesley Fellowship Hall,
150 Beaumont St. Hamilton.
Enquiries: Geoff 02 4981 1799 or Eleanor (02) 4997 5141 or Maree (02) 4971 4351

ORANGE & DISTRICT

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

PENRITH DISTRICT

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

Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

SHOALHAVEN

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

ST.GEORGE/SOUTH EAST

SYDNEY

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

SYDNEY SOUTH-WEST AREA

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

SYDNEY NORTHERN AREA

Meet: First Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Rd. Wahroonga.
Contact: Nerolie: (02) 9487 9061

WAGGA & DISTRICT

Meetings on first Monday of the month from 10am to 12 noon.
Venue: Horizon Club, Yathong St, Wagga Wagga (located rear of Yathong Lodge, Wagga Wagga Base Hospital)
Enquiries: David (02) 6971 3346 or Baz (02) 6922 4132

VICTORIA

BAIRNSDALE & DISTRICT

Available for people to talk to and for home visits in the local area.
Contacts: Janine: 0418 854 562 Derelle: 0448 458 997 Email: bdosg@hotmail.com

BENALLA / WANGARATTA

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

OSTWEST

Meetings held third Monday of the month in February, May, August and November.

7-9 pm at Melton Health, 195 - 209 Barries Road, Melton VIC 3337

Contacts: Jenny Brown (03) 9746 9121 Tricia Young (03) 9743 5868 or 0416 128 069 Cheryl Prendergast (STN): 9747 7600 (Tuesday and Fridays, every second Wednesday).

MILDURA

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

NORTHERN

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

SOUTH GIPPSLAND

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

SUNRAYSLIA / RIVERLAND

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

WESTERN AUSTRALIA

ALBANY

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

BUNBURY

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

GERALDTON

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

MANDURAH/ROCKINGHAM

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

QUEENSLAND

BEENLEIGH

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

LOGAN

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

BRISBANE

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

GOLD COAST

Supporting Ostomates Needs Group. Meet every 2 months at various venues. Private and Confidential C/- PO Box 703 Labrador, QLD 4215 Phone: 0429 126 163 Email: gcsong@live.com.au

MACKAY

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

REDCLIFFE

Meets first Tuesday each month at 10.00am in the Shillam Room, Redcliffe Cultural Centre - off car park Irene Street, Redcliffe. Enquiries: Dorothy Douglas (07) 5495 1335

ROCKHAMPTON

Meet: 1.30pm third Saturday, Feb - May - Aug - Nov. Venue: Community Health Centre, Bolsover St. Rockhampton Contact: Frank & Marge Noy Phone: (07) 4928 5248

SOUTH BURNETT

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

SUNSHINE COAST

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

WIDE BAY

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

TASMANIA

"Semi Colons" – a support group for men and women impacted by Colorectal cancer. Meets in Hobart on the third Thursday of every month, from 3.00 pm to 4.15 pm. Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on (03) 6233 2072.

SOUTH AUSTRALIA**CENTRAL**

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov. When: 7.45pm. Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End. Information: Val: (08) 8381 1646

SOUTHERN

Meet: First Wednesday of Feb, April, June, Aug, Oct, Dec. When: 2pm. Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs. Information: Val: (08) 8381 1646

YOUTH GROUP

Doris Steyer, Telephone: (02) 4296 5354

YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623 or Karen 0452 513 191 Web: www.youinc.org.au Email: helshaee@hotmail.com

BOWEL GROUP FOR KIDS INC

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

PARENTERAL NUTRITION DOWN UNDER

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

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

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