

Ostomy

A U S T R A L I A

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IN THIS ISSUE:

The Magic Bag PAGE 31

What's in your cupboard PAGE 34

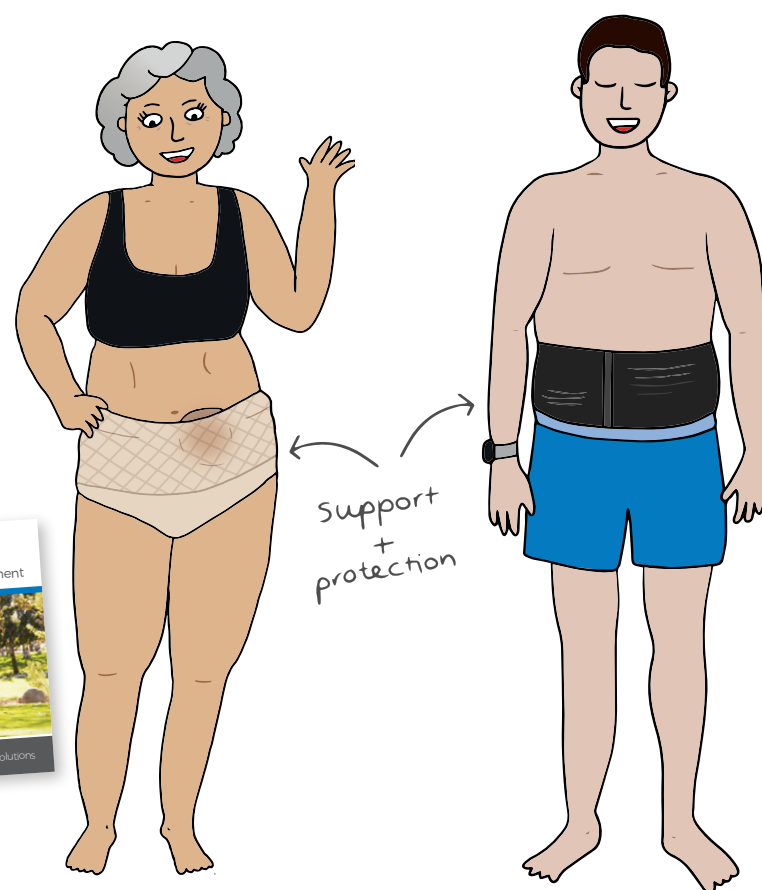
Enjoy some sunshine! PAGE 16

Up to 50% of ostomates may develop a parastomal hernia!¹

Don't lose the battle of the bulge!

Reduce your risk of developing a hernia by wearing a support garment and following the practical advice provided in the Omnigon Support Garments Guide.

Did you know?
A hole in Support Garments is not recommended by clinicians^{2,3}



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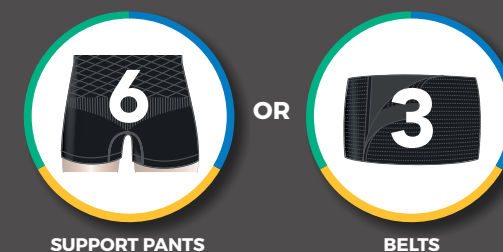
References: ¹Colorectal Disease [®] 2018 The Association of Coloproctology of Great Britain and Ireland. 20 (Suppl. 2), 5-19. ²Thompson JM. A summary on parastomal hernias, February 2009. ³Thompson MJ. Parastomal hernia: incidence, prevention and treatment strategies, British Journal of Nursing, 2008 (STOMA CARE SUPPLEMENT); 17 (2), 16-20

New year, new garments

From 1st January 2021, your support garment allowance starts afresh.

Your allowance is **6 support pants** or **3 belts** or a combination per calendar year

(1 support belt = 2 support pants)



RATING 3. MODERATE

After surgery

Wear during light exercise

Prevent or support a small bulge



Men's Support Pants



Diamond Plus Boxers



Diamond Plus Briefs

2x colours



Diamond Plus Support Waistband

2x colours

RATING 4. INTERMEDIATE

Wear during daily activities (housework, shopping, golfing)

Support a more developed hernia



Support Briefs for Her

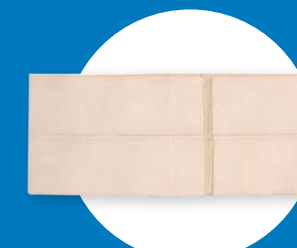


IsoFlex Support Belt

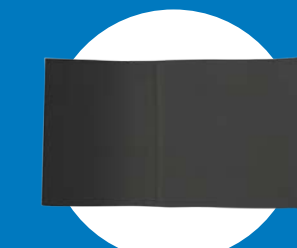
RATING 5. FIRM

Wear during active work or sports

Support a more developed hernia



Total Control Support Belt



KoolKnit Support Belt

2x colours

President's message



lockdowns, COVID safe plans and social distancing has forced associations to change the way they interact with their members. All associations are run by a small group of staff or volunteers or a combination of the two and for any of these people to be incapacitated due to COVID could have dire consequences for the continued supply of ostomy products to members. It has been appreciated that most members have accepted these changes in the knowledge that they have been implemented for the benefit of staff, volunteers and all members of the association.

Moving into the new year your association will be wanting to confirm your personal details, which will now include your Medicare or DVA card and date of birth, are up to date. Since the inception of the Stoma Appliance Scheme the SAS entitlement number you were issued with when registered to the scheme was all the association required to identify the SAS recipient when making a claim. Government has imposed changes to the information associations must provide to support each claim for payment which has now been expanded to include the SAS participants Medicare Card or DVA Entitlement Card, their name and date of birth. If this information is not provided as part of the claim record,

there may be financial penalties on the association through the rejection of the claim.

It has been appreciated that most members have accepted these changes

These changes have also required associations to make changes to their membership, ordering and claims management software. For many associations this will bring them onto ACSA's Stoma Appliance Management System (SAMS). Three associations are already on SAMS and for the last 12 months ACSA had been working on a gradual migration of the remaining associations onto the software. This migration has now changed to a sprint with the Government expecting all associations to provide their claims in the new format beginning in the new year. Whilst an associations existing software does many of the same functions of SAMS, moving to this

Continued page 6

Welcome

By David Munro

This certainly has not been a normal year and will go down as one to remember, although not for the right reasons. The COVID-19 pandemic has had a profound effect on the way we live, work and play and it is likely that life will not return to what it once was for some time. It has been no different for your stoma association. The introduction of

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email: skinhealthsolutionssupport@medline.com

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Do you have

peristomal skin itching?

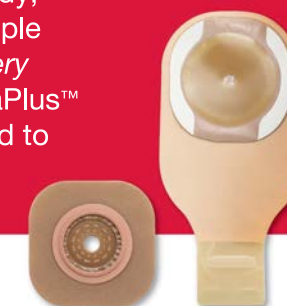
You don't have to tolerate itchy peristomal skin as part of living with a stoma.

Our CeraPlus™ skin barrier with Remois Techonolgy* is infused with ceramide, and helps protect against a possible cause of itching by working with your skin's natural moisture barrier.

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87 percent of people with stomas surveyed reported peristomal itching.¹

In the ADVOCATE study, significantly more people with ostomies were very satisfied with the CeraPlus™ skin barrier with regard to prevention of itching.²



1. Consumer Survey of Pruritus, 2016 Hollister Data on file.
2. As compared to Hollister non-ceramide skin barriers, Colwell J, Pittman J, Raizman R, Salvadale G. A Randomized Controlled Trial Determining Variances in Ostomy Skin Conditions and the Economic Impact (ADVOCATE Trial). J Wound Ostomy Continence Nurse. 2018;45(1):37-42

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*Remois is a technology of Alcare Co., Ltd. Remois



Ostomy Care
Healthy skin. Positive outcomes.

new software will require associations to change some of their processes and procedures. This may have a minor impact on the processing of orders as staff and volunteers become comfortable with the new software so please be mindful of this when placing your order.

Usually the pages of this issue of the journal would include reports from another successful ACSA Conference however due to COVID and the restrictions placed on travel between states association delegates were unable to enjoy the delights of Hobart this year. The Tasmanian Ostomy Association always put on a superb event and it was with some trepidation

that the decision was made to cancel the conference in May because of the uncertainty of what the situation would be in October. Time has proven this to be the right decision. By the time you are reading this we will have recently held our annual general meeting as a video conference. This I am sure will be a new experience for all delegates.

The 2021 stoma associations conference is to be held in beautiful Brisbane and we are hoping that association delegates will once again be able to meet and discuss the matters impacting them and their members.

This is my last president’s message as I am stepping down at the annual

general meeting. The last two years as president of ACSA have been a challenging time for me and the rest of the executive. The Government is showing more interest in the operation of the scheme and the associations than ever before and this has placed considerable pressure on the ACSA Executive. I would like to thank the members of the Executive and the committees of the 21 Stoma Associations for the support you have given me during this time.

Lastly, I would like to wish everyone a very healthy and peaceful Christmas season. May 2021 be so much better than this year.

products and support they need and that many found the Stoma Appliance Scheme Schedule long and difficult to navigate. Considering there is now some 3,830 products listed in the Schedule this is not surprising.

Most respondents were generally satisfied with access to the scheme and products they receive with many noting that if the Scheme was not available, they would not be able to afford the costs of the products. Not surprisingly the impact of out of pocket costs, like annual membership fees and postal charges, were of concern.

The Department is committed to working with ACSA and other Scheme stakeholders to ensure the viability of the scheme into the future. ●

Update on the Department of Health’s review of the Stoma Appliance Scheme

By David Munro

In July the Australian Department of Health released an outcomes summary document for the consultation process they undertook in late 2019. There were over 2000 submissions received to the consultation with 92% of respondents identifying as ostomates. Responses were received from across Australia, with just over 70% of respondents coming from New South Wales and Western Australia. Of the ostomates who responded just over half identified as living in a capital city. Considering the difficulties associations had in telling ostomates about the consultation this is an excellent response.

It was gratifying that most respondents provided positive feedback in relation to their stoma association and the additional support services offered including monthly meetings with other ostomates, Stomal Therapy Nurse (STN) clinics and

assistance over the phone during and after office hours. There was also an acknowledgement of the good work undertaken by volunteers within our stoma associations. Pleasingly it was also expressed by many respondents that they consider it important that associations are run by those with, or with an understanding of, lived experience of having a stoma and how this gave them the added security of personal privacy given the sensitive nature of stoma issues for individuals.

The consultation also highlighted the role STN’s have and that access to STNs and further product education would assist in managing waste and overuse of products. Many ostomates reported that they had not seen an STN since their surgery or that they had concerns their GP was not fully aware of how to care for ostomates.

Most respondents agree that the Stoma Appliance Scheme provides the

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On the cover: The Magic Bag, by Luke Escombe. Read his story on page 31.

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Presidents message, by David Munro	4
Update on the Department of Health’s review of the Stoma Appliance Scheme, by David Munro	6
Your Say, Letters to the editor	8
Congratulations Gerry Barry – 50 years as QSA President, by Kylie McGrory	11
ANZ ConvaTec Scholarships for Stomal Therapy Nurses announced	14
Nutrition for ostomates - Vitamin D – an excuse for ostomates to enjoy some sunshine!, by Margaret Allan	16
‘OH SH*T!!! I HAVE CANCER’, by Sabrina Rojas	20
What clothing should I wear with a stoma? by Nandani, STN QLD	23
Celebrating 60 Years with a Stoma, by Geoff Rhodes	24
My new life, The Gutless Wonder	26
Kylie’s desk, Assisting your Association with new reporting requirements, by Kylie McGrory	27
Hollywood’s First Ostomy, by R. S. Elvey, United Ostomy Associations of America	28
Phobias	29
The Magic Bag, by Luke Escombe	31
Rosanne meets Fred by Rosanne McKenna	33
Stomal Therapy Nurse - What’s in your cupboard? by Monica Stankiewicz	34
Our last soirée by Barbara Pitt	36
National Directory of Ostomy Associations	38
National Directory of Ostomy Support Groups	39
Directory of Stoma Appliance Scheme Product Suppliers	40

Index to Advertisers:

Ainscorp	10, 30
Coloplast	17, 29, 35
ConvaTec	15
Dansac	22, 37
Hollister	5, 19
Medline	4
Omnigon	2, 3, 12, 21, 26
Sutherland Medical	25
3M	9

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Complaints: Consumers who are concerned about the way in which stoma appliances are advertised are entitled to lodge a complaint with the Therapeutic Goods Administration. Such complaints should be addressed to the TGA Complaints Resolution Panel, PO Box 764, North Sydney, NSW 2059.

Your say

Letters to the editor

Dear Editor,

I was diagnosed at 50 years of age with bowel cancer, over the years since, I have had many colonoscopies, I'm sure others that have had cancer of the bowel or follow up surgeries have also had multiple colonoscopies like I have.

Procedures related to the bowel usually require bowel cleansing i.e. a bowel prep beforehand, the utilities that we use from day to day are too small or are often non-drainable, after consuming litres of the bowel prep solution, the quantities expelled are far too great.

My question to my fellow ostomates is how do we manage? How can we make it better? There appears to be no generalised kit available from the supply companies, my association does provide a kit however I think it could be improved.

While I understand we are often different in our requirements, surely our companies, ASCA the AASTN and our associations can come up with a universal kit with directions. Often our doctors refer us for this procedure without the involvement of a stomal nurse.

Even with advice and suitable appliances we are left to carry out the bowel prep alone and in private, having suitable instructions would greatly assist.

Ostomates living in rural and remote areas don't always have access to a stomal nurse. Even in a major city alone this can be a very testing procedure.

I suggest if you have experienced difficulties please speak up, it's the only way we can expect changes.

It's demoralising and stressful if things go wrong. Surely I'm not the only one that's had problems, and I guess many of us are too embarrassed to complain.

I intend to speak up, hoping that it's not just me, I think that things could be a whole lot easier and less stressful.

David Paterson, QLD

Dear Editor,

I read with interest an article by Margaret Allan titled 'The Importance of Zinc' (August 2020 edition). It dealt with nutrition for ostomates and the importance of Zinc in the diet.

As a result of many bouts of chemotherapy etc to cure bowel cancer, my husband's skin was left dry and scaly especially on his arms, with patches of hair turning white. He also suffered from bruising from taking blood thinners.

His surgeon recommended using zinc cream (Sudo Crem) on the affected areas.

The results were amazing. His surgeon had his patients use it on their ulcers and it worked where nothing else did.

Sudo Crem is available on the Stoma Appliance Scheme Code 9821

I thought that this was worth mentioning in the hope that it might help someone.

As always, thanks for a great and informative Journal.

Jan Driscoll, NSW

Dear Editor,

I've just received the August copy of *Ostomy Australia* and really enjoy reading how other ostomates manage and deal with the highs and lows of living with their best friend.

My best friend is named Thor (for obvious reasons!) and celebrated his first birthday here in hospital on 23rd August. It's been a great first year and the best thing that could have happened to address my various problems.

The habit of naming our various add-ons always intrigues me and I would love to hear what other people have come up with to make their friend feel part of the family!

Thank you for a really interesting and informative magazine; I look forward to the next issue in due course.

Carol Bouwens, SA

Dear Editor,

In response to the question posed by Gary about stoma guards (August 2020 edition), it is true that as far as I'm aware there are no producers in Australia.

I did order one from somewhere in outback NSW at one stage, but it was obviously a scam and I lost my money.

I have sourced a reasonably inexpensive design from a delightful Irishman that accommodates all sizes of stoma and types of bag. I have included his website - *Stoma Protector* (<https://www.stomaprotector.com/stoma-protector-design/>). The price is a very reasonable but I believe the prices are either in US dollars or euros. Delivery cost is next to nothing.

I hope this helps Gary!

Dr Lachlan Mairs BVSc PhD, NSW



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Dear Editor,

After reading the letter from lady nearly 80 with leakage problems (April 2020 edition) I think I may have a solution and have sent photos of a contraption my husband fashioned for himself when having similar trouble.

Rae Carrick



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Congratulations Gerry Barry – 50 years as QSA President

By Kylie McGrory



Celebrating
50 years at
the anniversary
(COVID safe
of course)

This year Queensland Stoma Association Ltd reached an incredible milestone, celebrating the 50th anniversary of Gerry Barry as its President and Chairperson.

Gerry was first introduced to ostomy in 1967 when, at age 29, he had surgery to remove his bowel and to have a stoma created as a result of ulcerative colitis. As soon as he was discharged from hospital, he joined Queensland Stoma Association, then known as QT Australia (Queensland Division), which was a very small peer support group of only about 70 members. Because of his background as a qualified accountant and university lecturer he was quickly recruited to the QSA Committee and in 1970, at 32 years of age he was elected as Association President. In the early days, the association was based in a room at the home of its then Secretary, Mrs Veronica Grayson, and there was only a very limited range of about ten appliances and other pharmaceuticals, all of which had to be purchased by members. As legend has it, Gerry had agreed to act only temporarily as President following a request by then President Harold Hayden to take 12 months leave. 50 years later, Gerry is still waiting for Harold to return ... and is yet to find anyone else to fall for the same trick he did!

During Gerry's first 14 years as QSA President, the association's membership numbers increased steadily and so it was agreed in 1984 that the association should move into its own rooms. Under Gerry's guidance and vision, the association purchased its first property: a two storey house situated on Newmarket Road, Windsor on the Brisbane's north side. The house was named 'Grayson House' after the association's first secretary and matriarch, Mrs Grayson. For the rest of the decade and into the next, the association happily operated from the ground floor of the house while the upstairs floor was rented to tenants to provide an additional revenue stream to help support the operations of the association.

Since 1960, QSA had operated successfully as a wholly volunteer organisation. In the early 1990's however as Stoma Appliance Scheme arrangements became increasingly complex, Gerry foresaw that Queensland Stoma Association's future relied upon its ability to attract and retain skilled staff to support its volunteer workforce. So, in 1992 Gerry was instrumental in changing QSA from a 100% volunteer organisation to one using a small number of paid employees

to provide the effective distribution of ostomy appliances under the Stoma Appliance Scheme. The first paid employee of QSA was appointed that year and Gerry developed the present operational concept of allowing the manager and staff to take responsibility for all operational matters, while providing strategic direction and high-level decision making both personally and through the Executive Committee and Board.

In 1998 with membership numbers still increasing consistently, it became very obvious that the association had grown too large to continue to work from the ground floor of Grayson House. So Gerry, with the support of the Committee, commenced searching for a warehouse that would provide additional space and goods handling facilities. The committee eventually settled on Unit 4/10 Valente Close Chermside as an appropriate site because of its size (more than double the Newmarket space), its central location and its proximity to the Prince Charles and Holy Spirit Northside Hospitals. Like Grayson House, the new warehouse was double story and so the ground floor space was custom

Continued page 13



Gerry with wife Yvonne at
Government House after receiving
his Member of the Order of Australia

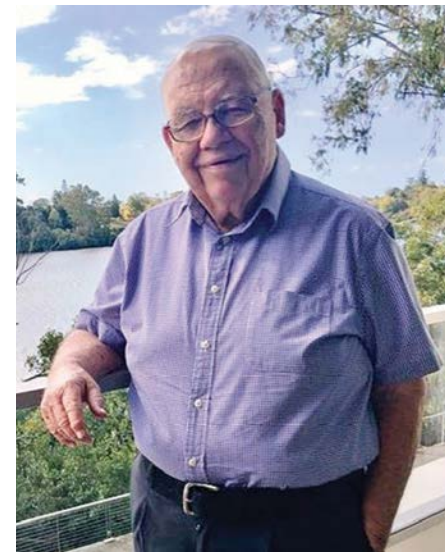
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seal reduces peristomal skin complications. Gastrointestinal Nursing 2018; 16(1):42-49.

Continued from page 11

outfitted for QSA operations and the
mezzanine floor developed so that it
could be rented for additional income
(after quite a bit of arm twisting by
Gerry).

By 2013, QSA membership had
reached 2,400 and was again bursting
at its seams. It was a complete stroke of
luck then that in that same year, Unit
1/10 Valente Close which was in the
same complex and which had nearly
double the capacity of Unit 4 became
available for sale. Despite the relatively
high price tag of Unit 1, Gerry was of
the view that the extra space would be
invaluable for meeting the future needs
of QSA and so recommended that the
QSA committee take advantage of the
opportunity and negotiate to purchase
the property. The committee accepted
Gerry's recommendation and the new
warehouse was purchased and
redeveloped. In August 2014, QSA
moved into Unit 1/10 Valente Close
which remains its home today. Gerry,
following his approach of using property
to provide an additional revenue stream,
convinced the Committee (and a
somewhat unenthusiastic manager) to
retain Unit 4 as a rental proposition.
Although it did take 12 months to find a
tenant for the ground floor space, Gerry
backed his judgment and this space is
now leased to a long term tenant who,
with the original tenant from the Unit 4
mezzanine, is providing a substantial
ongoing income source for QSA outside
of its Scheme activities.

In 2019, 44 years after the Stoma
Appliance Scheme product distribution
through the Australian Stoma

Associations commenced, it was
obvious that the distribution framework
was under scrutiny by the Department
of Health. Gerry recognised the threat to
QSA and agreed that it was time for the
association to reconsider its legal
structure and to adopt one which would
provide an enhanced level of assurance
to government that the associations
governance and capability was
consistent with what could reasonably
be expected from an organisation
dealing with taxpayer funds. Together,
Gerry and QSA Manager, Kylie
McGrory, worked to convert the legal
structure of the association from an
Incorporated Association to a Company
Limited by Guarantee, giving it access
to a wider range of government and
commercial benefits. The change in
structure also provided the impetus for
the decision to register QSA as an NDIS
provider and in 2020, QSA became the
first Australian Stoma Association to be
NDIS registered. Also in 2020, at the
height of the COVID-19 pandemic,
Gerry single handedly lobbied the
Queensland Government for financial
support to assist the QLD Stoma
Associations with the additional costs of
operating during a pandemic and
successfully secured a grant which was
shared with all six Queensland ostomy
associations.

Gerry was also involved in ostomy
activities at the national and international
level. He was ACSA President from
1997 to 2010 and from 1994 to 2004 he
represented Australia at the International
Ostomy Association and was a member
of the IOA World Executive.

While Gerry is the first to admit that it
has not always been smooth sailing
during his 50 year tenure with QSA, it is
clear that he has always had the vision
and the determination to make a
difference to the wellbeing and quality of
life of ostomates, not just in
Queensland, but also throughout
Australia and internationally. This vision
and determination was officially
recognised when Gerry was invested as
a Member of the Order of Australia (AM)
for his work with ostomy associations in
Queensland and nationally at a
ceremony at Government House on
3 September 2008.

Gerry's success with QSA over the
years can best be seen from the way he

provided leadership for the association
as it navigated its way from having just
70 members operating out of a small
room in 1970 to the great association it
has become in 2020 with over 4,000
members and its own spacious
premises and property investments. He
acknowledges that he has been able to
continue with his role as QSA President
and Board Chairman for so many years
because of the assistance and support
of dedicated and competent committee
members over the years, and through
the support of an outstanding team of
staff and volunteers. Most importantly,
Gerry's achievements at QSA could not
have been possible without the support
and understanding of his very patient
wife Yvonne and his four children Mark,
Paul, Kevin and Cathy who have stood
with him and encouraged his efforts
over the past five decades.

The members of Queensland Stoma
Association Ltd as direct recipients of
Gerry's efforts and commitment over
the past 50 years are very fortunate to
have had and to continue to have such
an incredible man at their helm. ●



Gerry receiving the
painting as a gift
after 25 years as
president in 1995

ANZ ConvaTec Scholarships for Stomal Therapy Nurses announced

ConvaTec ANZ is delighted to announce that three nurses have been awarded scholarships to take the Graduate Certificate in Stomal Therapy Nursing, which commenced in July 2020.

As part of a collaboration between The Australian College of Nursing (ACN), the Australian Association of Stomal Therapy Nurses (AASTN) and The New Zealand Nurses Organisation (NZNO), the scholarships, provided by ConvaTec, will help support the nurses to progress their careers in what is a dynamic and very demanding area.

This year's recipients, chosen by the nursing organisations' committee, are Vivian Nguyen who works within NSW Health; Linda (Ching Yi) Chen from The Wesley Hospital, Qld; and Rochelle Pryce from Capital and Coast District Health Board, NZ.



Linda Chen

Therapy and Wound Management. Inspired by her colleagues, she's enthusiastic about progressing her career in Stomal Therapy Nursing.

In New Zealand, Stomal Therapy Nurse, Rochelle Pryce, values her ability to deliver and co-ordinate evidence-based care for her patients, whilst staying abreast of new innovations that continue to shape the future of ostomy patient care.

Each of the nurses has a clinical background and the completion of the *Graduate Certificate in Stomal Therapy Nursing* will provide them with the skills and expertise necessary to deliver and

the scholarships, provided by ConvaTec, will help support the nurses to progress their careers in what is a dynamic and very demanding area.



Vivian Nguyen

Vivian Nguyen is a Wound and Stoma Clinical Nurse Specialist who's passionate about her work within the NSW public health system supporting highly vulnerable patients with complex care needs, throughout the state.

Linda Chen has been nursing for more than ten years and recently became a Clinical Nurse in Stomal

coordinate evidence-based care in the highly specialised area of stomal therapy nursing.

'This is a very challenging area and ConvaTec is delighted by the collaboration between the nursing organisations to provide Vivian, Linda and Rochelle with the opportunity to progress their careers in Stomal Therapy nursing', explained Karen O'Connor, General Manager of ConvaTec Australia and New Zealand.

'The calibre of applicants was very high and we'd like to thank everyone who applied. It was a hard decision for the independent selection committee to make but we are sure that the three recipients will really value and embrace the knowledge and leadership skills that



Rochelle Pryce

this course brings'.

'The scholarships are part of ConvaTec's commitment to improving stomal therapy care - valued at just over \$12,000 each, they bring an enormous saving to nurses' keen to advance their career.

'By supporting this specialist education and pioneering trusted medical solutions, ConvaTec seeks to help those with stomas to live the life they want', she concluded. ●



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Vitamin D - an excuse for ostomates to enjoy some sunshine!

By Margaret Allan

Margaret advises both ostomates and the public on diet and health-related matters. She is the director of the consultancy Nutrition For Ostomates. To contact her or read more nutrition articles supporting the health of ostomates, go to www.nutritionforostomates.com.au

There has been a lot of focus on vitamin D in recent years, and with good reason. It is a vitamin that provides many health benefits to humans, yet it is estimated that more than 30% of Australian adults have inadequate vitamin D status.

Part of the reason for this is that the number of foods naturally containing significant amounts of vitamin D is limited. It is primarily found in animal foods, such as fatty fish (salmon, herring, mackerel, sardines), eggs, butter, cheese, liver, meat and milk. However, these foods only provide small amounts. Most adults are likely to obtain only 5-10% of their vitamin D requirements from food, and a vegan diet cannot meet vitamin D needs.

The good news is that humans are not totally reliant on food sources to obtain vitamin D, as we have the capacity to synthesise the nutrient ourselves. This is very beneficial for ostomates. The absorption of adequate amounts of nutrients is an issue for many ostomates, and so a nutrient that is not dependent on food sources or intestinal absorption to maintain adequate status is positive.

The other reason for inadequate vitamin D status in Australia is the successful public health campaigns recommending that Australians avoid too much sun exposure to reduce their skin cancer risk. The synthesis of vitamin D depends on ultraviolet rays

from the sun shining on a cholesterol precursor in the skin. This creates a pre-vitamin molecule, which works its way slowly into the body. The pre-vitamin molecule must then become activated, which occurs through the action of the liver and kidneys.

Skin exposure to sunlight accounts for more than 80% of the vitamin D in the body, but the skin exposure must occur when the sun is directly overhead. Short periods of sun exposure are more effective at raising vitamin D levels than long periods. It should also be noted that a Sun Protection Factor (SPF) of 8 or higher reduces vitamin D synthesis significantly. Vitamin D stores from summer synthesis alone are not generally sufficient to meet winter needs, and many people become vitamin D deficient during the winter months. Interestingly, the sun imposes no risk of vitamin D toxicity, as prolonged exposure to sunlight degrades the cholesterol precursor in the skin, preventing its conversion to the active vitamin.



Nutrition for Ostomates



Vitamin D has many valuable functions in the body, and its effects are widespread. Vitamin D receptors have been found in cardiac tissue, muscle tissue, the pancreas, the brain, the skin and throughout the immune system. The nervous system and reproductive organs are also target tissues of vitamin D.

The primary function of vitamin D is to raise blood concentrations of important bone minerals such as calcium and phosphorous. However, vitamin D has also been shown to

Continued page 18

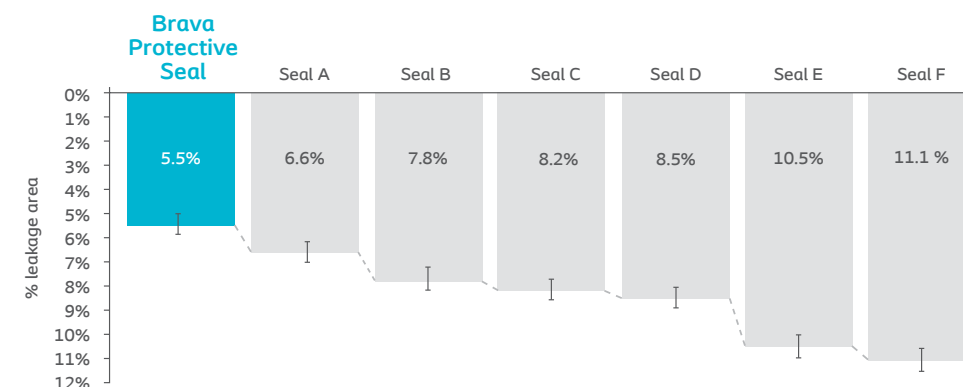
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maintain muscle strength, having a particularly positive effect on skeletal muscle, and to enhance the immune system's response to both bacterial and viral agents.

Some people are at greater risk of developing a vitamin D deficiency than others.

People with malabsorption issues are at risk of deficiency, which can be the case for many ileostomates. Vitamin D is a fat-soluble vitamin and therefore requires a fat-functioning digestive system to be absorbed from food. This includes adequate production of bile from the liver and digestive enzymes from the pancreas. Any diseases or issues that affect the ability of these organs to perform their functions will affect absorption of vitamin D from food, including those with chronic kidney failure.

The elderly, sick, debilitated and disabled with lack of access to sunshine are especially vulnerable, as well as those who are in good health but spend little time outdoors. Elderly people in particular do not always habitually consume foods containing vitamin D, such as fatty fish and milk, and tend to have inadequate exposure to direct sunlight to synthesise the vitamin. With advancing age they are also less efficient at synthesising vitamin D when they are exposed to the sun because their skin, liver and kidneys lose their capacity to make and activate the vitamin. A Tasmanian study revealed that 85% of people aged 60 years were vitamin D deficient.

Another group of people at risk of vitamin D deficiency are those with dark skin, as the pigments in dark skin reduce vitamin D synthesis. It can take up to six times longer for a person with dark skin to produce the same amount of vitamin D as a person with lighter skin.

Another factor that can lead to deficiency of the vitamin is obesity, as the vitamin becomes trapped in the fat cells and is therefore not available to the body.

Infants who are breast fed by vitamin D-deficient mothers are also at risk of deficiency themselves.

Deficiency symptoms for vitamin D include muscle aches and weakness, pain in the lower back, pelvis and legs, and disorders of calcium metabolism such as osteoporosis and osteoarthritis.

Observational studies have also indicated a correlation between low vitamin D status and: neurological issues such as schizophrenia; mental health conditions such as depression; respiratory illnesses such as asthma; diseases of the cardiovascular system

(for example high blood pressure and stroke); infectious diseases such as urinary tract infections.

Vitamin D also reduces expression of autoimmune conditions such as Multiple Sclerosis, Crohn's disease, Rheumatoid Arthritis, and Type 1 Diabetes, and demonstrates an inverse relationship with cancers of the breast, prostate, colon and skin. Therefore, a higher vitamin D status is thought to reduce

the incidence and severity of these illnesses.

It's important for ostomates to ensure that their vitamin D status is adequate to be supportive of good general health, especially if the reason for becoming an ostomate is cancer or Crohn's disease. In the case of a urostomy, poor immunity and repeated urinary tract infections can be an issue, and this may be reflective of low vitamin D levels.

Adequate sun exposure is a critical step in the synthesis of vitamin D. The Cancer Council has developed guidelines on how much sun exposure is appropriate in different regions of Australia. The trick is to get enough sun exposure at the right time of day to synthesise sufficient vitamin D, but not enough to increase the risk of skin cancer.

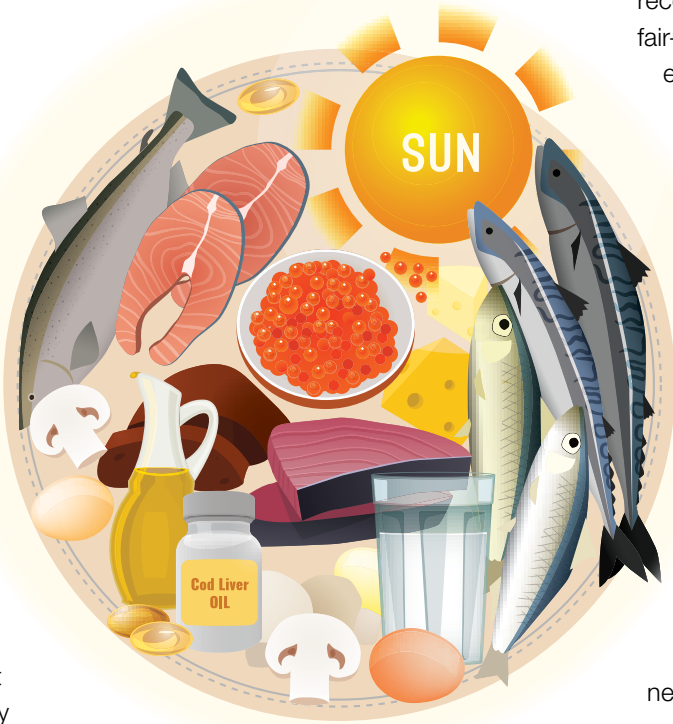
Generally, in Australia, the recommendation is for moderately fair-skinned people to walk with arms exposed for 6–7 minutes mid-morning or mid-afternoon in summer, and with as much bare skin exposed as feasible for 7–40 minutes (depending on latitude) at noon in winter, on most days. This is considered likely to be helpful in maintaining adequate vitamin D levels in the body.

However, if vitamin D status is compromised by any of the issues discussed above, then supplementation may be required, and during winter it may be essential. Care needs to be taken in choosing a supplement to ensure its appropriate and able to be fully absorbed by your intestinal tract after stomal surgery. If you need assistance in this regard, please contact me to schedule a consultation.

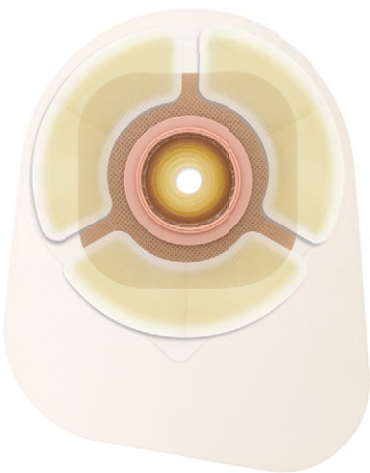
In these warmer months enjoy the summer sun to synthesise some valuable vitamin D. Just do so safely and appropriately. Moderation is the key!

Wishing you good health and happy days,

Margaret •



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'OH SH*T!!! I HAVE CANCER'

By Sabrina Rojas

Before I was diagnosed with bowel cancer in November 2019, I had always had issues with my bowels. Some of my earliest memories are of my mum taking me to a paediatrician to help with my severe constipation. I can remember being forced to eat very grainy, fibrous gunk that almost always made me throw up.

Throughout my teen years, I had bouts of severe cramping but when the pain passed, I was fine. It wasn't until I was 19 that I was diagnosed with Crohn's disease.

Crohn's is one of those diseases that has no cure and management by way of drugs, lifestyle and surgery (a subtotal colectomy at the age of 22) is what I've endured, like many others, every day since.

Before my surgery, my gastroenterologist explained that due to scarring from my surgery, I should try and have children as soon as possible as I might not get that chance when I was older.

I was already married, I had married the year before at the age of 21 and as soon as I recovered from surgery, we tried to fall pregnant. I was fortunate to be blessed with two beautiful children, my son Jordan and daughter Chelsea.

They are my angels.

Unfortunately, my marriage ended tumultuously in 2011, but I was lucky in love in my late 30's and I married my amazing husband John. We live in the beautiful Hunter Valley in New South Wales, Australia.

In November 2019, I was diagnosed with bowel cancer and my entire world imploded in a split second. I could not believe that at the age of 44 I faced the very grim and too real possibility of dying.



In the months following my diagnosis I endured an unimaginable amount of pain, despair, grief and anguish all leading up to the life changing surgery that would completely remove my colon, rectum and anus; and hopefully all the cancer cells. This was booked in for 13 January 2020, and so I had about five weeks to absorb my new reality and overcome the fear of being forced to live out the rest of my days with a permanent ileostomy. I was terrified of having a stoma bag attached to my stomach.

I recovered from the surgery well and decided to name my stoma Stella. I was handling Stella with a positive attitude, some laughter and a truly gracious mindset for still being alive.

In early February I was rushed to emergency room in the wee hours of the morning with a severe bowel obstruction. I needed a second surgery and it was touch and go. It was much too soon from my last surgery.

I am lucky to be alive today. I decided that if I survived this ordeal, I would write a book and share my experiences to help as many others as possible. By opening myself up and showing this vulnerable part of my life on my social media platforms and blog, I discovered a world full of other ostomates, cancer survivors and IBD warriors that were all ready to support me on my journey as well.

I truly am blessed.

About my book

My book "OH SH*T!!!...I HAVE CANCER" takes you through my life journey and my message will hopefully inspire you. I share the good, the bad and the ugly with tears, cheekiness and laughter with powerful life lessons and messages throughout.

I do not hold back with explicit details about living life with a stoma bag. I demonstrate how to have body confidence for women and men living with a stoma bag and I am proud to normalise



the stigma often associated with having a stoma bag.

My book will show you how I mastered the power of gratitude and the power of clarity, igniting the warrior within to be able to conquer ANYTHING life throws at you, resulting in living a life that you are in love with every day.

This is a snippet of some feedback I received about my book and it brought tears of joy to my eyes:

'What is striking about Sabrina's life story is her essence, courage, resilience, determination, gratitude for life and passion to be able to influence and make a difference in people's lives. Sabrina is a true inspiration and through her sassiness, spirit and warrior like bravery she reminds us all that we too have a warrior within us. We can achieve anything we want in life as long as we have the right mindset.'

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www.222mindset.com.au/my-book

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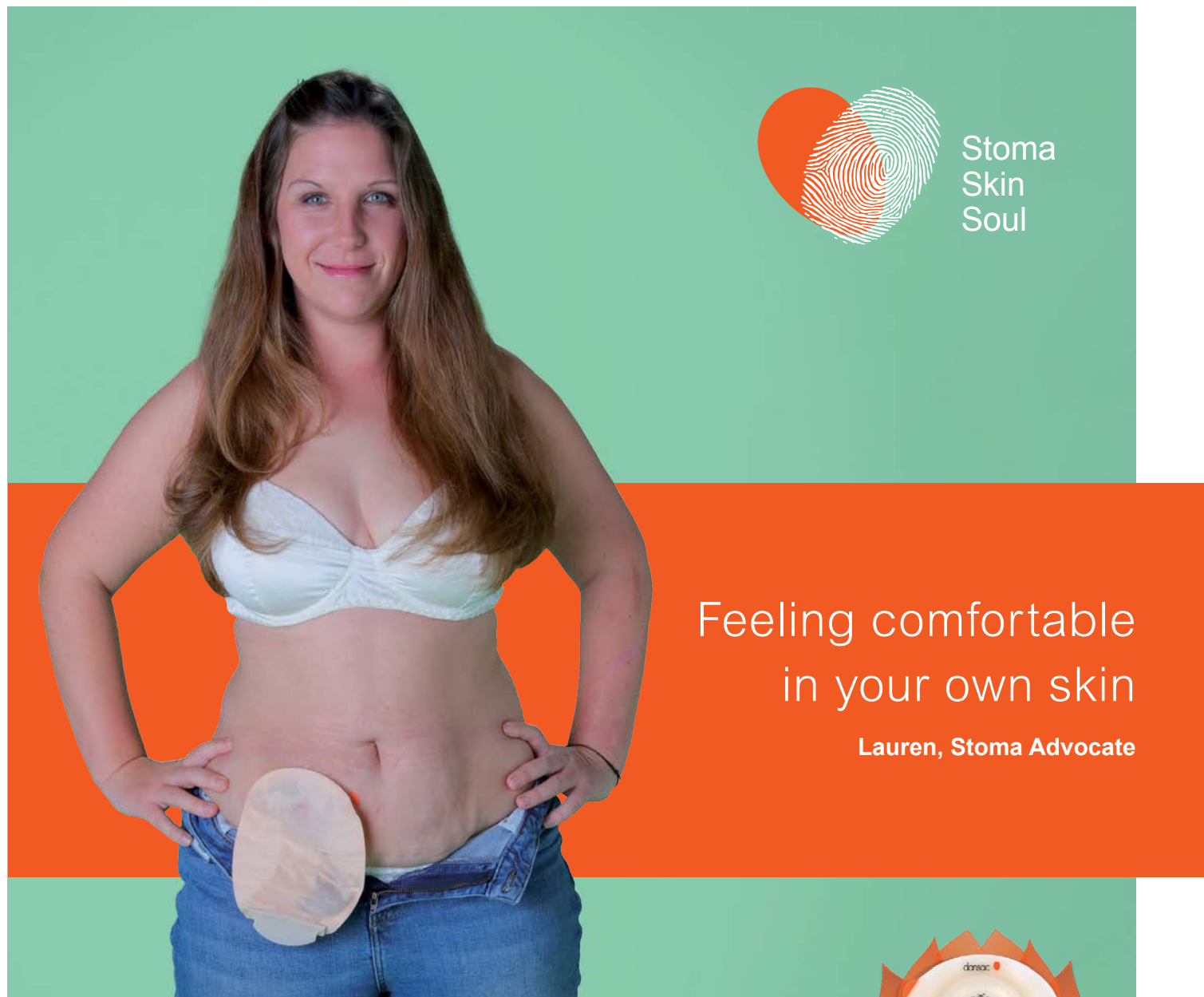
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What clothing should I wear with a stoma?

By Nandani, STN QLD



Having a stoma should not stop you from wearing your usual clothing. Initially you may feel more comfortable in loose fitting clothing due to the swelling in your abdomen after your surgery. It is normal to feel anxious and many ostomates often feel self-conscious thinking others will see their pouch. The following tips may be useful in helping you become more comfortable in everyday clothes and reduce the outline of your pouch under clothing.

CLOTHING CHOICES

- clothing can be fitted but not too tight as this will restrict the flow of the output and could cause leakage
- pants, trousers, skirts or underwear should either sit below the pouch or completely over the pouch. High waisted pants, jeans or skirts are great. Ladies may find full briefs more comfortable, and men often feel the boxer style underwear gives more freedom for the pouch
- try not to have clothing pressing on the pouch as it will reduce the amount the pouch can hold and could cause a leak more easily
- use of a belly band, tube top, bandeau or a maternity type band over the pouch can help to provide some support and reduce the outline of the pouch under clothing
- a singlet under clothing can also help to conceal, keeping things flatter against the abdomen
- use of patterns, pleats, layers, ruched or bunched up clothing can help to distract the eye from the pouch under your clothing
- layering your clothing can also help distract attention from the abdomen, and allow for looser fitting garments as the top layer
- ladies may find flowing dressings are often very comfortable, especially in the warmer summer months. Fabrics that do not make you sweaty are also more comfortable in warmer weather

- men may prefer shirts that sit out over their pants or shorts. A patterned business shirt may be more distracting than a solid colour, and darker colours often more camouflaging
- there are some companies who specialise in clothing for people with a stoma. Some even have an internal pocket to allow the pouch to sit comfortably without restriction.

INTIMATE APPAREL OR LINGERIE

- Use of a lacy or skin coloured bandeau or band can be used over the pouch
- There are companies who specialise in lingerie or undergarments for men and women who have a stoma. Here are a couple of websites that may help with choices: www.knightwear.com.au and www.ostomateactive.com.au but an internet search will deliver you a lot more options.

SWIMWEAR

Wear what you will feel comfortable in. Patterned materials are often more camouflaging and ruching or draped fabrics also provide more freedom across the abdomen.

- For women, a one piece or high waisted bikini may be an option
- For men, a rashie or swim shirt with board shorts may be a good option

There are also various pouch covers available online.

BELTS

- Avoid the belt buckle sitting directly near the stoma. It may cause damage to the stoma. Position the buckle slightly off centre away from the location of the stoma
 - Suspenders or braces could also be an option.
- And, always remember that you can still enjoy life to the full with a stoma.

Source: <https://omnigonconnect.com.au/advice/what-clothing-should-i-wear-with-a-stoma/>

60

Celebrating 60 Years with a Stoma By Geoff Rhodes

Readers might wonder at the title of this article. What could there be to celebrate about living with a stoma for 60 years. Well, in my case, everything.

About 10 years ago I wrote a piece for the journal entitled 'A Lucky Life'. Now 10 years on I'd like to expand on that article and my philosophy of 'I like birthdays because they sure beat the alternative'.

I was nine years old when my specialist informed my parents and me that an ileostomy was the only course of treatment left for my rapidly deteriorating ulcerative colitis. Surgery was performed on 2 December 1959 (my mother's birthday) and I spent Christmas 1959 in RPA hospital recovering. Surgery was successful and dad and I went about exploring the wonderful world of the primitive appliances then available. We quickly worked out that my skin was allergic to the rubber appliances predominant at the time. We however discovered through the local stoma association (now ONL) that one of the members made flanges (base plates) from a plastic material and using these in combination with Skin Bond Cement, a belt and plastic bags held in place with a rubber ring, we had a workable appliance.

I returned to my local primary school in 1960 and enjoyed being able to do a whole lot of things including Cubs and soccer that had previously been impossible. The nickname 'stinky' was not endearing but at least I could actively play with the kids who thought up that moniker.

I changed schools in 1961. This provided the opportunity to meet new kids and experience new things including school camps. Dad came along to help the teacher manage the class and me to manage my stoma.

I did OK at high school and ended up being accepted into the medical faculty at Sydney university. After three years the faculty and I reached a mutual decision that my future career lay elsewhere. However, the next chapter of my life was starting as Carol and I discovered our first child was on the way. I took on a series of jobs to pay the bills and in July 1972 our elder son was born.

This gave me incentive to seek a more stable career and in July 1973 I joined the Commonwealth Public Service. The medical for permanent employment proved challenging but I was accepted into the Provident Fund but not the full Superannuation Scheme. I worked in the Public Service Board's Sydney Office in areas ranging from recruitment to organisation and methods and picked up a diploma in Organisational Psychology along the way. In 1979 I asked to work in the area of the Board managing the new personnel

computer system and spent an interesting year coming to grips with this new-fangled technology.

In 1980 I was looking for a different challenge as my opportunities in the Board in Sydney were limited and we had just had our daughter in July 1979 and were building our first house on the northern outskirts of Sydney. In 1980 I took a transfer to Department of Defence in an internal consulting area as they were looking for someone with IT experience. This was the start of a very exciting and challenging five years. My area was tasked by the Royal Australian Air Force (RAAF) to investigate how computers could modernise their operational command and control. I was the junior member of our team working in conjunction with RAAF officers based at Operational Command in Glenbrook.

This project took me around Australia, usually in the back of a Hercules transport aircraft gathering information on how the various element of the RAAF operated. Whilst I was engaged on this the senior member of the team was promoted to Canberra and I took his place. Also, around this time the Royal Australian Navy became aware of the project and asked us to do a similar project for them. This saw me and my Navy teammate hitch a ride on a Hercules aircraft to Hawaii to look at US Navy systems. Two days in the back of a Hercules with an overnight at Kwajalein in the Marshall Islands proved a challenging exercise in stoma management but all worked out well.

In 1983 the Falkland War had concluded and the Royal Air Force in the UK had developed a system that contributed significantly to the British victory. Our RAAF team applied to go to the UK on a fact-finding mission. The RAAF would not authorise the cost of civil transport so my RAAF colleague arranged for us to hitch a ride on another Hercules going to UK via the USA which would allow us to spend four days with the RA. The return journey took 21 days but was an incredible experience.

By the middle of 1985 I had completed the work for RAAF and the Navy and was looking for opportunities outside the public service. I took a role with a Defence company in July 1985 but the position was in Canberra so the family moved to Cooma where we had friends and relatives. I began a two-and-a-half-year commute from Cooma to Canberra but the average travel time each way was less than my commute time in Sydney.

Continued page 26

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April 1986 saw the birth of our younger son and in December 1988 we moved to Canberra so our elder son could complete his final two years of high school. We have been in the same house in Canberra since December 1988. I held a series of sales, project management and consulting positions in Defence industry that included numerous overseas trips, retiring in December 2013.

I continue to enjoy good health and play social competition tennis two evenings a week and play golf every Saturday with four close mates. I remain involved with the ACT and District Stoma Association and volunteer on a regular basis.

We have three granddaughters through our elder son, one granddaughter and a newly arrived grandson through our daughter and one grandson through our younger son with another one on the way.

Having a stoma has not always been plain sailing with a couple of surgeries along the way and septicaemia after one surgery that almost took me out. So why am I celebrating 60 years with a stoma?

Without my stoma none of those 60 fantastic and rewarding years would have occurred and I would not have had the joy and happiness that a loving wife, three beautiful children and six, soon to be seven, adorable grandchildren bring. That is a true cause for celebration. ●

MY NEW LIFE

By The Gutless Wonder

Who would have thought that I could survive
After my entire colon was removed?
So many years later I'm not only alive
But the quality of my life has even improved!

In the early days it was not much fun
Learning to manage a stoma.
I was terribly ill when he was born
And almost existing in a coma.

Many of us experience embarrassing leaks,
My little friend was no exception.

He even made strange noises like squeaks
Hoping to attract my attention.

But after a while it no longer feels strange
To apply each morning's new pouch,
When the time comes for removal though
I might occasionally mutter an 'ouch!'

We eventually find that our little friend
Is really just an extension of us,
So with our constant companion we get on with our lives
Quite happily, and without all that previous fuss.

Assisting your Association with new reporting requirements

By Kylie McGrory, ACSA Administration Officer

Since 2010, the Stoma Appliance Scheme has been an area for ongoing review by the Department of Health as owners of the Scheme, and by Services Australia who have responsibility for paying claims made through the Scheme by the Australian Stoma Associations.

First there was the implementation of a stoma product pricing framework during the 2010/2011 and 2011/2012 financial years, quickly followed by the cessation of the regular pricing indexation in 2012. In 2013 we had the price premium review which further impacted the price of some products listed on the SAS schedule, and then in 2015 the Government announced that it would be 'piloting competitive tendering for a subset of products in the Stoma Appliance Scheme', a process that was later abandoned in 2017 after intense and ultimately successful lobbying by ACSA, associations, Stomal Therapy Nurses and ostomy product suppliers. In 2016, the Stoma Products Assessment Panel recommended a change to the monthly allowances and reimbursement prices of barrier wipe and remover wipe products which, after acceptance of the recommendation by Cabinet, resulted in some ostomy product suppliers choosing to remove their barrier wipe products from the SAS schedule as it was no longer financially viable for them to remain on it. In 2019, all Australian Stoma Associations were required to carry out a self-audit of their SAS operations and to verify their compliance with the requirements of the Stoma Appliance Operational Guidelines, and in 2020 the Stoma Appliance Scheme Operational guidelines themselves have been under review by the Department of Health. These changes have all impacted in some way on the Australian Stoma

Associations and the members that we support.

Probably the most significant change to Scheme arrangements from an association point of view however is the announcement earlier this year that there will soon be a change in the amount of information that associations will be required to capture and report to Services Australia to support each claim for payment submitted to the Scheme. Whereas our current claim format is limited to the SAS participants SAS entitlement number, product SAS code and issue quantity, from January 2021 the claim format will be expanded to include the SAS participants Medicare card number, full name and date of birth, and other information such as whether a claim includes additional products authorised by an Application for Additional Stoma Supplies (PB050), the details of the authorising practitioner (including their AHPRA registration number) and if the claim represents an approved holiday, remote or Norfolk Island supply. Services Australia have confirmed that the stoma associations will be allowed a transition period to update member information but that claims submitted after the transition period which do not include the required information may be rejected. The existing Services Australia SAS forms – the Stoma Appliance Scheme Application (PB049) and the Application for Additional Stoma Supplies (PB050) – will also be updated to ensure that the required information can be collected.

What does this mean for you as a SAS participant and how can you help your association to continue to process and be paid for your requests for SAS funded products? First, it is critical that your association holds current and correct details for you, particularly your current Medicare card details including

Kylie's desk



your cards expiry date. For the purposes of the Stoma Appliance Scheme, the Medicare card number should be the 10 digit card number appearing on your card plus the Individual Reference Number (IRN) which is the number beside your name. The association must also have your date of birth and the correct spelling of your name (as appearing on your Medicare card). Much of the information required to be collected by an association will already be requested on the current version of their order form so please make sure that the latest version is the only one that you use to submit your request for supplies. Please also make sure that all sections of the order form are completed. From January 2021, associations will also only be able to accept the new version of the SAS forms (PB049 and PB050) so, to ensure that your request for Scheme registration or additional supplies can be accepted and processed, please ask your STN or GP to only use the current form versions and to complete each section as applicable to your request.

With over 46,000 people now accessing the Australian Stoma Appliance Scheme, the associations have a massive job ahead of them over the next few months. Please assist them where possible. ●

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Hollywood's First Ostomy

By R. S. Elvey, United Ostomy Associations of America



Subject of the movie *White Boy Rick* reveals why depicting his ostomy was critical to the story.

Hollywood movies, both fictional and nonfictional, thrive on melodramas depicting romance and violence. Car crashes, explosions, shootings, and all kinds of mayhem deliver gruesome injuries to victims and survivors. The 2018 film *White Boy Rick*, starring Matthew McConaughey and Richie Merritt, has all these components but is unique in showing the personal aftermath of a violent act – in this case scenes depicting an ostomy.

The film, set in the 1980s on Detroit's eastside, tells the true story of Rick Wershe, Jr., called by the local newspapers 'White Boy Rick' and his father Richard Wershe, Sr. During that decade, Ronald Reagan's War on Drugs is in full swing and the FBI is anxious to break up drug dealing and crooked police in Detroit. Agents observe 14-year-old Rick mingling with a local drug lord and his father selling illegal guns to drug gangs. They meet with Rick and his father and offer them a deal. To prevent his father from going to jail, Rick, at 14, would become an informant working for the FBI. His father agrees to the deal and Rick becomes

the youngest informant ever undercover for the FBI.

While working for the FBI, Rick becomes more and more involved in the daily activities of a leading Detroit drug lord and his gang. They become suspicious of Rick and he is shot in the stomach by a .357 magnum. The bullet enters and goes clean through, severely damaging his large intestine. He is rushed to Ascension St. John's Hospital, Detroit, where lead surgeon Dr. Norman Bolz and others save his life. He awakes with a lifesaving ostomy.

The first time the ostomy pouch appears in the film is when Rick and his father are coming home from the hospital. Rick has his left hand over his stomach and the pouch is overlapping his pants. He is also depicted emptying his pouch. In a recent correspondence with Rick from prison he said, 'When I woke up, I didn't realize that I had it. I think I touched my stomach and then first felt the bag. I didn't know what the bag was. Dr. Bolz came in and explained to me what the bag was and how it worked. The bullet had torn through my intestines and the doctors were hoping the intestines would heal and that it could be reversed, but that it would take a while'.

While in the hospital the staff showed him how to empty and change his pouch. At home he was never seen by

an ostomy nurse or received any other ostomy maintenance training. He said, 'I basically had to learn on my own. Fortunately, I really didn't have any skin problems. I had to keep the bag clean and was able to do a pretty good job. I had skin irritations but it was not too bad. I was lucky'. His friends were young and they were shocked when they saw his bag. But he said, 'My family, especially my dad and grandparents, tried to be as helpful and supportive as they could'. He also met others who had ostomies. Rick had to pay for his own supplies at a local pharmacy which proved very expensive. His father wanted him to wash and reuse the pouches but Rick wouldn't do that. He would use two-three new pouches a day.

Andy Weiss, one of the movie's screenwriters, spoke numerous times with Rick while working on the screenplay. When asked why the ostomy scenes were included he said, 'The ostomy scenes are the core of showing Rick's vulnerability and what I was hoping to get from it was the sympathy and empathy that he deserved but never received from law enforcement or the people around him at that time'. Rick insisted that his ostomy should be part of the movie saying, 'We included the ostomy scenes because I thought it was important to show young kids and adults that you can go through this and still be ok'. And get through it he did. Rick says that the ostomy proved to be no hindrance either socially or in his daily dealings. A year and a half after his original surgery, Dr. Bolz performed a successful revision.

Rick soon faced even greater challenges. Abandoned by the FBI and his family needing money, Rick and his father turned to the only way they knew how to make money, dealing drugs. Eventually, Rick was arrested and sentenced to 30 years for drug dealing. Now 49-years-old, he is scheduled to be paroled in 2020.

When ostomates watch the movie, the ostomy is immediately recognizable.

Congratulations Janey Coates

Ileostomate, NSW

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But numerous reviewers of the movie never mention the ostomy scene. Ostomate, Robin Glover on ostomyconnection.com, wrote after viewing the film, 'There were some inaccuracies, but it will definitely raise awareness and change what the word 'ostomy' conjures up in the mind of anyone that sees it'. Joy Hooper, United Ostomy Associations of America's 2019 WOCN of the Year was enthusiastic in her response to the film and said of the screenwriter, 'I appreciate his way of displaying life with an ostomy. He did a superb job. He was able to show what many consider a negative aspect of life respectfully'.

White Boy Rick is available on Amazon Prime's streaming service in Australia.

This article originally appeared at www.ostomy.org

Editors note: Richard Wershe Jr. 'White Boy Rick' was released from prison in July this year ●

PHOBIAS

- Acrophobia fear of heights
- Aerophobia fear of flying
- Alektorophobia fear of chickens
- Arachnophobia fear of spiders
- Astraphobia fear of thunder and lightning
- Autophobia fear of being alone
- Claustrophobia fear of confined or crowded spaces
- Cryophobia fear of ice or cold
- Hydrophobia fear of water
- Nephophobia fear of clouds
- Onomatophobia fear of words or names
- Ophidiophobia fear of snakes
- Pogonophobia fear of beards
- Zoophobia fear of animals

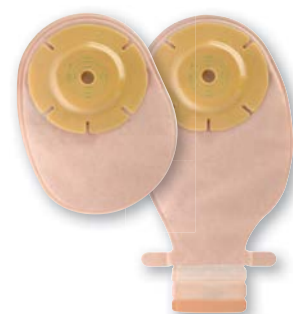
And finally: Hippopotomonstrosesquippedaliophobia is one of the longest words in the dictionary - and, in an ironic twist, is the name for a fear of long words.



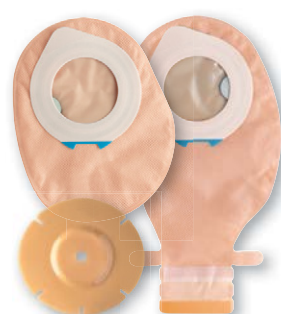
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The Magic Bag By Luke Escombe



My fifteen-month-old son Harry is fascinated by my ostomy bag. He crawls across to me while I'm eating, reading or otherwise relaxing, grins impishly and whips up my T-shirt like a magician unveiling a trick: *ta da!*

He still doesn't quite know what to make of it. His eyes fill with wonder and then look up at me as if to say 'what is this thing Dad and when am I going to get one?' I'm happy to let him prod it for a while – after all it's nothing to be ashamed of – but as soon as he starts trying to rip it off I politely shoo him away and draw my shirt back down.

Seconds later, with a shriek and a cackle, he is back at it. Up. Down. Up. Down. It never ceases to amuse him.

Now he has discovered the location of my bag stash and his new favourite activity is methodically scooping up all my pouches and seals with his tiny pink pincers and plunking them on to the floor like potato peelings. I pretend to be exasperated by this mischief, which only delights him further.

The truth is I am even more delighted than he is. What a transformation has taken place in my life in the last 18 months. To see this object, once the cause of my worst nightmares, now morphed into a source of childish fun, is cause for unbridled celebration.

I was diagnosed with Crohn's disease at the age of 14 and struggled with it for twenty years without once giving serious thought to a surgical solution. I tried every medication available, and many more that had no scientific backing behind them.

I saw naturopaths, homeopaths, sociopaths and psychopaths and gave money to them all. I endured hospitalisations, abscesses, fistulae, months and months of bleeding and severe weight loss, years of being housebound, and other things so bad I still can't bring myself to talk about them... and yet whenever a surgeon suggested to me that all my misery could end if I just had my rotten large intestine removed from my body I closed my ears and sang the same old protest song. Surgery, no way! The bag, not in a million years!

The worst period of all also ended up being one of the most life-changing. In early 2009 I spent 11 nights in a hospital ward at St Vincent's in Sydney sharing a room with three old men with noisy bowel conditions. I'd been very sick for the last three months and had lost more than 30 kilos. I looked like a skeleton with a moustache. Things were desperate.

The irony about hospitals is that one of the most crucial things you need to feel better is sleep, and yet hospitals seem to go out of their way to stop you getting it. All through the night there are lights blinking, alarms going off, people waking you up to take your blood pressure or put tubes in your ear. Every morning at 6am, just as I was finally dozing off, the nurses would come in, fling the curtains wide and drain 13 vials of my blood out of my arm with no explanation whatsoever. What did they do with the blood? No-one told me. But after ten days of this happening they told me I was low on blood and needed a

transfusion. As I watched the new blood trickling into me I wondered: 'Is that mine?'

My wife Kamilla was an angel throughout this ordeal. I'm sure there are many of you reading this who could say the same about your own partners, at least I hope you can. To be loved in these circumstances is a miraculous and beautiful thing, more precious than anything in the world.

We'd married early, at the age of 22, and our love had been severely tested just a year later. My initial Crohn's flare at 14 had been nothing compared to the first relapse in my early 20's. It's no surprise to hear that the guy who wrote that unforgettable dinner scene in *Alien* (arm yourself with a sick bucket and Youtube it if you don't know what I'm talking about) had Crohn's. It's like there's a monster living inside you, eating you from the inside out. The illness takes over your whole mind, becomes your whole world. Only an experimental and very expensive regime of heavy antibiotics saved me that time. It took three years until I was ready to face the world again. Kamilla stood by me throughout, albeit with some tough love towards the end, to lift me up off the

Continued page 32



sofa and march me out to face the world again. I'm so thankful she did.

The 11 nights in hospital in 2009 happened just months after the release of my first album. I'd been all set to go and live out my rock and roll dreams overseas. Instead I spent night after night on my knees on a hospital toilet floor wrestling with a rectal prolapse. That's a let-down, in anyone's language.

A few months later I started writing songs again. Guitar is usually my instrument, but I was too weak to hold one, so I started messing around with drum loops and keyboards instead. Soon I found myself with a whole new repertoire of quirky tunes, written in a style somewhere between funk, pop, comedy and hip-hop. I called it 'Flip Flop'.

In early 2011 I unveiled these songs at the Melbourne Comedy Festival in a show called 'Chronic'. I'd never performed comedy before and was terrified, but the fear was also good for keeping the Crohn's at bay. By now I was on an injectable medication called Humira that was also helping. I'd written a lot of 'jokes' into the show that were mostly greeted with awkward silences, but one night I started talking about my hospital experiences and found that people were laughing. I was encouraged. The show got some good reviews and I was able to take it to the Edinburgh Fringe and then all around Australia. By the end of the year I was telling my story to a room full of teary-eyed politicians at Parliament House.

In early 2012, with my Crohn's just about under control, my wife and I started trying for our first child. It was also around this time that my gastroenterologist sat me down and told me I had a stricture in my bowel that could only be removed by surgery. Although she'd always respected my decision not to consider it, she informed me that the benefits of surgery now far outweighed the risks. I could have a tumour hiding somewhere beyond that stricture and they wouldn't find it until it was too late.

A few weeks later Kamilla and I met with the colorectal surgeon. His recommendation was exactly what we didn't want to hear: ileostomy surgery with a permanent bag. I bargained and pleaded for another option but to no avail.

In my comedy show, to make it easier to talk about the bag, I referred to it as 'the iPad' (you know, it comes with a range of accessories and you can do your business on the go). I asked the surgeon if the iPad would affect our chances of

making babies. He said it might. That was all the reason I needed to delay the operation.

Not long after that I went for my first fertility test. I have to say, it was a lot more fun than a colonoscopy.

Unfortunately, despite decades of practice, I flunked it, and so Kamilla and I now found ourselves plunging headlong into three bleak months of IVF consultations and treatments. Both of us fell under a heavy cloud of depression as we contemplated the very real possibility that, after all we'd been through together, we would not be able to have children.

When we got the news that only one of our embryos had survived the first cycle we were not hopeful, but our spirits were lifted when we saw our lone survivor on the TV screen in the implantation chamber. The cells had barely begun to divide in this tiny speck of life but already we began imagining its possible future – birthdays, first dates, high school formals and graduations. Two weeks later came the momentous news: we were pregnant.

When I woke up from the anaesthetic and saw my stoma for the first time I thought it was the most adorable thing I'd ever seen. Instantly I gave it a name: Spongebob. Whether it was the relief of

knowing that my rotten colon was now gone, the euphoria of taking such a positive step for our future, or (more likely) just the incredible amount of painkilling morphine and ketamine rampaging around my body, I felt delirious with happiness. My wife was sitting in a chair beside my bed, her belly swollen with our baby boy.

On 24 April last year Harry arrived into the world, early and urgent, and spent the first few weeks of his life with tubes up his nose surrounded by bleeping machines. This time it was me who was the strong, capable one, looking after him and his mother – Crohn's free and medication free for the first time in a decade, heavier, healthier and happier than I've ever been.

Harry, you truly are a magician. One day, I hope you will understand what a gift you have given me. Until then, play on you little rascal, your daddy plans to be around for a long while yet.

Written by musician/comedian and award-winning health advocate Luke Escombe in 2014

Source: <https://omnigonconnect.com.au/story/luke-nsw/>



Rosanne meets Fred

By Rosanne McKenna



My story begins many, many years ago. I was born in New Zealand, a small town called Waipawa, in the Central Hawkes Bay area of the North Island in 1934. My health issues began in 1976, about three months after I married my husband when I was diagnosed with cervical cancer and had surgery and radiation treatment. The troubles with my bowel started after that and for the next 25 years I was plagued by terrible bowel issues, frequently swinging between constipation and diarrhoea, urgency and often embarrassing incontinence where I would not make it to the toilet on time. I had major surgery a few years after my cancer treatment, to reconstruct the vagina, but it did not go well and I had a three month stay in hospital, needing rehabilitation to recover. The bowel issues continued and I suffered from what I know now is radiation colitis, serious damage to my bowel from the radiation treatment for my cancer. I was forever fearful and always needed to know where the nearest toilet was. I enjoyed lawn bowls and have a

horrendous memory of my white bowls outfit after a terrible accident on the lawn green! Thankfully I had a wonderfully understanding husband who always loved me despite my many problems. In 1988, after my husband retired, we enjoyed the most amazing three-month holiday back to his home country of Scotland. It was a holiday of a lifetime and I don't quite know how I managed, always looking for a toilet and forever fearing a bowel accident. In 2010, my husband and I decided to make the move to live in Australia so we could both be closer to our family. Our children and grandchildren are so important to us. We had a lovely home in Redcliffe, and I enjoyed indoor bowls and gardening. I would spend many days walking along the waterfront, leaving my husband in the car with his binoculars, watching the surfers! Sadly I lost my husband in 2011, after only a year of being in Australia. We had been married for 40 years. In 2018 I moved from our home into a care facility. Not really what I wanted, but my family thought it best. This was very hard for me, as I also lost my driver's licence, bad eyesight prevented Doctors from giving me medical clearance to drive. I didn't like giving up my independence and freedom, after 57 years of driving it was a very sad day.

Over the years, I have had so many admissions to hospital with bowel obstructions, often caused by a twisted bowel. I have had many trips to the operating room for bowel resections, with the ends re-joined together each time. Still the bowel troubles continued to get worse, and life was a juggle of medicines to stop me going to the toilet (gastrostop up to 12/day) and then some others to make me go when I got blocked. I have suffered with weight loss and was down to 39kg at one point. For my eightieth birthday, my daughter and I took a well-earned break and went on a four-day cruise but sadly, my bowels really affected our time away, as I was always looking for a toilet! Two years ago, a lovely GP referred me to an also lovely colorectal surgeon and discussions about my bowel

problems resulted in an offer to do a colostomy. After visiting with the surgeon and discussing having a stoma, my daughter and I met with the stomal therapy nurse to talk about what life with a stoma would mean. I have severe arthritis and I needed to know I could manage the products and stoma cares. I wanted to be sure I could maintain my independence. It was decided I would be booked for surgery in the coming weeks, but my bowel had other ideas, and that same day, in terrible pain, I went into hospital with another bowel obstruction and woke up in ICU with my colostomy. After three days in ICU I was back in the ward learning to look after my new stoma. I now call him Fred and I have been looking after my stoma independently ever since. It wasn't easy getting used to things, and I thank the stoma nurses who helped me adjust to wearing a bag. I am fine with Fred now, and even though there are days he makes me go to the toilet so much I get very tired, he has certainly given me a better quality of life. I use a two piece with a stick-on pouch, which is easier for my hands to manage, which was recommended to me by my stomal therapy nurse when I was in hospital. Even though my bowel is still very active, but I am careful of what I eat when I go out to make sure he doesn't misbehave too much and I manage very well. I have had some problems with a parastomal hernia and Fred decided to prolapse too, so I now I wear a support belt when I am up and about. Fred lays low as long as I have my belt on! My belt sits by my bed at night and I slip it on before I get up in the mornings. I have wondered often, why someone did not offer me a Fred long ago.

Last year, I had the most memorable eighty-fifth birthday. My wonderful daughter arranged all my favourite people to come for a lovely luncheon. It was well worth celebrating since it had been a whole year without a trip to hospital or the need for any surgery. It was a truly great day of celebrations and happy memories.



When I was working in my local hospitals, ostomates or their loved ones would bring old, out of date or unused products back to our service/hospital. More recently I have consulted in residential aged care facilities (RACFs). When consulting in the RACFs I would look at the ostomates supply of products. I have always been amazed at how much product can be stored or wasted. In one RACF I found at least 50 bottles of stomahesive powder for one resident; to which staff were inappropriately using the product by placing it onto the stoma and furthermore continued to order the product every month even when there was an abundance of the product in their resident's cupboard. In another RACF I found over 200 base plates; in this situation I had been asked to review the resident due to pre-cut peristomal skin loss as stool was coming into contact with

What's in your cupboard?

By Monica Stankiewicz

her skin, the size of the resident's stoma was significantly smaller than the pre-cut base plates and therefore new product had to be ordered for the resident. When speaking with the staff at both facilities, they believed that what the resident was originally ordered (post-operation) was what they required. Both residents had not been reviewed in a long time (both over five years).

COVID-19

In the April and August additions of Ostomy Australia, David touched on the effect of COVID-19. Regarding ostomy products, a demand for supplies increased with increased pressure on our stoma associations and their volunteers. The Department of Health has been working with the Australia Council of Stoma Associations and Australia Post to minimise the impact of COVID-19 on the distribution of medical supplies.

SUSTAINABILITY OF THE PROGRAM

Did you know that the most expensive and utilised products from the Stoma Appliance Scheme have repeatedly fallen into the 'accessory' group. This includes pastes, powders, seals, removal wipes, barrier wipes, belts, hernia prevention etc. Whilst many products are vital to maintain skin integrity, appliance adhesion and hernia prevention, some products are only required for small amounts of time. Therefore, it is vital that ostomates review the products in their cupboard, what is being ordered and what they require.

To maintain the sustainability of the



Scheme, the Department of Health consults with the Stoma Product Assessment Panel who frequently review products relating to supply, pricing and comparing between like versus like products, eligibility and maximum monthly quantities. Products can be added to the list or removed.

HOW YOU CAN HELP REDUCE WASTAGE

- Review your order form and remove products which you are not using
- For next of kin or RACF staff responsible for ordering products – don't be afraid to ask for a stomal therapy review. This can be done by accessing your local stomal therapist (in the hospitals, community or over the phone)
- Over the phone consultation is also useful for our regional ostomates who have limited access to expert advice, with some ostomy companies offering stomal therapy nurse support/access
- Check the ordering guidelines put out by your association
- Stoma Appliance Scheme Schedule of products can be downloaded from the Department of Health regarding products

Continued page 36



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- on the Scheme, additions, variations and deletions from the Scheme
- If you feel that you need more of a product than your monthly supply, please see a stomal therapist. Your stomal therapist will complete an 'Stoma Appliance Scheme application for additional supplies for clinical and other reasons form (PB050)', documenting the rationale for additional supplies
 - The Department of Health recommends an annual review of your stoma by a stomal therapist to keep up to date with new products, best

products for you, product education and to facilitate appropriate management of ostomy products.

Monica is a Wound Management, Stomal Therapy and Dermatology Nurse Practitioner* for Community and Oral Health, Metro North, Queensland Health and can see ostomates with any skin or general concerns, through a referral from a GP.

Your GP can refer you through Central Patient Intake (Via e-referral CCI-Portal icon) OR fax the referral to 1300 364 952. Attention to: Nurse Practitioner Wound-Stoma Community and Oral Health.

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

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



Our last soirée

By Barbara Pitt

Earlier this year, just before COVID-19 had us all sheltering at home, some of my fellow ostomates came to my farm in Northern Tasmania for an afternoon of friends and fun. Everyone bought their own lunch which we ate picnic style outside enjoying the view and each other's company. After our lunch together we went inside for a soirée.

Everyone participated, with my fellow ostomates showing off their various talents - musicians, raconteurs, jesters, historians, comedians and auto biographers - keeping us highly entertained and amused throughout the afternoon.

In fact, we were all so busy having a good time that we forgot to take many pictures, me included, as I was one of the musicians of the day, playing the piano.

Our other musicians on the day were Dr John Sands (cello) and Mrs Janet Sands (flute). Their polished performance of classical music added a touch of class

to our afternoon. Many thanks to them both.

After we had all shown off our individual skills, we joined together – complete with orchestra - for a good old fashioned sing-along. Such a delightful sound emanated... That we wondered, should we become a choir? A few possible names for our choir were suggested including:

- Ostomy Operettas
- Choir of hard bags
- Colonic Chorists
- Songsters with Stomas.

Our choir was most ably conducted by Mr. Robert McManus. Under the skilful brandishing of his baton the sopranos, altos, tenors and basses harmonized with great aplomb.

Robert, a volunteer at Ostomy Tasmania Headquarters in Hobart, had kindly driven from the south of the state for the occasion.

Not only was Robert's musical talent demonstrated, but he was top of the bill when he recited Banjo Paterson's 'The

Man From Snowy River' in its entirety and without reference. Thank you Robert.

Travelling with Robert was a young man, Wayne. Despite his new stoma Wayne continues to train and run in marathons. His determination to continue competing in marathons despite becoming an ostomate inspired us all.

As the weather begins to warm up and hints of the Christmas season start to appear, I'm reminded of the simpler and brighter days and look forward to enjoying such care free days, when we can all be together in person again. ●







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National Directory of Ostomy Associations

Covid-19 notice

Most associations have stopped all in person services to protect staff, ostomates and the wider community. Please make sure to check with your association to find out how they are operating.

AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSOCIATION

W: actstoma.net.au
E: stoma@actstoma.net.au
T: (02) 5124 4888
A: Floor 2, 1 Moore Street Canberra ACT 2600

Open: First and second week of each month on Monday, Tuesday, Wednesday 10:00am to 1:00pm

NEW SOUTH WALES

NSW STOMA LIMITED

W: nswstoma.org.au
E: info@nswstoma.org.au
T: 1300 Ostomy or (02) 9565 4317
A: Unit 5, 7-29 Bridge Road Stanmore NSW 2018
Open: Monday to Thursday 8:00am to 4:00pm, Friday 8:00am to 2:00pm

OSTOMY NSW LTD

W: ostomynsw.org.au
E: orders@ostomynsw.org.au
T: (02) 9542 1300
F: (02) 9542 1400
A: Ground Floor, 20-22 Yalgar Rd Kirrawee NSW 2232
Open: Monday to Thursday 9:00am to 2:00pm

NORTHERN TERRITORY

CANCER COUNCIL NORTHERN TERRITORY

W: nt.cancer.org.au
E: ostomy@cancernrt.org.au
P: (08) 8944 1800
F: (08) 8927 4990
A: Unit 2, 25 Vanderlin Drive Casuarina NT 0811
Open: Monday to Thursday 8:30am to 2:00pm

QUEENSLAND

GOLD COAST OSTOMY ASSOCIATION

W: goldcoastostomy.com.au
E: gcoa@bigpond.com
T: (07) 5594 7633
F: (07) 5571 7481
A: 8 Dunkirk Close Arundel QLD 4214
Open: Tuesday and Thursday 9:00am to 3:00pm

NORTH QUEENSLAND OSTOMY ASSOCIATION

E: admin@nqostomy.org.au
T: (07) 4775 2303
F: (07) 4725 9418
A: 13 Castlemaine Street Kirwan QLD 4812
Open: Monday and Thursday 8:00am to 4:00pm, Wednesday 8:00am to 12:00 noon

QUEENSLAND OSTOMY ASSOCIATION

W: qldostomy.org.au
E: admin@qldostomy.org.au
T: (07) 3848 7178
F: (07) 3848 0561
A: 22 Beaudesert Road Moorooka QLD 4105
Open: Tuesday and Thursday 9:00am to 3:30pm

QUEENSLAND STOMA ASSOCIATION

W: qldstoma.asn.au
E: admin@qldstoma.asn.au
T: (07) 3359 7570
F: (07) 3350 1882
A: Unit 1, 10 Valente Close Chermiside QLD 4032
Open: Monday to Thursday 8:30am to 2:30pm, last Saturday of each month 8:30am to 12:30pm

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

E: bob.schull@bigpond.com
T: (07) 4636 9701
F: (07) 4636 9702
A: Education Centre, Blue Care Garden Settlement, 256 Stenner Street Toowoomba QLD 4350
Open: Tuesday 9:00am to 3:30pm

WIDE BAY OSTOMATES ASSOCIATION

W: wboa.org.au
E: wbostomy@bigpond.com
T: (07) 4152 4715
F: (07) 4153 5460
A: 88a Crofton Street Bundaberg West QLD 4670
Open: Tuesday, Wednesday, Thursday 8:30am to 3.00pm

SOUTH AUSTRALIA

ILEOSTOMY ASSOCIATION OF SOUTH AUSTRALIA

W: ileosa.org.au
E: orders@ileosa.org.au
T: (08) 8234 2678
F: (08) 8234 2985
A: 73 Roebuck Street Mile End SA 5031

Open: Monday, Tuesday, Wednesday and Friday 10:00am to 2:00pm

OSTOMY ASSOCIATION OF SOUTH AUSTRALIA

W: colostomysa.org.au
E: colosa@colostomysa.org.au
T: (08) 8235 2727
F: (08) 8355 1073
A: 1 Keele Place Kidman Park SA 5025
Open: Monday to Thursday 10:30am to 2:30pm

TASMANIA

OSTOMY TASMANIA

W: ostomytas.com.au
E: admin@ostomytas.com.au
T: (03) 6228 0799
F: (03) 6228 0744
A: Amenities Building, St. Johns Park, St. Johns Avenue, New Town TAS 7008
P: PO Box 280 Moonah Tasmania 7009
Open: Monday 9:00am to 3:00pm Tuesday 9:00am to 1:00pm

VICTORIA

BENDIGO AND DISTRICT OSTOMY ASSOCIATION INC

T: (03) 5441 7520
F: (03) 5442 9660
A: 43-45 Kinross Street Bendigo VIC 3550
P: The Secretary, PO Box 404 Golden Square VIC 3555
Open: Tuesday, Wednesday and Thursday 10:00am to 2:00pm. Second Tuesday of each month from 9:00am to 3:00pm

COLOSTOMY ASSOCIATION OF VICTORIA

W: colovic.org.au
E: info@colovic.org.au
P: (03) 9650 1666
F: (03) 9650 4123
A: Suite 221 - Level 2, Block Arcade, 98 Elizabeth Street Melbourne VIC 3000
Open: Weekdays 9:00am to 2:00pm

GEELONG OSTOMY

W: geelongostomy.com.au
E: goinc@geelongostomy.com.au
T: (03) 5243 3664
F: (03) 5201 0844
A: 6 Lewalan Street Grovedale VIC 3216
Open: Monday, Wednesday, Friday 9:30am to 2:30pm

OSTOMY ASSOCIATION OF MELBOURNE

W: oam.org.au
E: enquiries@oam.org.au
T: (03) 9888 8523
F: (03) 9888 8094
A: Unit 14, 25-37 Huntingdale Rd Burwood VIC 3125
Open: Tuesday to Friday 9:00am to 4:00pm

PENINSULA OSTOMY ASSOCIATION

W: penost.com.au
E: poainc1@bigpond.com
T: (03) 9783 6473
F: (03) 9781 4866
A: 12 Allenby Street Frankston VIC 3199
Open: Monday, Thursday 10:00am to 3:00pm

VICTORIAN CHILDREN'S OSTOMY ASSOCIATION

W: rch.org.au/edc
E: edc@rch.org.au
T: (03) 9345 5325
F: (03) 9345 9499
A: Equipment Distribution Centre, Royal Children's Hospital, Basement 2 (green lifts), 50 Flemington Road Parkville VIC 3052

WARRNAMBOOL & DISTRICT OSTOMY ASSOCIATION

E: warrnamboolostomy@swh.net.au
T: (03) 5563 1446
F: (03) 5563 4353
A: 279 Koroit Street Warrnambool VIC 3280
Open: Friday 12:00 noon to 4:00pm

WESTERN AUSTRALIA

WESTERN AUSTRALIAN OSTOMY ASSOCIATION

W: waostomy.org.au
E: info@waostomy.org.au
T: (08) 9272 1833
F: (08) 9271 4605
A: 15 Guildford Road Mount Lawley WA 6050
Open: Monday to Friday 9:00am to 4:00pm, Tuesday 6:30am to 4:00pm. Fourth Saturday of each month 9:00am to 1:00pm

National Directory of Ostomy Support Groups

Covid-19 notice

Most support groups have temporarily ceased meeting to help protect members. Please make sure to check with your group to find out if or how they are meeting.

AUSTRALIAN CAPITAL TERRITORY

WODEN VALLEY

Meet the second Tuesday of the month – no meetings in December / January from 10:00am to 12:00 noon
Hellenic Club – Woden, Matilda Street Phillip, ACT
Contact: Clare Jacobs 0400 921 901 or aucldo@coloplast.com

NEW SOUTH WALES

ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec.
Venue: Hilltop Accommodation Centre, 600 Keene Street, East Albury NSW
Contact: Alex Watson 0428 578 385

BANKSTOWN AREA

Meet the 6 May, 5 August, 4 November from 10:00am to 12:00 noon
Revesby Workers Club, 2B Brett Street, Revesby
Contact: Clare Jacobs 0400 921 901 or aucldo@coloplast.com

BATHURST

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

BEAT BLADDER CANCER

Dates: Last Tuesday of every month
Time: 7pm to 8:30pm
Address: Macquarie University Hospital 3 Technology Place, Macquarie University.
Contact: Adam Lynch, President BEAT Bladder Cancer 0421 626 016

BOWRAL STOMA SUPPORT GROUP

Meeting dates are decided at the beginning of each year. Meeting times 1:00pm to 2:30pm
Bowral Bowling Club, 40 Shepherd Street, Bowral
Contact: Clare Jacobs 0400 921 901 or aucldo@coloplast.com

BROKEN HILL

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

CENTRAL COAST

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

COFFS HARBOUR

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

EUROBODALLA REGION

Meets first Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11am
Venue: Laughter Room, Moruya Hospital.
Phone: Betty (02) 4476 2746

FAR NORTH COAST

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

GOULBURN COMMUNITY STOMA SERVICE

Dates: Wednesdays 19th Feb, 20th May, 19th August, 18th Nov 2020.
Time: 9am to 3pm
Address: Goulburn Workers Club, 1 McKell Place, Goulburn, (02) 4821 3355
The STN is Kelly Taylor RN STN 0402 250 475
e. kelly@communitystomaservice.com
Kelly will provide individual consultations by appointment.

GRAFTON & DISTRICT

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

GRIFFITH & DISTRICT

Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)
Enquiries: Barry (02) 6963 5267 or 0429 635 267
Email: ann.bar@bigpond.com
Karan: 0434 785 309

HASTINGS MACLEAY

Meet: The Old Hospital at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries: Neil 0427 856 630 or Glennie 0410 637 060

ILLAWARRA OSTOMY INFORMATION GROUP 2021

Meet 10.00 – 12.00 on the following Wednesdays, Education Room Figtree Private Hospital
1 Suttor Place Figtree NSW 2525
10th Feb - 14th April - 9th June - 11th August - 13th Oct - 15th Dec (Xmas luncheon. Venue to be advised)
For Further Information contact: Helen Richards CNC STN Wollongong Private Hospital phone: 42861109 richardsh@ramsayhealth.com.au
Julia Kittscha CNC STN Wollongong Hospital mob: 0414421021 office: 42551594 julia.kittscha@health.nsw.gov.au

LIVERPOOL AREA SUPPORT GROUP

Dates: Thur 26th Sept, Thur 28th Nov
Time: 1pm to 3pm
Address: Cabra Vale Diggers Club, 1 Bartley St Canley Vale 2166
Contact: Erin or Lu on (02) 8738 4308

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)
Web: www.mglostomy.co.cc
Contact: Karla MacTaggart on (02) 6592 9469

NEWCASTLE DISTRICT

Meet at 1.30pm on the last Saturday in Feb - May - Aug (AGM) - Nov.
Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.
Enquiries: Geoff (02) 4981 1799 or Lynda 0425 209 030 or Maree (02) 4971 4351

ORANGE & DISTRICT

Meet: Mar - June - Sept - Dec From 12 noon.

Venue: 15 Olver St, Orange. NSW
Contacts: Louise: (02) 6330 5676 and Joanne: (02) 6362 6184

SHOALHAVEN SUPPORT GROUP

Dates: 26/02/2020, Nowra Community Health Centre
29/04/2020, Nowra Community Health Centre.
24/06/2020, Ulladulla Civic Centre
26/08/2020, Nowra Community Health Centre
25/11/2020, Nowra Community Health Centre, Christmas meeting
09/12/2020, Ulladulla Civic Centre, Christmas meeting.
Time: 2 pm
Address: Nowra Community Health Centre, 5-7 Lawrence avenue Nowra.
Contact: Brenda Christiansen STN CNC. Ph. 02 44246300
e. brenda.christiansen@health.nsw.gov.au

ST GEORGE AREA

Meet the third Tuesday of each month – no meetings in December / January from 10:00am to 12:00 noon
Ramsgate RSL Club Ramsgate Road and Chuter Avenue, Sans Souci NSW 2219
Contact: Clare Jacobs 0400 921 901 or aucldo@coloplast.com

SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets: Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).
Janelle Robinson: 0409 762 457
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SYDNEY - PENRITH AREA

Nepean Educational Support Group meets 2pm-3.30pm, 10 May, 26 July, 27 September, 29 November
Venue: Sydney Medical School, Clinical School Building, 62 Derby St., Kingswood.
Family and friends welcome, afternoon tea supplied.
Enquiries: Naomi Houston (stomal therapist) (02) 4734 1245

SYDNEY - NORTHERN AREA

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

TWEED-BYRON

Meets 3rd Tuesday of March, June, Sept., 2nd Tuesday in Dec., noon to 2pm.
Venue: South Tweed Sports Club, 4 Minjungbal Dr., Tweed Heads South
Contact: Lisa Clare STN (07) 5506 7540.

WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00am to 11:00am.
Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga
Enquiries: David (02) 6971 3346 or 0428 116 084 Baz (02) 6922 4132

NORTHERN TERRITORY

DARWIN

Meet: 5.30-6.30pm on the first Tuesday of every month.
Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810
Contact: Marie Purdey: (08) 8944 1800

QUEENSLAND

BEENLEIGH

Meet first Monday of every second month from 09:30 to 10:30am Feb, April, June, Aug Oct, Dec (Christmas Function)

Logan Hospital, Room 1E.
Cnr Loganlea and Armstrong Road, Meadowbrook 4131
Ph: Leanne Johnson STN (07) 3299 9107

BOWEN

Meets at the Bowen PCYC on the first Monday of every month
10:00am – 12:00pm

MACKAY

Meets at 2.00pm on the fourth Friday of every odd-numbered month (Jan -Mar - May - Jul - Sep - Nov).
Venue: St. Ambrose Anglican Church Hall, Glenpark Street, North Mackay.
Contact: Graham Stabler for further information on 0428 776 258 or email: grahamstabler@bigpond.com

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

Sunshine Coast Stoma Support Group meets at Maroochy RSL Events Centre, Memorial Avenue (off First Avenue), Maroochydore, second Monday of every month, commencing 10am.
Enquiries:Laurie Grimwade: (07) 5445 9008 sid.and.laurie@gmail.com
Janelle Robinson: 0409 762 457
candjrobinson@bigpond.com
Kathy Himstedt: (07) 5445 9270
greg.kath1@bigpond.com

INSIDEOUT TOOWOOMBA

Insideout Toowoomba Stoma Support. These stoma mates would love to hear from you: ring for a chat or send an email. Margaret Brabrook (07) 4635 1697, emby1936@gmail.com; Leanne Wilshire (07) 4630 0629, leanne.wilshire@bigpond.com; emby1936@gmail.com; Laurel Czynski, 0413 805 809

WIDE BAY

Bundy Osto Mates
Meets from 10am- 12 on the third Thursday of each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West. Please contact Wide Bay Ostomates (07) 4152 4715

SOUTH AUSTRALIA

CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov.
When: 2pm.
Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End.
Information: (08) 8234 2678 or speak with Val Macey (08) 8381 1646

FLEURIEU

Meets first Monday of March, June, September, December
Flinders Rural Health, Bay road, Victor Harbour
10am to 12 noon
Contact: Lyn Sandford STN on 0421 000 960 or llynsandford09@gmail.com

PORT AUGUSTA AND BEYOND

Meet: Fourth Tuesday of every month at 1.30pm in the Library/Bookshop behind St Augustine's Anglican Church, Church St. Port Augusta.
Please contact Anne Wensley for more information on 0429 422 942

PORT PIRIE

Meet: Third Tuesday of each month 1pm – 2.30pm at GP Plus Medical Centre, 50 Gertrude Street, Port Pirie.
Contact STN Jenni Edwards (08) 8638 4536

SOUTHERN

Meet: First Wednesday of Feb, April, June, Aug, Oct, Dec.
When: 2pm.
Where: Elizabeth House, 112 Elizabeth Rd, Christie Downs.
Information: Lyn Sandford STN 0421 000 960 or Sharmaine Peterson STN 0438 853 082

YORKE PENINSULA

Meet : Third Wednesday of Feb, April, June, Aug, Oct, Dec at 1.30pm.
Initial venue Moonta Aged Care Activity Room, Majors Rd, Moonta.
Venue may change to accommodate distant ostomates.
Contact Helen Colliver on 0419 839 869

TASMANIA

'SEMI COLONS'

Meet the third Friday of each month from 2pm-4pm
Southern Cancer Support Centre, 15 Princes Street, Sandy Bay
Contact Marg, Cancer Council Tasmania (03) 6169 1900

NORTH & NORTH-WEST

North – 10 am - 12 noon, Cancer Support Centre - 69 Howick Street, Launceston, Mon 1st June and Mon 7th September
North Western – 10 - 12 noon, Ulverstone Senior Citizens Club, 16 King Edwards Street, Wed 10th June and Mon 14th September

SOUTHERN TASMANIA

Meet at Ostomy Tasmania Office, New Town, 10am-noon on Wed 3 June and Wed 9 September. Further information: Adrian Kok: 0498 196 059

VICTORIA

BAIRNSDALE & DISTRICT

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

BALLARAT & DISTRICT OSTOMY SUPPORT GROUP

Meets: 2pm 2nd Wednesday of each month
Venue: Barkly Restaurant, cnr Barkly St and Main Road.
Contact: Graeme on 0400 979 742 or David Nestor on (03) 5339 4054
Emails: david.nestor2@bigpond.com or graob44@gmail.com

BENALLA / WANGARATTA

Meets 2.00pm on the third Monday of each second month.
Venues: Wangaratta: North-East Health, 4-12 Clarke St., Wangaratta, April, Aug., Dec. Benalla Community Health, 45 Coster St., Benalla, Feb, June, Oct.
Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943.
Email: mgpwwang@gmail.com

COLOSTOMY ASSOCIATION OF VICTORIA STOMAL SUPPORT GROUP

CAV offers support to all clients. We offer 30 minute consultations with a qualified STN, by appointment, two or three days per week.

MILDURA

Meet: Every second month
Venue: Mildura Base Hospital Conference room 1
Contact: Vicky (03) 5022 3333 or Norma 0409 252 545

SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on 0447 942 406 for more information.

SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre
Enquiries: Norma Murphy
0409 252 545

WARRNAMBOOL & DISTRICT

Meets at 10.30am on the second Friday of the month in Feb - Apr - Jun - Aug - Oct - Dec.
Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093
Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

WESTERN AUSTRALIA

ALBANY

First Friday of March, June, September and December from 1:30pm to 3:00pm
Albany Hospice, 30 Warden Ave, Spencer Park
Contact Gerry 0498 666 525

KALGOORLIE

Contact: Lorrie Gray on 9272 1833 or info@waostomy.org.au

MANDURAH

First Wednesday of each month from 5:30pm to 7:00pm
Training Room 3, Peel Health Campus 110 Lake Road Mandurah
Contact: Lorrie Gray on 9272 1833 or info@waostomy.org.au

BUNBURY / BUSSELTON

Facebook support group: www.facebook.com/groups/561233347760977

ESPERANCE

Contact Len 9075 9099

PERTH

Fourth Saturday of each month from 12:00 noon to 1:00pm (New Members') and 1:00pm to 3:00pm (General support)
WAOA office, 15 Guildford Road, Mount Lawley
Contact: Lorrie Gray on 9272 1833 or info@waostomy.org.au

NORTHERN SUBURBS SUPPORT GROUP

Date/s: Second Saturday of each month
Time: 3:00pm to 5:00pm
Location: Various
Contact: d.carrybrown@me.com or call 9272 1833

BOWEL GROUP FOR KIDS INC

Tel: 0458596185
Email: enquiries@bgk.org.au
Web: www.bgk.org.au

YOUNG OSTOMATES UNITED (YOU)

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

PARENTERAL NUTRITION DOWN UNDER

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

MITROFANOFF SUPPORT AUSTRALIA

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

Stoma Appliance Scheme Product Suppliers



AinsCorp

PO Box 572, Niddrie, Victoria 3042
Toll Free Number: 1300 784 737
Email: service@ainscorp.com.au
Website: www.ainscorp.com.au



Dansac

PO Box 375, Box Hill, Victoria 3128
Phone: 1800 880 851
Email: priority@dansac.com.au
Website: www.dansac.com.au



Coloplast

PO Box 240 Mt Waverley Vic 3149
Freecall: 1800 653 317
Email: au.care@coloplast.com
Website: www.coloplast.com.au



ConvaTec

PO Box 63, Mulgrave, Victoria 3170
Freecall: 1800 335 276
Email: connection.au@convatec.com
Website: www.convatec.com.au



Sutherland Medical

Unit 2, 195 Chesterville Road Moorabbin Vic 3189
Phone: 1300 664 027
Email: orders@sutherlandmedical.com.au
Website: www.sutherlandmedical.com.au



Future Environmental Services

PO Box 319, Blairgowrie, Victoria 3942
Phone: +61 3 5985 2828
Email: health@futenv.com.au
Website: www.futenv.com.au



Hollister

PO Box 375, Box Hill, Victoria 3128
Freecall: 1800 880 851
Email: priority@hollister.com.au
Website: www.hollister.com.au/anz/



Nice Pak Products

Free call: 1800 506 750
Email: healthcare@nicepak.com.au
Web: www.nicepak.com.au



Omnigon Pty Ltd

PO Box 5013, Burnley, Victoria 3121
Freecall: 1800 819 274
Email: info@omnigon.com.au
Website: www.omnigon.com.au



3M Australia

Locked Bag 19, North Ryde NSW 1670
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