Ostomy
AUSTRALIA

Volume 23
Number 1
April 2014

Print Post Approved
PP 100008088
ISSN 1329-959X

AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC.
ACSA

National Directory of Ostomy Associations

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

AUSTRALIAN CAPITAL TERRITORY

ACT & DISTRICTS STOMA ASSN INC.

Second Floor, ACT City Health Centre,
1 Moore St, Canberra City, ACT 2600
Postal Address: GPO Box 1260,
Canberra City, ACT 2601
Telephone/Fax: (02) 6205 1055
Website: www.actstoma.org.au
Operating hours:
1st & 2nd week of each month Mon, Tues, Wed. 10.00am - 1.00pm
Office Manager: Lindsay Foster
Email: actstoma@alphalink.com.au
Secretary: Tanya Harber

NORTHERN TERRITORY

CANCER COUNCIL OF THE NORTHERN TERRITORY INC.

Unit 2 Casi House
25 Vanderlin Drive, Casuarina
Phone: (08) 8927 4888
Fax: (08) 8927 4990
Email: ostomy@cancernt.org.au
Web: www.cancercouncilnt.com.au

WESTERN AUSTRALIA

WA OSTOMY ASSN INC.

15 Guildford Rd, Mount Lawley 6050
Telephone: (08) 9272 1833
Fax: (08) 9271 4605
Enquiries email:
waostomy@waostomy.asn.au
Orders Email:
orders@waostomy.asn.au
Operating hours and appliance pickup: Mon, Tues, Thurs 9.00am - 1.00pm
Secretary: Jess Whitehouse

NEW SOUTH WALES

COLOSTOMY ASSN OF NSW INC.

Unit 5, 7-29 Bridge Road,
Stanmore 2048
PO Box 164, Camperdown 1450
Operating hours: Mon to Thurs
9.00am - 4.00pm and
Friday 9.00am - 2.00pm
Office Manager: Mrs Jenny Kemp
Secretary: Norma Toohey
Telephone: 1300 OSTOMY or
(02) 9565 4315
Fax: (02) 9565 4317
Email: ostomy@iinet.net.au
Website:
www.ColostomyNSW.com.au

OSTOMY NSW LTD

Unit 6, 555 Princes Highway
Kirrawee NSW 2232
Postal Address: PO Box 3068
Kirrawee NSW 2232
Operating hours: Mon to Thurs
9.00am to 2.00pm
Telephone: (02) 9542 1300
Fax: (02) 9542 1400
Email: orders@ostomynsw.org.au
Website: www.ostomynsw.org.au

QUEENSLAND

GOLD COAST OSTOMY ASSN INC.
PO Box 703 Labrador 4215
8 Dunkirk Close, Arundel 4214
Telephone: (07) 5594 7633
Fax: (07) 5571 7481
Email: gcoa@bigpond.com
Operating hours:
Tues & Thurs 9.00am - 3.00pm
Office Manager: Norm Kelly

NTH QLD OSTOMY ASSN INC.

Shop 4, 52 French Street, Pimlico
Telephone/Fax: (07) 4775 2303
Fax only Mondays & Thursdays
All correspondence & orders to:
PO Box 1017
Hyde Park, Castletown 4812
Operating hours:
Monday 9.00am - 4.00pm
Thursday 9.00am to 3.00pm
Secretary: Barbara Myles
A/H (07) 4775 2303

QLD COLOSTOMY ASSN INC.

22 Beaudesert Rd, Moorooka 4105
P.O. Box 198 Moorooka 4105
Operating hours: Tues & Thurs
9.00am - 3.30pm
Secretary: (07) 3848 0138
Fax: (07) 3848 0561
Email: admin@qldcolostomy.org
Web: www.qldcolostomy.org

QLD STOMA ASSN INC.

4/10 Valente Close, Chermside 4032
Telephone: (07) 3359 7570
Fax: (07) 3350 1882
Website: qldstoma.asn.au
Operating hours:
Mon, Tues & Thurs 8.30am - 2.30pm
Emergency No: (07) 3359 7570
PO Box 370, Chermside 4032
Email: admin@qldstoma.asn.au

TOOWOOMBA & SOUTH-WEST OSTOMY ASSN INC.

Education Centre, Blue Care Garden Settlement, 256 Stenner Street,
Toowoomba 4350
All correspondence to:
PO Box 7314, Toowoomba MC 4352
Telephone: (07) 4636 9701
Fax: (07) 4636 9702
Operating hours:
Tues 9.00am - 3.30pm
Secretary: Bob Schull
Telephone: 0418 717 199
Email: bob.schull@bigpond.com

WIDE BAY OSTOMATES ASSN INC.

88a Crofton Street, Bundaberg West,
QLD 4670
Operating hours: 8.30am - 3.00pm
Tues, Wed, Thurs.
Telephone: (07) 4152 4715
Fax: (07) 4153 5460
Appliance Officer: Trina McRae
Email: wbostomy@bigpond.com

SOUTH AUSTRALIA

OSTOMY ASSN OF SA

(formerly Colostomy Assn of SA)
1 Keele Place, Kidman Park 5025
Telephone: (08) 8235 2727
Fax: (08) 8355 1073
Email: colosa@colostomysa.org.au
Website: www.colostomysa.org.au
Distribution of supplies: Mon - Fri
10.30am - 2.30pm
Secretary: Ruth Horne

ILEOSTOMY ASSN OF SA INC.

73 Roebuck St. Mile End. SA 5031
Telephone: (08) 8234 2678
Fax: (08) 8234 2985
Office hours: Mon-Fri 10am to 2pm
Distribution times: Tuesdays 10am to 2pm 1st & 3rd Tuesday evenings 7pm to 8pm.
Secretary: Dawn Osborne
Telephone: (08) 8268 3645
Email: ileosto@bigpond.net.au

TASMANIA

OSTOMY TASMANIA INC

Amenities Building,
St. Johns Park
St. Johns Avenue, Newtown 7008
P.O. Box 280, Moonah 7009
Telephone: (03) 6228 0799
Fax: (03) 6228 0744
Operating hours:
Mon 9.00am - 3.00pm
Tues 9.00am - 1.00pm
Sec/Treas: Sue Hoyle
Email: admin@ostomytas.com.au

VICTORIA

BENDIGO & DISTRICT OSTOMY ASSN INC.

43-45 Kinross Street, Bendigo 3550
All correspondence to:
PO Box 404, Golden Square. 3555
Ostomy Rooms: (03) 5441 7520
Fax: (03) 5442 9660
Operating hours:
Tues, Wed, Thurs 10.00am - 2.00pm and second Tues of each month from 9.00am - 3.00pm
Secretary: PO Box 404,
Golden Square, VIC 3555

COLOSTOMY ASSN OF VIC.

Suite 221, 2nd Floor, Lift 3,
Block Arcade, 98 Elizabeth Street
Melbourne 3000
Telephone: (03) 9650 1666
Fax: (03) 9650 4123
Email: colostomy@mail2me.com.au
Operating hours:
Mon - Fri 9.00am - 2.00pm
Stomal Therapy Nurse
Tues 9.30am - 2.00pm
Contact: Kathleen Allan

GEELONG OSTOMY INC.

Geelong Ostomy Inc.
6 Lewalan St. Grovedale VIC 3216
Postal Address: PO Box 1069,
Grovedale VIC 3216
Telephone: (03) 5243 3664
Fax: (03) 5243 6335
Email: goinc@geelongostomy.com.au
Website: www.geelongostomy.com.au
Operating hours: Monday,
Wednesday, Friday 9.30am to 2.30pm
Administrator: Joanne Holmes

ILEOSTOMY ASSN (VIC) INC.

Suite 322, 3rd Floor, The Block,
98 -100 Elizabeth Street,
Melbourne VIC 3000
PO Box 32, Flinders Lane VIC 8009
Telephone: (03) 9650 9040
Fax: (03) 9650 1723
Email: ileovic@onestream.com.au
Web Site: www.ileostomyvic.org.au
Operating hours: Mon to Thurs
9.30am - 2.00pm
Secretary: Wendy Taylor

OSTOMY ASSN OF MELBOURNE INC.

Axxess Business Park,
71/170 Forster Road,
Mount Waverley VIC 3149
Telephone: (03) 9543 1224
Fax: (03) 9543 1994
Email: enquiries@oam.org.au
and orders@oam.org.au
Manager: Sue Read
Operating hours:
Mon to Fri 9.00am - 4.00pm
STN by appointment only - Tuesday only: 9.30am - 2.30pm

PENINSULA OSTOMY ASSN INC.

12 Allenby Street, Frankston 3199
Telephone: (03) 9783 6473
Fax: (03) 9781 4866
A/H Emergency only: 0417 011 075
Operating hours:
Mon & Thurs 10am - 3pm
Secretary: Alexandra Terdich
Email: poainc1@bigpond.com.au

VICTORIAN CHILDREN'S OSTOMY ASSN.

Equipment Distribution Centre,
Royal Children's Hospital,
Flemington Road, Parkville 3052
Telephone: (03) 9345 5522
Fax: (03) 9347 5046
Operating hours:
Mon to Fri 8.30am - 4.30pm
Orders: 24-hours notice
Coordinator: Mrs Jacque Harrison

WARRNAMBOOL & DISTRICT OSTOMY ASSN INC.

279 Koroit St, Warrnambool 3280
Telephone: (03) 5563 1446
Fax: (03) 5563 4353
Email:
warrnamboolostomy@swh.net.au
Operating hours:
Friday 12 noon - 4.00pm
Secretary: Heather Love

Ostomy AUSTRALIA

Volume 23
Number 1
April 2014

Print Post Approved
PP 100008088
ISSN 1329-959X

AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC.
ACSA

Editor: Kim Lyell

Editorial Contributors:
Margaret Allan, Kirsti Dixon, Carmen George, Kerry Kimbrey, Paula Lawrence, Kylie McGrory, Roger McMillan, Richard McNair, Peter McQueen, Bob Newman, Geoff Rhodes, Phillip Watt, Valerie von Willisen, Barbara Worme

Correspondence/Contributions to:
The Editor, *Ostomy* AUSTRALIA
PO Box 195, Frenchs Forest, NSW, 1640
Phone: (02) 8011 3535
Email: **Journal@AustralianStoma.com.au**
These contact details apply only to matters directly associated with *Ostomy* AUSTRALIA
Only Email, Word or PDF documents, and hard copy submissions accepted.

Published by:
Australian Council of Stoma Associations Inc.
Website: www.australianstoma.com.au
Email: feedback@australianstoma.com.au

Patron:
His Excellency General Peter Cosgrove AC MC
Governor-General of the Commonwealth of Australia

Executive Members:
Peter McQueen - President
P.O. Box 283, Bentleigh East, VIC 3165
Email: petermcqueen1@bigpond.com

Geoff Rhodes - Vice President
P.O. Box 152, Wanniassa ACT 2903

Peter Lopez - Treasurer
P.O. Box 427, Miami, QLD 4220

Rosemary Quick - Secretary
PO Box 2427, Salisbury Downs, SA 5108
Email: acsasec@australianstoma.com.au

Printed by:
Graphic Print Group
Graphic House, 10 - 14 Kingston Avenue,
Richmond. SA 5033
Phone: (08) 8443 8011 Fax: (08) 8234 0226

Graphic Design by:
Graphic Print Group
Phone: (08) 8443 8011

Advertising Enquiries to: The Editor

Advertising & Copy Deadlines:

Issue	*Copy and Advertising*
April	1st February
August	1st June
December	1st October

Cover Picture:
Smith O'Brien's Cottage, Port Arthur, Tasmania
Photo by Kim Lyell

IN THIS ISSUE

Index to Advertisers:

Contributions to the Letters pages must include your name and address for publication. If you do not wish your name published, please say so in your letter, and only your initials will be printed. Please also note that an electronic copy of this journal is available to non-Ostomates on our and other internet websites. The editor and publisher take no responsibility for any information contained in 'Letters to the Editor' and 'Handy Hints' and specifically disclaim all liability. Concerning any medical information contained in any letter to the editor, the reader is strongly advised to first obtain appropriate medical advice before implementation.

Advertisements in this journal are published as submitted by advertisers. The publisher has not checked the veracity of the advertisements and accepts no responsibility for their content. The publisher specifically disclaims all responsibility and liability for any material contained in this journal and in particular any material that may breach any confidentiality or privacy or may be regarded as defamatory. Such liability will be assumed by the relevant author of the material.

The Australian Council of Stoma Associations Inc. advises that it has no control over the use of personal particulars, supplied by Ostomates to companies in response to advertisements contained in *Ostomy* AUSTRALIA. Unless the advertiser states otherwise, your name and address information may be used by the company to let you know about its products in the future. If you do not wish to receive future advertising, we suggest that when you respond to any advertisement, you tell the company you do not wish to receive future advertising. Most of the companies have assured us that they will comply with your request. If you do have any problems, contact the company concerned or advise the Editor of Ostomy AUSTRALIA.

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

From The Editorial Desk

Having a stoma certainly isn't a disability for many Ostomates. Without fail, after each new journal we receive new stories from courageous Ostomates - or their family and friends - relating what can sometimes be a very difficult journey with their new and very close companion – their stoma.

In the first article in this issue, *"From Health To Hell And Back"*, Phillip Watt tells of his traumatic journey to overcome bowel cancer and several other major health problems he has experienced since late 2010. Throughout his journey Phillip endured ongoing severe and debilitating pain, but thankfully he now has this under control and *"finally has his life back"*. Phillip also provides us with a great summary of the lessons he learnt over the course of his journey.

After receiving his stoma in October 2003, Roger McMillan was given a second chance and was determined not to let it ruin his life. In his article *"Sailing the Sydney to Hobart Yacht Race - with a Stoma"*, Roger describes this iconic yacht race and his difficulties while changing an ostomy bag in a tiny cubicle, with the boat on a steep angle and in very rough seas. Roger also still swims three times a week, rides a bike to the shops or train station rather than driving, and has also done a triathlon and a ten kilometre fun-run.

Having a stoma certainly hasn't slowed Barbara Worme either. In her *"Get Out There and Do It!"* story she describes how she is still living a normal and active life since receiving a permanent ostomy six years ago. Now seventy-seven, Barbara continues to play competition tennis and golf, enjoys dog walking, gardening, hiking, swimming and snorkelling. To quote Barbara, *"I would encourage everyone with an ostomy bag to just get out there and do it!"*.

Janelle and Greg Solomon's daughter, Lilah, was born with Bladder Exstrophy and has endured many surgical procedures and emergency department visits for bladder infections and stones over the last ten years. In *"Our Story - Mitrofanoff Support Australia"*, Janelle and Greg relate how Mitrofanoff surgery helped to finally resolve their daughter's condition. As a result of their experiences, they also helped to co-found Mitrofanoff Support Australia, a new organisation which aims to raise awareness of this procedure and provide support to others.

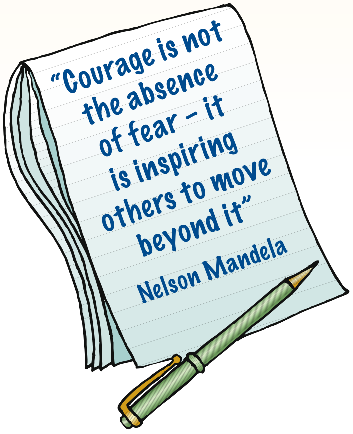
The role of ostomy associations across Australia has changed significantly over the last forty or so years. Geoff Rhodes writes in his *"The Ostomy Movement in Australia: Opportunities & Challenges"* article how associations were initially established to primarily provide emotional support and encouragement to fellow Ostomates. Over time the function of associations has transformed to a point where distributing stoma appliances to members has become their main focus. Geoff asks *"Can we honestly say that an organisation, system and structure that was developed and established during the 1970s is appropriate to carry Ostomates through the 21st Century?"*. Something for us all to ponder I think.

Our very own Stomal Therapy Nurse, Carmen, again provides some great medical advice to Ostomates. She has also included a recipe for St Mark's solution, the drink formula medically developed to help avoid dehydration in Ostomates with a high output ileostomy.

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

Take care and stay healthy.

Kim Lyell EDITOR


"Courage is not the absence of fear – it is inspiring others to move beyond it"

Nelson Mandela

HELP!

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

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

Journal@AustralianStoma.com.au

Hard copy submissions may be posted to:

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

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

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

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

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

LIKE TO BE ON THE FRONT COVER OF THIS JOURNAL?

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

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

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

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

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

President's Message

We are well and truly into another new year and with it comes new challenges and expectations. I wish every reader success in whatever 2014 may bring.

In the last issue of *Ostomy Australia*, I focussed on the 50th anniversary of ACSA and the development of the national association. Continuing on with the historical theme, I would like to consider how those people who were involved in establishing our associations would view the current landscape of the ostomy community in Australia.

Almost every Australian Stoma Association was established through the drive and dedication of one or two people who devoted much of their lives to the cause. These pioneers were either Ostomates themselves or the husbands, wives or parents of an Ostomate, who undertook a leadership role as each association was formed. On some occasions, dedicated healthcare professionals with the ongoing welfare of their patients at heart were also instrumental in establishing these very early ostomy support groups. In a similar way, support groups that have formed in more recent times owe their viability to one or two people who have been prepared to provide the leadership and vision required to make them a success.

The passing of an era of Australian ostomy pioneers leads me to think of some of the changes that have occurred in ostomy support since those early days, forty or more years ago. What would our pioneers think about the evolution of ostomy association operations and the impact that this has had on the method of meeting the needs of thousands of Ostomates reliant on association support? Whereas in the early years it was possible to give personal support to the small number of members who came together once a month to obtain appliances and to talk about mutual problems, an explosion in both the number of ostomy appliances available and in the number of members needing those appliances has meant that the nature of support has had to change to meet the demands of modern times. The task of matching a range of more than two thousand appliances to the needs of over forty thousand Ostomates alone has necessitated the adoption of modern methods of product distribution to ensure that everyone's supplies can be made available in a timely manner.

While the vision of the early pioneers and that of their modern counterparts is essentially the same, ie that Ostomates within our community should have access to ostomy related support and medical appliances to assist in their wellbeing, the method of turning that vision into a reality is quite different. The first change has been in the level of post-operative support provided by associations to new members who are experiencing problems with managing a stoma and resuming normal activities. Whereas in the early days this support was largely delivered by association volunteers within the hospital environment, the advent of Stomal Therapy Nursing has extended post-operative medical support for new Ostomates into the recovery and adjustment phase. This has left associations with the role of helping new members to adjust to the practical and social aspects of life with a stoma. The need for this support is dealt with on a more immediate basis than that provided through the earlier concept of coming together in a support group. While there are still gaps in association support, particularly for those Ostomates living in remote areas, these problems have always been present and will continue to be so until such times as associations are funded to provide remote support services. Taking all factors into account however, associations have kept to the vision of providing support when needed even though the methods used to meet modern demands are different.

The second change has been with the availability of ostomy appliances. In this regard associations have excelled beyond the wildest dreams of our early pioneers. Whereas in the early days associations acted as bulk buying groups for a limited number of ostomy appliances to be purchased by members, the perseverance and dedication of our pioneers ultimately led to the introduction of the Stoma Appliance Scheme which provides fully subsidised ostomy appliances to all eligible persons who need them. As a result, associations now collectively distribute a range of over 2,000 fully subsidised Stoma Appliance Scheme listed products with a value of more than $80 million to over 40,000 registered Ostomates per year.

Overall, associations can take great pride in the way that they have kept to the vision of our pioneering founders. Associations must always be prepared though, to balance this vision with the demands of the modern environment and to redefine their systems and to adapt their practices to strive for best practice procedures. For it is inevitable change will come and when it does we must keep open minds, embrace new ideas, find ways to manage our responsibilities and above all, maintain and improve the level of support to our members.

Peter McQueen PRESIDENT

Letters to the Editor

Dear Editor

I read with interest the article regarding *'Responsible Use'*, especially *'Principle 2: Keep an adequate but not excessive stock reserve on hand'* [August 2013 issue of *Ostomy* AUSTRALIA].

How does one manage to accumulate sufficient stock of some appliances to keep some in reserve?

The monthly allowance of the pouch that I use, which incidentally is very good, is only thirty units. As there are thirty-one days in seven months of the year, and as it is necessary for me to change the fitting daily, there is a shortfall. Leakages causing the pouch to be changed more than once a day should also be taken into account.

I have contacted the supplier of the product to ascertain if they are able to suggest to the authorities that an increase in supply could be recommended. I have also written to my local ostomy association which advised that it was necessary to get an authority for additional supplies from one's GP or Stomal Therapy Nurse.

Whilst I can understand that there has to be legislation regarding responsible use, I do however believe that a realistic monthly amount of pouches should be addressed without having to waste the valuable time of one's GP in order to complete the extra documentation required.

I feel that an extra box of ten pouches per quarter is not unrealistic.

J.M., QLD

Dear Editor

Thank you for the timely article, *"Hydration For Ostomates"*, by Margaret Allan [*Ostomy* AUSTRALIA, December 2013].

As an Ileostomate, I found out the hard way, ending up in hospital due to dehydration and a kidney stone. The Urologist who treated me said I would have to be extremely careful in the future due to losing extra fluid through my stoma, and recommended a considerable increase in my fluid consumption.

I can assure readers that the pain from a kidney stone is absolutely excruciating and is worse than childbirth. The treatment initially involved a general anaesthetic to insert a stent then two or three days in hospital. You are then required to return a few weeks later for day surgery to remove the stent and crush the stone. This entails another general anaesthetic and a further one or two days in hospital.

The whole thing is a very painful and inconvenient experience, and all because of lack of fluid.

I trust my cautionary tale is of benefit to your readers.

Holly Fallows, NSW

Dear Editor

Re the Belts and Braces article [*Your Say* - *Ostomy* AUSTRALIA, December 2013], I also had the same problem as my stoma was placed right on my belt-line. Standard braces were not very useful.

However, I bought some great braces after seeing them in a Carba-Tec catalogue. There are two styles and many colour options available Australia-wide via mail-order or online (www.carbatec.com.au), all costing just $14 plus postage and handling.

- Casual Braces - 50mm x 1220mm long. Fully elasticised. Black heavy duty clips and genuine black leather cross patch.
- Construction Braces - 50mm x 1220mm long. Non-elasticised fronts with double-elasticised backs. Black heavy duty clips and genuine black leather cross patch.

These American-made braces have clips that will tear your clothes to pieces before letting go.

Ian, VIC

●

Bulletin Board

Ostomy Association Changes

COLOSTOMY ASSOCIATION OF SA (CASA)

New Name and Location

The Colostomy Association of SA (CASA) has changed its name to **Ostomy Association of SA (OASA)** and have also relocated from their old Torrensville premises to newly renovated and much larger premises at 1 **Keele Place, Kidman Park.**

Ostomy Support Group Changes

FLEURIEU OSTOMY SUPPORT GROUP

New Support Group Established

Meets: 3rd March, 30th June and 20th October from 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor.

Please contact Sue McKay STN for further information on 0412 692 418

The original and still the best way to extra security

SIMPLE, TWO PIECE APPLICATION*

HydroFrame®

Proven track record since 2005

Hydroframe® is the original and still the best flexible hydrocolloid extension, if you want to "picture frame" your pouch to get the security you need.

*2 PIECES provide total coverage, HydroFrame® can give you full protection for the entire month.

- Stop your pouch lifting and rolling
- Fits any 1 or 2 piece skin barrier or flange
- Guaranteed comfort from the soft, flexible edges
- Easy to apply and kind to your skin on removal
- Helps minimise the risk of leakage

Size	SAS Allowance (Aust)
Standard	20 pairs 3 packs per month
Mini	30 pairs 3 packs per month

For more information and samples, please contact our Customer Service Team on:

Freecall 1800 819 274
or samples@omnigon.com.au
www.omnigon.com.au

omnigon
Your healthcare partner

Your Say, In Your Own Write

Sensitive skin? Not a problem for me now!

Submitted by ***Betty****, NSW*

I have been considering sending this tip in for ages but have hesitated in case it does not suit some people – anyway, here goes and I hope I can help someone with this information.

Many years ago, in the 1970s, I had a Colostomy for eighteen months. During that time, I had terrible trouble with the skin around my stoma. My skin is very sensitive and I just could not get it to heal. After having the stoma reversed, I was left with a terrible dread of ever having to go through that agony again.

When it was decided in 2004 that I again needed “the dreaded bag” (for urine this time), I was filled with apprehension and fear, not only about the whole concept but also about how I would manage my sensitive skin.

Sure enough, for the first couple of months I had problems and was not able to get a solution from anyone. Then along came an “angel” in the form of a wonderful home nursing sister who used to look after me all those years ago. We had kept in touch and she always gave great advice. Her advice on this occasion was to “just treat it like you did your baby’s bottom when she was very young and sensitive”. She advised getting rid of all the different lotions and potions and just showering without a bag on the day of changing and treating the stoma as a simple opening similar to a baby’s bottom, not like something from outer space.

This was a great breakthrough for me and every third day I now shower without the bag, using medicated soap (which I have found to be gentle on the skin while thoroughly cleansing). After the shower I pat the area dry, then apply a no-sting skin barrier wipe, allowing it to DRY THOROUGHLY before applying the new ostomy bag. I then hold my hand over the bag for a minute or so, warming it to make sure that the adhesive sticks. It is as simple as that!

I also find it very useful to keep the bathroom free of steam by having the exhaust fan on and, if nobody is around, I leave the door open too. This helps with getting the skin really dry before applying the new bag.

My skin has been fantastic for all this time. I do not have any build-up of adhesive and don't do anything except stick to the above routine.

Good luck to all my fellow bag ladies and gentlemen.

• •

Just a Stone’s Throw Away

Submitted by ***Lee Heylin****, NSW*

On the 12th of June 2013 I attended an Ostomy Information Day seminar along with my very own unofficial Stomal Therapy Nurse [my wife]. This was held at Figtree (near Wollongong, NSW) at a nice venue which was nicely catered for and at a very modest price. We both enjoyed the event and made sense of the line-up of speakers. Some “spraying in the corners to mark their territory” but at the end of the day they were there to provide information that you could digest, and they did. Representatives of the various manufacturers were also in attendance, the old “show and tell”.

That evening I noticed a small lump in my Urostomy bag, which I thought had passed through to the night bag. My wife said it may have been a kidney stone so I sought advice from Dr Google and it was listed as a complaint for those missing the old bladder. Unfortunately this complaint had not been covered during the seminar.

At the end of September I saw my Urologist and I brought the issue of the stone to his attention. He looked at the very current scans and report and said “Well, you are showing no signs of stones now”.

On the 3rd of November I removed another stone from my urostomy bag. It was eight millimetres across. I see my GP this week and will have my stone sent off to Pathology. A lot can be learnt from that by all accounts. For all intents and purposes I did not even realize I was passing a stone.

Initially I did not have a dream run having my bladder removed but I managed with help from Hospital and Stomal Therapy staff as well as six weeks of daily Home Nursing. I developed a serious allergy to a tape around my stoma but my wife thought outside the box and solved the problem.

The lesson learnt over the last two odd years? Your wife is your best (unofficial) Stomal Therapy Nurse as she will notice any changes. No wife? Use a camera to take a photo to note any changes. Always keep your official Stomal Therapy Nurse informed of any problems you have noticed. Think outside the square. Surprising what problems you can solve yourself. As an example I had a particular urostomy bag that did not like urine, and the manufacturer did not even acknowledge receipt of my emails. Share your knowledge to help others.

Those “show and tell” days are very worthwhile and you may learn something.

Sometimes having a stoma can cause a lot of soul searching. On Sunday 17th November the Illawarra community once again come together to support the annual Truck Convoy parade, raising funds for Camp Quality Illawarra which helps to brighten the lives of kids living with cancer and their families. Thousands watched on, not including the endless number of volunteers, all showing support for our youth, past and present. It was pouring rain for most parts of it but it helped wash away the tears. Having a stoma puts you way back at the end

Continued page 10

ConvaTec

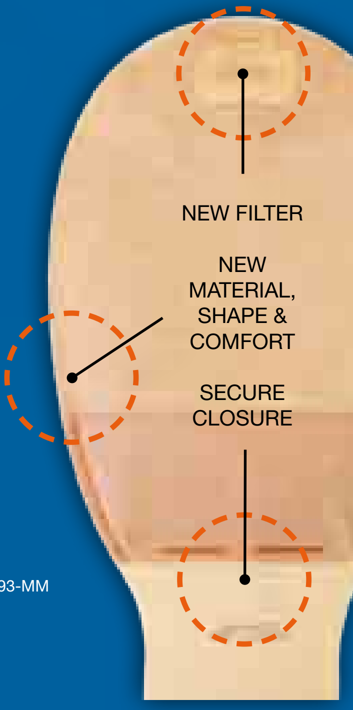
Celebrate the feeling of nothing.

ConvaTec ⊕ Pouches are softer, quieter and more comfortable than ever.

Available in
1-piece and 2-piece
ostomy systems.

ConvaTec ⊕ Pouches feature softer materials, a rounded, more comfortable shape, discreet closures and a cutting-edge filter that let you focus on your life, not your ostomy.

Experience the comfort.
For a FREE sample, call
1800 335 276



Product comparisons are internal product comparisons to existing ConvaTec product. ®/™ Indicates trademarks of ConvaTec Inc. ©2014 ConvaTec Inc. AP-011093-MM

ConvaTec (Australia) Pty Limited. ABN 70 131 232 570. Unipark Monash, Building 2, Ground Floor,
195 Wellington Road, Clayton VIC 3168 Australia. PO Box 63, Mulgrave, VIC 3170. Phone: (03) 9239 2700 Facsimile: (03) 9239 2742.
ConvaTec (New Zealand) Limited. AK2135265 PO Box 62663, Greenlane 1546 New Zealand. Phone: 0800 441 763. www.convatec.com

Continued from page 8

of the convoy in a VW beetle when compared to others. There is plenty of support out there for you!

More Urostomy Helpful Hints

Submitted by ***Albert Ogilvie,*** *TAS*

I have had my urostomy for over three years and have learned to cope well with it. It hardly affects my daily life and I have adopted the following practices, which may be of interest to others.

Night-Bag Stopper - I use a night-bag which allows me to remain in bed all night. The night-bag rests on the floor next to the side of the bed. When going to bed there is always the need to be careful that the bottom outlet tap is closed, especially when away from home, to prevent any unpleasant and embarrassing spills.

I discovered that it is possible to purchase a set of "Rubber Leg Tips" for stool or chair legs from a hardware store, which fit snugly over the end-tube and give a complete seal and peace of mind.

Kits - Every two or three days I use a one-piece pouch, an adhesive-remover wipe and a no-sting skin barrier wipe. When I receive my supplies I pack sets of these three items plus a folded medium size plastic freezer bag into small plastic sandwich bags.

I find it very convenient to just take one of these kits into the bathroom for change-overs and to take the appropriate number of these kits when travelling, especially as I can have some in my suit-case and some in my carry-on bag in case of lost luggage.

When I change my pouch I put all the used items into the sandwich bag, seal it and then put it into the freezer bag which I tie off. This leaves a discreet, hygienic little pack to discard, especially when I am away from home.

Leg Bags - I have cut down the length of the tube on a regular night-bag and attach this modified bag with an elastic strap just below my knee and tuck the bottom of the bag into my sock. This enables me to enjoy dinner parties, movies, plane travel, outings, etc without having to empty my stoma pouch at shorter intervals.

My Innovative Storage System

Submitted by ***Lindsay Campbell***

Tucked away, all neat and tidy

About a week before Christmas I had a visit from Helma, our local Stomal Therapy Nurse. I'd been having a few problems with my colostomy, otherwise known as "George". She needed me to take her to my toilet to show me where I was going wrong in understanding "George's" needs. She was delighted when she saw my setup, saying she'd never seen such a good setup and suggested I take photos and write to the Journal about it.

When I first saw the Bathroom Floor Cabinet advertised in a product catalogue, I reckoned it would be just the thing for all of "George's" bits and pieces, so I ordered one at a cost of just under $80 delivered. My daughter put it together for me and it was exactly what we thought it would be. I have since acquired a second cabinet and now ALL of "George's" gear is safely on hand whenever I need it.

Cabinet 1 open to show compartments

Another idea which Helma thought was good is that I use those small round lint make-up removal pads (obtainable from most supermarkets) along with a tiny spray bottle of water for the extra clean-up that "George" frequently needs and for which I find damp toilet-paper not very satisfactory. The spray bottle and a few pads tuck neatly into my travel pack.

•

Cabinet 2 showing lint pads and water spray bottle on top

NEW

Change your life with the latest 1- and 2-piece convex appliances

NOW AVAILABLE WITH ALOE EXTRACTS

The Salts range of 1- and 2-piece convex appliances features **the latest technology.** These new appliances provide **greater adhesion, absorption and mouldability** and can significantly help to improve your chances of **stopping leaks and sore skin.**

Confidence® Natural Soft Convex

- Soft convex insert for flexibility and comfort
- Stickier, stronger adhesive for added security
- Infused with extracts of Aloe Vera to help soothe and protect skin
- Improved filter system *(drainable)* to help prevent 'ballooning'

Harmony® Duo convex with Flexifit® & Aloe

- Stronger, stickier hydrocolloid for extra security
- Infused with extracts of Aloe Vera to help soothe and protect skin
- Easy to apply, with intelligent wafer locator
- A wide range of closed and drainable pouches is available

17%

higher adhesion*

5X MORE

resilient to breakdown*

FOR FREE SAMPLES call TOLL FREE 1800 784 737 (NZ 0800 100 146)
or visit www.ainscorp.com.au

*Compared to our standard hydrocolloid. Data on file at Salts Healthcare Ltd.

AinsCorp

BRITISH SKIN FOUNDATION
Recognising Salts research into healthy stoma skin

SKIN HEALTH ALLIANCE
DERMATOLOGICALLY ACCREDITED

SALTS HEALTHCARE
www.salts.co.uk

® Registered trade marks of Salts Healthcare Ltd. © Salts Healthcare Ltd 2014. Products and trade marks of Salts Healthcare Ltd are protected by UK and foreign patents, registered designs and trade marks.

From Health to Hell and Back

Phillip's Story

Submitted by: ***Phillip Watt****, QLD*

My wife and I have lived on Moreton Island in Queensland for sixteen years and operate a small real estate business specialising in holiday accommodation. I had been in pretty good health throughout the first fifty-eight years of my life, despite the usual excess. Fortunately I quit smoking two years earlier.

Despite my father having died from bowel cancer, I was still shocked when a polyp removed during my regular colonoscopy in November 2010 tested positive for cancer!

Whilst there was a fear of the unknown, my surgeon was confident that the cancer could be removed and I would be back to normal in no time after some follow-up chemotherapy. Being a "glass half full" type of person, I had a positive attitude and was confident I would overcome my battle with cancer, although I had to postpone the start.

For the six months prior to my cancer diagnosis I had been experiencing increasing episodes of pain in my chest, jaw and left arm. My GP assured me that it was anxiety and gave me some relaxant medication. These episodes became more frequent and were longer lasting. My wife, who had never accepted the GP's diagnosis, approached a specialist who was holidaying on Moreton Island and asked if he could take a look at me. This was on New Year's Day 2011 and within one hour I had been diagnosed with acute angina, booked into hospital and a heart specialist had agreed to operate as soon as possible. So my bowel cancer operation had to be deferred and the angiogram proceeded, resulting in me having two stents inserted to fix three 90% blockages. All agreed that it was a miracle I was still alive.

In March 2011 I was booked into the Oncology Ward at the same hospital for my rescheduled bowel cancer operation. I was taken to surgery where I discussed the operation with my surgeon and anaesthetist, went to sleep and woke up in ICU only to be told that the operation did not proceed (which explained why I felt so good and there were no tubes etc) because my heart had started to "race" whilst I was on the operating table and the anaesthetist had decided to stop the operation.

I was transferred to the Heart Ward where they performed tests to diagnose the problem, which was a minute piece of skin attached to the side-wall of a vein on the outside of my heart. This required an operation called an Ablation and my bowel cancer operation was again deferred until I had recovered.

In April 2011 I was back in the operating theatre and all positive about finally getting rid of the cancer. The operation was considered a success and I did not get the temporary stoma which I had been marked out for. However, there were some concerns about the "margins" and was advised that if there were any cancer cells left, they should be killed off by the chemotherapy treatment.

In May 2011 I had my first appointment with the oncology specialist, who was also located within the same hospital. He advised me that the best treatment for me was to undertake a program of monthly intravenous sessions followed by tablets for the next twenty days and then a week off, to be continued over the next six months. Little did I know how bad the next eighteen months would be.

Whilst I had recovered well from my operation, I was experiencing trouble with my bowels, in that I was always going to the toilet, sometimes up to twenty-plus times a day. There was no pattern to it, except that once I started it could take several hours to finish and resulted in my anus bleeding from all the wiping. This went on for twelve months. The doctors advised me that these issues were partly a result of the operation and my bowel having to learn how to function all over again, plus the chemotherapy side-effects.

I was also experiencing severe side-effects from the chemotherapy. I was constantly tired and could not touch anything cold (which I solved by wearing a gardening glove when I held a glass of wine). I also experienced mouth ulcers and everything I ate had a metallic taste, except for peanut-butter. And of course the chemotherapy was also having an effect on my bowel function.

I finished my chemotherapy treatment in August 2011 but the issues were still there and on it went with little or no improvement. My quality of life was terrible and I was of little or no help in assisting my wife with the running of our business. I could see no end to all this. I was still in pain and did not want to see or talk to anybody. I just took my pills, toileted and read books. That is no life and it was very hard to maintain a positive attitude, but the doctors were still confident things would get better.

By November 2012 I was over it. Above everything else, I could no longer handle the constant pain. I decided to go to Brisbane and see my GP and ask for some stronger medication and was prescribed Celebrex. I went back to my motel room and starting "eating" these tablets, but by midnight the pain was still there and getting worse so I ended up in Emergency at the same hospital and asked that they stop the pain.

I was given morphine, which solved the problem and was checked into hospital to undergo tests and scans that showed nothing suspicious. Whilst in hospital my colostomy surgeon came to see me and it was decided that I should have a procedure to tighten my anus, which would help with ongoing bowel problems. I returned home with new pain medication and waited for things to improve, which did not happen. We did not have a very good Christmas.

Whilst there had been some bowel control improvement, by April 2013 I had again reached a point that I could not tolerate the constant pain. I kept saying that it felt like "someone keeps kicking me in the backside". So it was back to Brisbane, into Emergency at the same hospital and I again requested they fix the pain. Unfortunately, a PET scan revealed that the cancer had returned (that's assuming that it ever left) in the same spot, but was now growing outside the bowel wall. At least I now had my answer as to why I was still in pain.

On the same day of the scan, I saw my bowel surgeon and oncologist plus was introduced to a radiation oncologist and a plan was put in place to again remove the cancer. I was to have six weeks of daily radiation, along with six weeks of 24/7 chemotherapy in an effort to reduce the size of the tumour prior to operating. This first required having day surgery to have a Port-a-Cath inserted through which the chemotherapy was to be injected from a pouch on my hip.

Life seemed to be going from bad to worse. I was still dealing with the side-effects from the original chemotherapy treatment and I had now started a new course. Everything turned ugly and eventually I again presented to Emergency with unbearable pains in my stomach where they treated me with more morphine, which always stopped the pain but did not fix the problem. Scans showed that the chemotherapy had stripped the internal lining from my bowel, so they suspended the treatment for a week.

Meanwhile I continued with the radiation with the major side-effect being a very sore anus, which felt like it was badly sunburnt. That whole anus/bowel thing was a mess, and I could not wait to have my operation so it would all be fixed - hopefully.

Having waited a further six weeks for things to settle down, I was ready to have my second bowel operation in August 2013. It was explained that this time they would be opening my pelvic area and depending on what they found, possibly also around my anus. I was also told that I would have a permanent stoma.

The operation took five hours. When I awoke, I could not believe what had happened. Besides a twenty centimetre wound across my pelvis, I also had a huge scar down my bottom, which was very swollen and sore. I also had the promised stoma along with a drainage tube in my stomach and a catheter. I was on self-administered morphine for the pain and could not get enough of it.

They got me out of bed the next day and my rehabilitation started. The wounds started to heal, the tubes were removed and after ten days I went home with a supply of Endone and Panadol to keep the pain under control.

I quickly came to terms with the stoma and in some ways was thankful that my bowel issues had been resolved. However I was again having trouble keeping the pain under control. In September 2013 I went to Emergency again and was given morphine and another scan. This showed a pocket of nasty infected fluid trapped within my wound, hence the pain. I had a "pigtail" inserted to drain this fluid. After a week in hospital I was discharged with my pigtail still in place. This continued to drain and was finally removed when I went for my scheduled check-up six weeks after the operation. I was still in pain.

Five days later the pain was worse and I was in danger of overdosing on Endone, Panadol and anything else I could get my hands on. For the first time since this ordeal started three years ago, I had slipped into a dark place, was struggling to maintain a positive attitude and was beyond caring about anything.

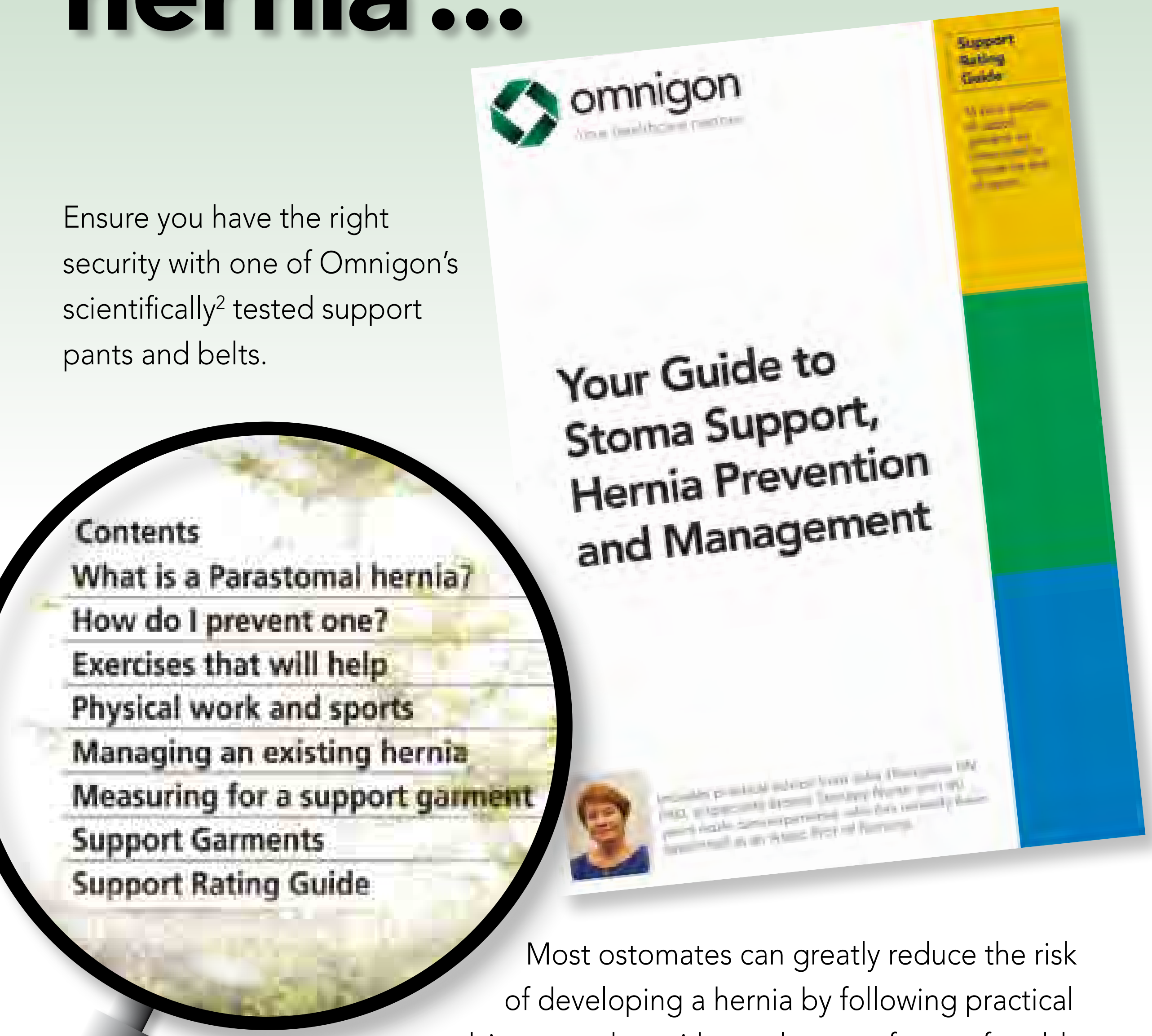
After a very bad weekend, my wife and I went to the hospital for help and some answers. We just turned up at the Oncology Ward and the wonderful staff took us aside, talked us through the issues and explained that this was not uncommon and things would get better. They gave me a new plan to medicate the pain and assured us that things would turn around. So home we went.

By October 2013 things were no better and I was still in constant pain. What was worrying me was that it felt like the same pain I had when all this all started and so I assumed that the cancer had returned yet again. So back to Brisbane and into Emergency and I said I was not leaving

Continued page 16

3 out of 10 people with a stoma will develop a hernia[1]...

Ensure you have the right security with one of Omnigon's scientifically[2] tested support pants and belts.



omnigon

Support Rating Guide

Your Guide to Stoma Support, Hernia Prevention and Management

Contents

What is a Parastomal hernia?

How do I prevent one?

Exercises that will help

Physical work and sports

Managing an existing hernia

Measuring for a support garment

Support Garments

Support Rating Guide

Most ostomates can greatly reduce the risk of developing a hernia by following practical advice, together with regular use of a comfortable, well fitted support garment.

Support Rating **3** **MODERATE**

Support Rating **4** **INTERMEDIATE**

Support Rating **5** **FIRM**

---

[1]: Data on file Omnigon 2012 [2]: A review of 16,470 on the American United Ostomy Association Register revealed 30% incidence over all types of stomas. (Gray et al, 2005)

Please contact our Customer Service Team for advice on how to correctly measure yourself for a Support Garment and to receive a FREE copy of "Your Guide"

Diamond Plus Boxers & Briefs

- Advanced seamless technology
- Extra support with diamond double panel

Men's Support Pants

- Firm yet flexible support
- Available in standard and high waist

Diamond Plus Waistband

- Seamless circular knit which moves with the body
- Discreet and comfortable support

Support Briefs for Her

- Comfort of pants with the benefit of a belt
- Discreet yet very supportive

Isoflex

- Excellent support for all activities
- Cotton based fabric provides an even balance of comfort and support

Total Control

- Infinite adjustment for the correct support
- Slimline belt with firm support

KoolKnit

- Aerated fabric-perfect for active people
- Moulds to the body to provide firm support

Australian Stoma Appliance Scheme Allowance:

Allowance per calender year is:

6 pairs of support pants

OR

3 support belts

OR

A combination of both

1 Support belt =
2 pairs of support pants

Continued from page 13

until someone stopped the pain. I was admitted to hospital where blood tests and a scan both came back negative for cancer, which was a great relief but I still had pain.

A pain specialist came to see me and after some discussion, said he thought the pain was due to nerve damage suffered during the operation, which is a common occurrence. He said it would settle in time and prescribed Lyrica, which blocks out the pain signals to the brain. It did the trick and I was somewhat pain free. It was manageable at last.

From then my health radically improved. I continued with this medication for about three weeks and realised that the pain had diminished. After another couple of days the pain had gone! Around the same time, the swelling in my backside finally subsided, the colour returned to my face and I felt human again. Unbelievable!

But my journey had not finished just yet. My bowel surgeon said that when I had fully recovered, he wanted me to see the Stomal Therapy Nurse and have her teach me how to irrigate! To do what? So I Googled it and found it was like a colonic irrigation, except the water went in through the stoma. So in November 2013 I had my irrigation lesson and then did it myself the next day, and at the same time each day after that, which for me is in the morning after breakfast. The process takes about thirty minutes.

One week on and I cannot believe the difference to my life. After I have irrigated I don't even need to wear an appliance as there is no bowel action until I irrigate the next day. The reality is that I cover my stoma with a Band-Aid though I do still wear an appliance at night just to be safe. They say I may be able to extend my irrigation period to once every three days. How good is that? I HAD MY LIFE BACK !

Throughout my ordeal, I could not find fault with any of my doctors and clinical staff, the hospital and all the nurses, ward, theatre, catering and cleaning staff and the Stomal Therapy Nurses. Thank you all for your skilful treatment, support and caring. ●

Looking back, there are a number of lessons I have learnt from my experience:

1. Ask question and get answers

I was reluctant to ask too many question for a number of reasons. Maybe I didn't want to hear any more bad news or take up too much of the doctor's valuable time. Maybe I did not want to give the impression that I was scared! Whatever the reasons, I should have asked more questions. I remember I was angry when I woke up from the major operation; I could not believe what they had done to me. It had been explained but I was not listening and I did not ask for more detail. It may also help to write down your symptoms and the questions you want answered.

2. You do not have to live with pain

If you are experiencing pain you must keep asking why and what can be done to fix the problem. There is a long list of pain killers and blockers that can control pain without major side-effects. It is also important to keep taking your pain medication to maintain the pain at a manageable level. Don't let the pain build up until it's unbearable and then start with the medication.

3. Let family play a role in your recovery

It is true that you cannot fully understand what the patient is going through unless you have experienced a cancer diagnosis. However, it is important that you involve your family and tell them how you are feeling, if you are not coping and that you appreciate their support. It is also very helpful to have family involved in your medication plan as it is easy to get your dosages confused. Don't hesitate to seek professional help if you are having trouble dealing with everything.

4. Understand the financial costs involved

Having top level medical/hospital insurance is no guarantee that you will not incur significant expenses. The cost of scans can be significant, and if you are an out-patient there can be a large shortfall in your refund. Also with anaesthetists, who may invoice an amount but offer a significant discount if paid within thirty days. This deadline could easily be missed which costs you hundreds of dollars. Then there is the ongoing medication; generic brands and discount pharmacies should be considered.

5. Allow plenty of time to recover

Yes, they get you up and walking within twenty-four hours and it's important that you keep this exercise up. It's good for circulation, breathing and muscle tone, and will get you home sooner. However, you must rest and listen to your body. Going back to work before the body has fully recovered will extend your recovery time.

6. Maintain a positive outlook

We all know the benefit of positive thinking but it's hard to keep it up, particularly when you are in constant pain, in and out of hospital, having tests and treatment. But if you give in and just accept your lot, things will get worse and this also affects those around you. Things could always be worse, and there is always someone worse off than you. Stay positive.

Change your life with Simplicity®

Simplicity® stoma support wear is made from a lightweight breathable fabric which contains no cotton. Soft and comfortable, the two-way stretch fabric allows you to move around freely, while ribbing on the front provides a flush finish, making your pouch virtually invisible. And now, our ladies' briefs and unisex boxers are available in a discreet, neutral colour – perfect under any clothes.

Ribbed fabric for secure pouch support and flush finish

Deeper, higher waistband covers the pouch for extra comfort

Soft and comfortable against the skin

Available in black, white and neutral

Virtually invisible under most clothing

Lightweight and breathable antibacterial fabric

XXL SIZE

Available in a full range of sizes, including XXL

ASSOCIATION MEMBERS ARE ENTITLED TO

6 PAIRS

OF SUPPORT WEAR PER CALENDAR YEAR

CALL TOLL FREE 1800 784 737 (NZ 0800 100 146)
or visit **www.ainscorp.com.au**

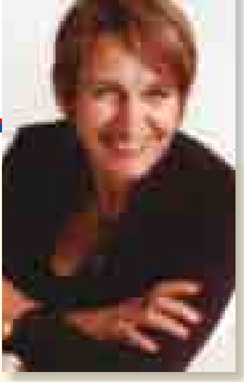
AinsCorp

Simplicity® STOMA SUPPORT WEAR

SALTS HEALTHCARE
www.salts.co.uk

Ask Carmen

OUR Stomal Therapy Nurse



Dear Carmen

I have a urostomy and get frequent Urinary Tract Infections (UTI) so am frequently on antibiotics which make the skin around my stoma very red and sore. What creams can I use that won't affect the adhesion of my appliance?

In between infections my doctor has me taking Hiprex anti-bacterial tablets, which I can't take at the same time as antibiotics or else they work against each other, but I still get frequent infections. My doctor says that I am past taking cranberry juice, which doesn't help me anyway. Often I feel quite ill with the UTI and on one occasion ended up in hospital for several days because of it.

I would be grateful if you or any Ostomates have any solutions to this problem?

Thank you, P.W.

Dear P.W.

I am sorry to hear of your problem with frequent UTI, which are unpleasant as they do make you feel very unwell. You may also notice your urine's odour and colour will alter before any other symptoms, plus your stoma may produce more mucous.

I don't think it is the antibiotics that make the skin around your stoma red and sore. It will be exposure of that skin to urine. Your normal skin-barrier may require more frequent changing or you may benefit from adding a seal to the skin immediately around the stoma. I would recommend using an Eakin seal as it is highly absorbent and has some antifungal properties as well. It may be worth seeing your Stomal Therapy Nurse and ensuring that the appliance's skin-barrier is the correct size.

If you do want to add something to your skin directly before applying the seal/skin-barrier then I suggest you avoid crèmes but instead use a no-sting wipe. Some of the companies have these: 3M's Cavilon No Sting Barrier Film Wipe or Welland's WBF No Sting Barrier or Coloplast's Brava No Sting Skin Barrier Wipe. These need to be applied to clean and dry skin and are available through your ostomy association.

I am sure you are well aware of the importance of basic hygiene when handling the outlet tap, night connections and any time you touch the stoma or skin around the stoma. Making sure your hands are clean and dry before doing this and cleaning all equipment thoroughly can really assist in preventing infections. Drinking plenty of fluids may also help. I am sure you do all this but it is important to persevere.

I will be interested to hear what other suggestions our readers have.

Sincerely, Carmen

Dear Carmen

It was with great interest that my husband and I read an article by M.S. [Ostomy AUSTRALIA December 2013 - page 24], which dealt in part with a high output ileostomy and dehydration.

My husband has been an Ostomate for twelve years and this is the first time we have found a reason for him always being tired and eating salty and sugary foods. I can now understand why he adds so much salt to his food and uses so much sugar on everything.

It seems that dehydration is more of an issue than we imagined and we don't have to put up with it after all. I wonder how many others are having the same problem and whether you would be able to supply more information please.

M.S. also noted that her Stomal Therapist suggested a medically developed drink formula combining glucose, salt and bicarbonate soda in exact amounts in water and with a little cordial, which she makes up daily and sips throughout the day. If possible, could you provide a recipe for this or a similar drink formula for my husband.

Thank you, Jan D. NSW

Dear Jan D.

I think the solution M.S. was talking about is what is known as St Mark's solution. St Mark's is the famous United Kingdom hospital which specialises in diseases of the gut. I have taken the recipe directly from UK patient information brochures. We use it here frequently and most hospitals can make it up for in-patients but on discharge it is easily made at home. It may be worthwhile checking with your GP that there are no contraindications with your husband having additional sodium bicarbonate.

Also, to reduce output volume it is probably advisable to reduce your intake of fluids which don't offer any nutritional or electrolyte value (such as water, tea and coffee) down to one litre in each twenty-four hours, and drink this along with one litre of the St Mark's solution.

St Mark's Solution

Make up a fresh solution every day with:

- Sodium bicarbonate 2.5g (measure using one heaped 2.5ml spoonful)
- Glucose powder 20g (measure using six level 5ml spoonful's)
- Sodium Chloride 3.5g (measure using one level 5ml spoonful)
- Make this up to one litre with tap water and stir well until all powder is dissolved.

The taste of the mixture may be improved by keeping it chilled or by adding a small amount of fruit squash (lemon flavouring is most effective).

The solution should be sipped throughout the day.

I read the other reader contributions under the Weight Control for Ostomates with a high-output stoma and they all give good advice and share what works for them.

Slowing the gut down so that more fluid is absorbed can sometimes be achieved with medications such as loperamide and codeine phosphate.

As far as fibre is concerned: when one has an ileostomy fibre is not needed to prevent constipation as the ileostomy is upstream from where it is most effective (i.e. in the large bowel). Further, for some people with an ileostomy, strands of insoluble fibre collecting together may cause a bowel blockage whereas soluble fibre can have an absorbing and thickening effect without the potential to cause a blockage. Commercially available products such as Benefiber might help or there are lists of foods containing soluble fibre available from dieticians or via reputable websites. Anecdotally, consuming rice water also has a thickening effect on stoma output as do most starchy foods.

It is probably worthwhile that your husband has his electrolyte levels checked regularly by his GP.

Sincerely, Carmen

NEED MORE HELP?

Please send any questions or concerns you might have to Carmen, our journal's Stomal Therapy Nurse.

Ostomy AUSTRALIA *does not endorse the contents of readers' letters nor do we vouch for the accuracy of any claims made in those letters. Readers should not rely on any such claims in the absence of medical advice and should consult with their treating doctors prior to embarking on any course of treatment.*

A Hollister Technology

New Soft Convex Skin Barrier

Designed with the Individual in Mind

Introducing the new range of **Moderma Flex** closed one-piece pouches with a soft convex skin barrier. Designed especially for individuals that will benefit from the conformabilty, and flexibility that Hollister soft convexity offers.

- Designed to conform to an individual's body shape which may help form a closer seal
- Offers comfort and security that people with ostomies desire
- Incorporates the technologically advanced features you expect from Hollister
- May help to minimise the need for additional accessories to create an effective fit

For more information or samples
Please Call 1800 279 179

Hollister Ostomy. **Details Matter.**

Hollister

www.hollister.com.au

The Ostomy Movement in Australia: Opportunities and Challenges

Technology gives associations an opportunity to streamline operations and recapture some of their original purpose as support organisations, GEOFF RHODES writes.

I am writing this discussion paper from the perspective of someone who has been an Ostomate for fifty-four years, and who was involved in the movement almost from the beginning. I raise these issues as a member of the ACT and District Stoma Association (ACTDSA) and not in any other role.

I acquired my stoma at the age of nine and attended the early meetings of what is now Ostomy NSW Limited from 1960. In the late 1970s I joined the committee of the Ileostomy Association of NSW (now ONL) and remained until I took up a job in Canberra in 1985. I have been a Committee member of the ACTDSA for eleven years, including seven as President. I was elected ACSA Vice-President in 2010 and in that position have acted as the ACSA Liaison Officer with the Department of Health, a role that includes representing ACSA on the Stoma Products Assessment Panel (SPAP).

I have included this biographical information because it outlines the experience which has led me to identify what I feel are the opportunities and challenges that our federation of associations will face in the coming years. In his messages to members, both in this edition and the December 2013 edition of *Ostomy* AUSTRALIA, Peter McQueen (ACSA President) has reviewed the history and evolution of the ostomy movement in Australia to date.

In his messages, Peter has identified two primary functions by which associations support Ostomates. These are:

- distributing appliances under the Stoma Appliance Scheme (SAS); and
- providing emotional support and encouragement.

I have deliberately listed the functions in this order because I have observed that this is the priority that most member associations give to their activities. I would suggest it is not their preferred priority but is a result of the need to accept and process the orders for appliances submitted by our 40,000 members around Australia. Initial analysis would indicate that at least half of our 40,000 members have their appliances delivered rather than collecting them. This means that associations are, collectively, running an $80,000,000 a year distribution business which has at least 20,000 mail-order customers.

The introduction of Stomal Therapy Nurses (STN) has significantly improved the clinical management of stoma patients. They have eliminated a significant part of the need for Ostomates to provide support and expertise for their fellows — the kind of support that I and my parents were so grateful for in those early post-operative months and years. However, from personal experience I believe that a large number of people who are facing ostomy surgery also benefit from meeting and talking with Ostomates who have been through the experience and emerged with a successful outcome, and a positive outlook on returning to their pre-surgery life.

To a large degree those visit/interaction programs have fallen away as associations have been obliged to apply their limited volunteer resources to supporting the extensive and expanding SAS distribution activity.

A significant challenge for all associations and Ostomates is to both:

- manage and maintain the expanding SAS distribution responsibilities; and
- provide the emotional and social support essential for people to adapt effectively and successfully to life with a stoma.

How can that challenge be met?

I have spent over thirty-five years working with information technology (IT), which I have come to regard as an enabler, not a panacea. When the SAS was introduced, IT was in its infancy, extremely expensive and complex. The number of ostomy appliances was limited and manual systems were effective in managing supplies for the smaller number of Ostomates. Over time, IT systems were developed that allowed associations to better support the SAS activities. At the same time the number of associations increased to support the growing number of Ostomates.

In the thirty-eight years since the SAS was introduced, technology has advanced at an astounding pace. Therefore, I ask, how can associations use technology to enhance and improve the delivery of the full range of support that was envisaged and delivered in those early years?

In 1980 I joined an internal management consulting group in the Department of Defence. I was part of a team that was asked by the RAAF Operational Commander to review headquarter functions and see how IT could improve the efficiency of Air Force operations. The advice we ultimately provided is also valid for ostomy associations today. Our advice, which provided the basis for the systems that were developed, was to look closely and critically at structure and process as well as technology.

As a group of associations we need to look not only at technology but also at the way we are structured. We need to ensure that we can retain and enhance personal face-to-face support services at the same time that we deliver supplies to an expanding client base. To do this we need to collectively and critically review our structures and processes and embrace positive change.

Can we honestly say that an organisation, system and structure that was developed and established during the 1970s is appropriate to carry Ostomates through the 21st Century?

I think not. I would therefore encourage all associations and members to think about these issues:

- Do we need twenty-two associations to be engaged in mail-order distribution?
- Can we restructure ourselves to deliver the same or better face-to-face services under a different management model?
- How can the professional expertise of STNs be better integrated and deployed?
- How can we use our volunteers more effectively to support new Ostomates?
- How can we work more efficiently with suppliers?
- How can we work more effectively and efficiently with Government agencies to deliver the Scheme?

We have an opportunity to work in partnership with Government and suppliers to change the way Ostomates are supported. However, it will require more than just a technology update. It will need an open-minded analysis and a critical review of the way in which associations achieve our Charter and meet our obligation to all Ostomates in Australia.

I have no doubt that all areas of Government expenditure will come under review. The Stoma Appliance Scheme will again come under scrutiny by both the bureaucracy and the Government. I would prefer that we Ostomates initiate positive change and control our own destiny.

The Stoma Appliance Scheme came about because associations worked together to develop a process and procedure appropriate to the political climate and technology of that time.

Collectively, we are at a juncture where associations need to recapture that spirit of collaboration and act to bring about the kind of change that will sustain us in the future. ●

New Zealand Ostomy Societies Inc

2014 Annual Conference Invitation

The Federation of New Zealand Ostomy Societies Inc would like to extend a warm welcome to anyone from Australia who would like to attend our 2014 annual conference, which is being held over the period 1 - 3 August 2014 in the fantastic tourist centre of Rotorua in the central North Island.

A very good range of speakers have been arranged, covering topics of medical and outside interest plus a dinner-dance on the Saturday evening.

In New Zealand we have a very strong emphasis on encouraging youth Ostomates and so would love to see participation in the conference by young Australian Ostomates as they are the future of all our organisations. Provided we can get enough Youth and Parent registrations we will hold a separate function just for them at a local adventure park during the day on Saturday.

We are hosting the conference in the Hotel Millennium which is a beautiful hotel and conference centre located just a brief stroll from Lake Rotorua, the world famous Polynesian Spa, the town centre and only minutes from Rotorua's key tourist attractions and adventure activities. Those from Australia who attended the 2006 conference, which was also held at this venue, will be able to testify just how nice it is.

Please contact me by email or phone if you are interested in attending our conference and I will send you further information.

The Millennium is a four-star deluxe hotel with 227 individually air-conditioned rooms, each with ensuite, colour TV, Sky TV, DDI with voice mail, modem, refrigerator and mini bar. The hotel also has an indoor swimming pool for guests to use. We have arranged a very competitive hotel room rate for people attending the conference and this rate would extend for the duration of their stay after the conference. Hotel bookings can be made directly with the Hotel Millennium reservation coordinator on: phone +64 7347 1234, fax +64 7348 1234 or by email to jenny.matchitt@millenniumhotels.com

Rotorua is both a tremendous starting point and major destination for a New Zealand holiday so we recommend that anyone attending the conference should try to extend their stay for a great New Zealand holiday. As organisers, we would be happy to make suggestions as to what people might see and do. ●

Richard B. McNair
President: Federation of NZ Ostomy Societies Inc
Phone: +64 7 5737443
Mobile: +64 274 749 812
Email: richardmcnair02@gmail.com

Do you worry about leakage? Think ag

FACT

#1

The number one worry of people with a stoma is

leakage[1]…

60%

… and this with good reason, since more than 60% of people with a stoma experience leakage… with negative consequences for quality of life.[1]

PROBLEM

6 months

Body changes during the first six months following surgery cause leakage

Typical changes are:

- The stoma matures and changes
- Gaining/losing weight
- Scars healing
- Outward bulks, cavities and folds may develop

Leads to changes in body profile compared to body profile at time of discharge.

This can cause a mismatch between appliance and the current body profile, causing leakage.

A reassessment of body profile is then required.

> “Soon after surgery I started to put on weight again, and the pouch I had did not fit anymore”.
>
> – Tony Langham, Australia, ostomate

ain. Think Brava™

SOLUTION

BAGS

Do you have an ileostomy or use a drainable bag?

Do you have a urostomy or use a bag with a tap?

2 RECOMMENDED SOLUTIONS FROM COLOPLAST ARE:

Brava™ Mouldable Rings

Brava Mouldable Rings create a tight durable seal providing extra insurance against leakage. They are soft and flexible, without any hard edges to avoid irritation.

Brava™ Elastic Tape

Brava Tape is ELASTIC - it adapts to changes in your body contours while preventing the edges of your baseplate from rolling and lifting. This ensures your baseplate stays firmly in position when moving around.

Call Coloplast on 1800 653 317 for free samples

au.care@coloplast.com

References

1. Data on file

www.coloplast.com.au

Coloplast

Bright Lights Signal Bright Future For Ostomates

Submitted by: Bob Newman, Ostomy NSW Ltd

Extracts courtesy of the Cowra Guardian

Georgie Hodder from the **Cowra Ostomy Friendship Group** has plenty of reasons to be smiling right now.

Their traffic-stopping Christmas light display at 65 Lachlan Street in Cowra raised a grand total of $1,230.20, more than tripling their fundraising total from 2012, as well as taking out top honours in the annual Cowra Guardian Christmas Light competition. The prize for their winning Christmas Light Display was a $100 gift voucher from a local business, which will be used to purchase something to go towards another raffle or to purchase some pens with “Ostomy” printed on them which could then be sold to raise more funds in 2014.

Ms Hodder said that she was blown away by the response to their annual Christmas light display, which featured thousands and thousands of bulbs, glow-sticks and sweet treats. Even the children were decorated and Santa also dropped in on Christmas Eve to hand out presents to passers-by from a roof-top perch.

"We had people come back two or three times to donate," Georgie said. "Being in the busier area got us a better response."

With festive ornaments and lollies in abundance, Ms Hodder said that it's a great fund and awareness raising exercise to get the community talking about an issue that often doesn't spend any time in the spotlight.

Georgie is one of nearly 40,000 Australians currently living with a stoma - or ostomy - a surgically created opening where a small section of the bowel, colon or small intestine is rerouted to allow waste evacuation when a person has lost normal bowel or bladder function. This could be due to disease or injury; however some people are born without normal function and need to wear a bag for their whole lives.

Ms Hodder gave a huge thank you to everyone who donated and reaffirmed the Group's commitment to their campaign to bring a Stomal Therapy Nurse to Cowra for a clinic once or twice a month, to save people having to travel to Orange or Bathurst for check-ups. Training in the field can be funded through a scholarship to the value of $5,000 with Ostomy NSW Ltd (ONL), and the Group would love to see a local nurse step up to the plate.

"We still really want a nurse to step up and say 'Hey, I'll do that!'," Ms Hodder said. "We had a lot of nurses interested in the display. A lot didn't come from here either, some nurses actually travelled over from Canberra and Orange. We had nurses saying how well we'd done to bring this out in the open, that it needs to be brought out into the open."

The Group’s other major fund-raising for 2013 was their annual raffle, with prizes of a Gastronaut® hand-puppet (Janet) as well as Nivea products and a dart-board donated by local businesses. Drawn on 4th December, members Shaun Platt and Gaye L’estrange, plus Georgie’s grand-daughter Topia, assisted with the sale of raffle tickets.

Along with the $1,230.20 received during their Christmas Light display, the Group raised a further $505.35 from the sale of raffle tickets, lilac ribbons and donations, which culminated with a cheque for $1,725.55 being sent by the Group to ONL for their Stomal Nurses Education Fund.

Georgie was also instrumental in forming the Cowra Ostomy Friendship Group to support people in Cowra living with a stoma. They meet once a month at The Terrace to talk bags and bodily functions over a cup of coffee. “It's also great to debrief with people who understand the challenges of having a stoma,” Ms Hodder said.

"I started the Group because after I had emergency surgery, I didn't want to be alone with it. It's not an easy thing to deal with. You can say to your family and friends that you have it but they don't really understand unless they actually have one."

"No one wants to talk about this sort of thing because it's got to do with your bowel and your bladder," Ms Hodder said. "No one wants to step up and say 'I've got a bag' but you've got to do it to get that awareness." •

Ostomates who would like to join the **Cowra Ostomy Friendship Group** please contact Georgie Hodder on 02 6342 4160 or 0422 678 141. Members of the group do not have to participate in fundraising and names can be kept confidential.

Essential
to daily care

Repeated adhesive use on vulnerable skin may cause a range of on-going issues:

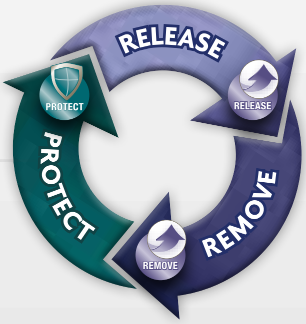
- Pain & stinging
- Skin stripping & trauma
- Irritation & redness
- Residue build up

Introducing the newest additions to the ConvaTec line of skin protection products! Designed to be used together – to keep skin healthy.

A versatile, full line of adhesive releasers, removers and skin barrier products designed to protect vulnerable skin from the damaging effects of adhesives, body waste and friction.

☑ Sting free[1] ☑ 100% Silicone-based[1] ☑ Fragrance and dye free ☑ Fast drying

☑ Residue free ☑ Hypoallergenic[1] ☑ CHG compatible[1]



Release, Remove & Protect to keep skin healthy & reduce pain.

Niltac™ Sting Free Adhesive Releaser Spray:

Easily and rapidly releases appliances or dressings adhered with adhesive[1]

- Helps minimise trauma to patient with "No Touch" removal
- Helps minimise skin stripping that causes pain

Niltac™ Sting Free Adhesive Remover Wipe:

Quickly removes adhesive residue

- Fast drying with no residue left behind
- More coverage: the largest wipe with generous 3ml saturation[1]

Silesse™ Sting Free Skin Barrier:

Creates a breathable barrier that protects the skin from damage caused by adhesives, body waste and friction

- Ideal for daily use: no residue build up or bonding to skin folds
- On-going skin protection for up to 72 hours[2]

Call 1800 335 276 for your free samples

Reference: 1. Data on file. ConvaTec Inc. 2. Voegeli D, LBF® "No-Sting" Barrier Wipes: Skin Care Using Advanced Silicone Technology. British Journal of Nursing, 2008; Vol. 17: No. 7

See package insert for complete Instructions for Use.

ConvaTec (Australia) Pty Limited. ABN 70 131 232 570. Unipark Monash, Building 2, Ground Floor,
195 Wellington Road, Clayton VIC 3168 Australia. PO Box 63, Mulgrave, VIC 3170. Phone: (03) 9239 2700 Facsimile: (03) 9239 2742.
ConvaTec (New Zealand) Limited. AK2135265 PO Box 62663, Greenlane 1546 New Zealand. Phone: 0800 441 763. www.convatec.com

Travelling with a Stoma

Submitted by: **Kerry Kimbrey,** NSW

Recently my husband and I returned from a two-month overseas cruise holiday, which turned out to be quite an organisational feat following my colostomy surgery in August 2012. We spent four days in each of London and Paris, followed by a seven-week cruise back to Sydney via South America.

We had originally booked to go in March 2012, but due to the unexpected discovery of a bowel tumour, we cancelled just one week before sailing. However, following six weeks of radiation and chemotherapy, fourteen weeks recovery, a non-reversible colostomy and fourteen more weeks of chemotherapy, we've finally had our overseas holiday.

Before leaving I had a very active stoma (due to the chemotherapy) and was using five ostomy bags every day. Because I still had the chemotherapy very much still in me, I had to plan on using five bags each day. This meant taking three hundred for our sixty-day holiday, and that didn't include any spares! Three hundred ostomy bags takes up a lot of space - too much to fit in our suitcases. What to do?

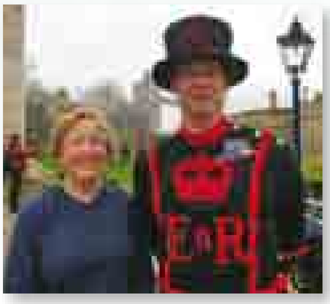
Our cruise was leaving from Southampton (England) and fortunately I have a very helpful niece in London. So I decided to send my ostomy bags to her and collect them when we arrived. Firstly I needed enough bags to last the trip, which is not easy when ordered month by month. Instead, I bought additional bags directly from the manufacturer. Secondly, I bought the largest Australia Post padded-packets available and managed to fit one hundred in the first packet. I then waited a few weeks until my niece confirmed it had arrived safely. Then I sent another packet of one hundred bags, and finally a third packet of fifty bags. The rest would go with me as I needed to have enough bags with me for our journey to London via Paris. It cost about $53 for each parcel but at least I knew that I would have enough for our trip.

For everything else, I bought a small travel case with wheels which would travel with me as hand-luggage and I wouldn't let out of my sight. I packed this case with the remaining fifty bags plus some spares, base-plates and collars, adhesive-remover wipes, silicon wipes, dry-wipes, nappy-sacks, stoma gel sachets, packs of wet-wipes, some pre-made "change packs" for the plane, and at the last minute some drainable bags (suggested by my wonderful STN) – just in case!

I also asked my niece to check on the availability in London of nappy-sacks, paper bags and anything similar to Chux Soft Wipes. I also diligently cut some Wipes into four pieces each so they were a more useful size. I hoped that two boxes would be enough for eight weeks, but I couldn't be sure. Luckily I was able to buy four packs in London because I couldn't find nappy-sacks or anything resembling Chux in South American supermarkets.

Before leaving home, my ostomy association also told me that we have a reciprocal arrangement with an association in London and that I could contact them if necessary. However, once we had left for South America we were "on our own". If I had any problems, we would have gone to the nearest hospital.

I was concerned about things going wrong on the long plane trip to Paris so decided to break the journey into three to four hour sections and change my ostomy bag on a regular basis, rather than wait for it to fill up. I labelled each "change pack" with a time and place and kept my watch on Sydney-time until we arrived in Paris. This included a change at Sydney Airport just before leaving, one during our one-hour Dubai stopover, and another so I was ready to get off in Paris. I kept packs for the Sydney to Dubai leg in my handbag, and those for Dubai to Paris leg in my wheelie-case and then transferred these to my handbag in Dubai. Everything worked like clockwork on the way over. The only real problem was a distinct lack of public toilets anywhere outside of Australia. But I managed.

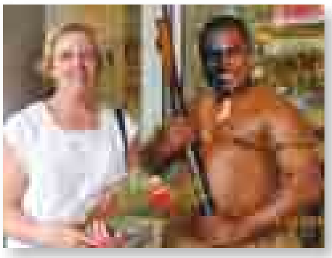


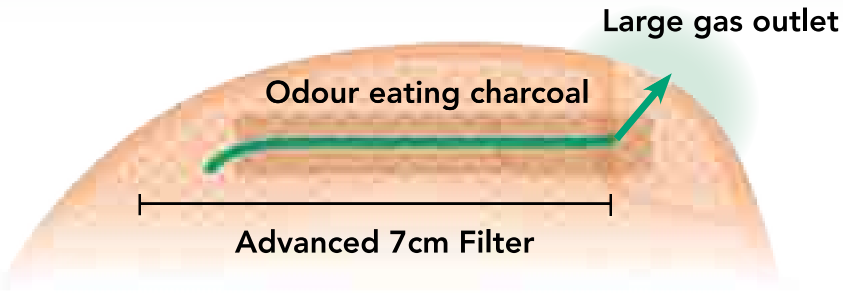
I had also been concerned about how to dispose of my bags on the ship, having never been in this situation before. I read a travel article on the British ostomy site which mentioned that cruise ships provide a special disposal bag for ostomy passengers, and they were able to supply me with these throughout. I spoke with our lovely cabin steward and she removed the bags twice a day. Incidentally, my output hasn't gone down since the chemotherapy effects have worn off.

What would I change for next time?

- Sending ostomy bags to my niece worked very well, but she won't always be where we are travelling. Perhaps I can send them to a local ostomy association if I don't have a personal contact, and this needs to be done well in advance.
- We are hoping to take advantage of last-minute discount rates, so I think I will need to purchase sufficient ostomy bags and take these with me.
- I'm also considering stomal irrigation. As I have a large output it could mean fewer bags would be needed, but that is for down the track a bit.

There's not much else I'd change, but I'm still very much a novice so if anyone has any tips or suggestions for travelling, I'd love to hear them. ●





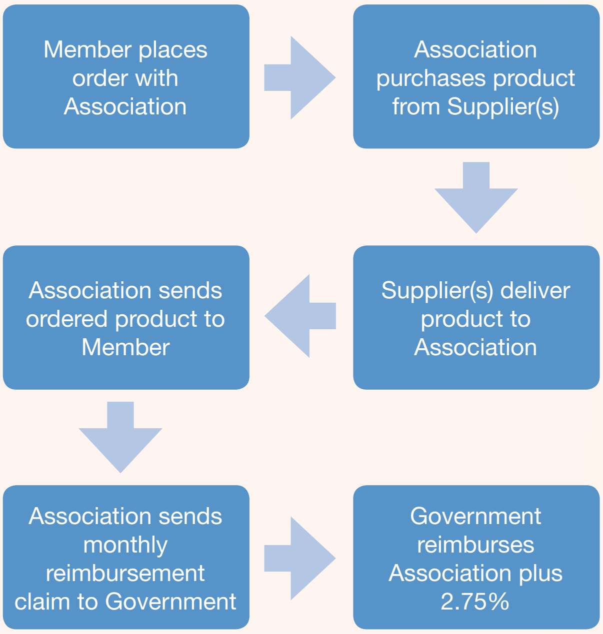
Flexima® 1 Piece

Flexima® Key 2 Piece

"Ask Kylie" A.C.S.A. Administration Officer

I have been a member of my association for many years and have always been very impressed at how my orders are processed so quickly and efficiently, particularly when the association always seems to be so busy and with most of the work carried out by volunteers. I have often wondered where my products come from and who pays for them and so it would be great to know a little bit more about the Stoma Appliance Scheme and the role that my association plays.

The Stoma Appliance Scheme (SAS) is a Commonwealth Government program which provides fully subsidised stoma appliances to all eligible Ostomates who need them. Responsibility for the Scheme is shared between the Department of Health which has program management responsibility and develops Scheme related policy, and the Department of Human Services which is responsible for the registration of eligible persons to the Scheme and for payment of Scheme related claims. The Scheme itself was established in 1975 following an amendment to section 9A (1) of the National Health Act 1953 which also provides the authority for distribution of Scheme-listed appliances through the Australian Stoma Association network.



To access stoma products through the SAS, a person must be an "eligible person" as defined by section 4.1 of the Commonwealth Government Operational Guidelines for Stoma Associations. They must be certified as eligible by a Stomal Therapy Nurse (STN) or a doctor and lodge an application form for membership of the SAS with one of the twenty-two Australian Stoma Associations. There is a compulsory SAS annual access fee payable but the payment of the annual association membership fee is sufficient to meet this requirement.

Once an eligible person has paid their fee for the current financial year, a request for subsidised appliances may be submitted, usually on a monthly basis. However a number of factors must first be confirmed by the association before the request can proceed: the products requested must be listed on the SAS schedule and the quantities of supply requested must fall within Scheme allowances (although an STN or doctor may authorise additional supplies if they are necessary for valid medical reasons). It's important to remember at this point that the association from which you get your supplies will have its own arrangements for orders and you should make yourself familiar with the times when orders are to be lodged and how long it will be before they can be posted or collected. Also keep in mind that when associations fill your order they must comply with the Commonwealth Government Guidelines which set out the rules and limits for supply of subsidised appliances.

Currently, there are more than 2,000 individual products spanning eleven product groups listed on the SAS schedule. The price of each of these products is negotiated directly between the Department of Health and the supplier prior to the product being listed on the SAS schedule. It is this negotiated price that is charged to an association by the supplier when a listed product is ordered on behalf of a member. It's also this price plus an additional 2.75% handling fee (to assist with the cost of supplying SAS products on behalf of the Commonwealth Government) that is paid to the association by the Department of Human Services following the submission by each association of their monthly bulk claim for reimbursement of the cost of SAS products supplied to their members. For interest sake, during the last financial year, the collective operating costs of associations were in excess of $4.8m. Approximately $2.23m of this cost was met by the 2.75% handling fee with the balance covered by association membership fees, postage charges and donations.

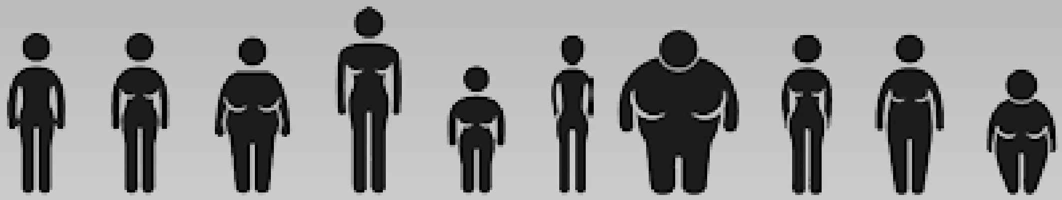
Internationally, many countries have programs in place to assist Ostomates to meet the cost of stoma appliances. However the Australian Stoma Appliance Scheme is unique in that it is the only government funded stoma appliance program in the world to have program related distribution managed by not-for-profit organisations utilising largely volunteer resources.

The incredible level of productivity demonstrated by our associations can be illustrated through Scheme-related distribution during the 2012-2013 financial year when approximately thirty-two million individual subsidised appliances with a collective value of approximately $81m (per Department of Health, 2013) were distributed to nearly 40,000 registered members across the association network.

Truly a remarkable feat for which our associations should feel very proud, and their recipients very fortunate. ●

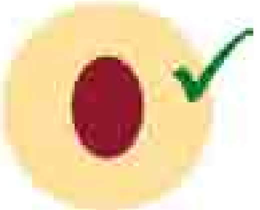
Please send your "Ask Kylie" questions via email to feedback@australianstoma.com.au
Alternatively, hard copy submissions may be sent to The Editor, *Ostomy* AUSTRALIA, PO Box 195, Frenchs Forest. NSW 1640

People come in different shapes and sizes and so do stomas!



Do you want to give the skin around your stoma the BEST PROTECTION there is?
Then use the world's top selling seal: Eakin® Cohesive and experience the difference.

Eakin®
Cohesive
Seal



An Eakin® Seal hugs your stoma's exact shape & gives you the best skin protection possible.

A Pre Cut
Seal

A Pre Cut seal leaves gaps and can result in sore, red irritated skin.

Eakin® Cohesive Seals have been scientifically proven to be the most moisture absorbing stoma seal available* so they will stop leaks and give you the best possible protection.

Don't settle for second best, order your FREE SAMPLES today.

eakin®™

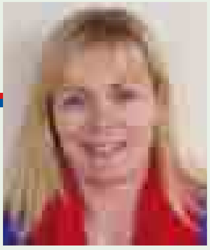
* Effect of a long life ostomy seal on faecal enzyme activity by " Grace McGroggen, TG Eakin & Dr Lorraine Martin, Queens University Belfast

For more information and samples, please contact our Customer Service Team on:

Freecall 1800 819 274
or samples@omnigon.com.au
www.omnigon.com.au

omnigon
Your healthcare partner

AASTN President's Report



Submitted by ***Kirsti Dixon*** *- AASTN National President (Australian Association of Stomal Therapy Nurses)*

I hope that this finds you all well and that your Christmas and New Year were fun times spent with family and friends.

For many life is now back into full swing. The AASTN is currently working towards our AGM, which will be held on 21st March via teleconference to our many members across this great nation of ours. It is a time to welcome new members to the committee, and to thank those that have contributed to our committee in many ways, shapes and forms. These include, Sue Delanty (Tasmania), Sue Vaughan (Victoria), Sharon Gibbons (New South Wales) and Louise Walker (Queensland).

Stomal Therapy Nurses (STN) in particular, are passionate about their jobs and are often called on to be innovative, multi-skilled, multi-talented and diverse. Much of the time we can put our hands to any job that you throw at us (within reason of course). With this in mind, Elizabeth English and their team have returned from Kenya very enthused about the education that they are providing for Registered Nurses (RN) in Kenya and the difference that it is making to Ostomates in Kenya. Many will soon be travelling back to Kenya to provide the second part of the course. With limited resources in Kenya, this is a time for STN's to draw on their many innovative skills to ensure that the Kenyan nurses are able to provide the best possible care to their clients within the constraints of a third-world environment.

There are a couple of conferences coming up in the not too distant future, including WCET (World Council for Enterostomal Therapists), which is to be held in Gothenburg (Sweden) during June. I believe there are a number of Australian Stomal Therapists who plan to attend to update their skills and knowledge. This is always a great time to catch up with our overseas colleagues and to see what is happening overseas that could improve the way we care for our Ostomates, or to identify what we are doing well here in Australia (which is often the case).

The other conference is for the Australian Wound Management Association, which is being held on the Gold Coast during May. Wound management is another facet of being a Stomal Therapy Nurse. The conference is held every two years and also enables nurses to come together, workshop ideas and look at research innovations.

Nurses in general are always updating their skills to ensure that our clients are being cared for within best practice guidelines and will have the best possible outcomes. So next time you see your STN, please remember that we provide diversity and innovation to our roles in providing the best possible care for the Ostomate.

Enjoy the rest of summer and the beginnings of autumn with all its spectacular ever changing colours.

CASA is now OASA

The Colostomy Association of SA (CASA) has started the New Year with a new name and a new home.

We are now the **Ostomy Association of SA (OASA)** to better reflect the fact that 20% of our members have other stomas (ileostomy or urostomy) and/or multiple stomas.

We have also relocated from our old South Road, Torrensville premises to newly renovated and much larger premises at: **1 Keele Place, Kidman Park**

Our team spent most of the first few weeks of the year moving. To celebrate and show off the new premises we held an open day on 10th January. We are very proud of our new home.

Please call in and see us if you are in the area.

Get Out There and Do It!

Submitted by: ***Barbara Worme,*** *VIC*

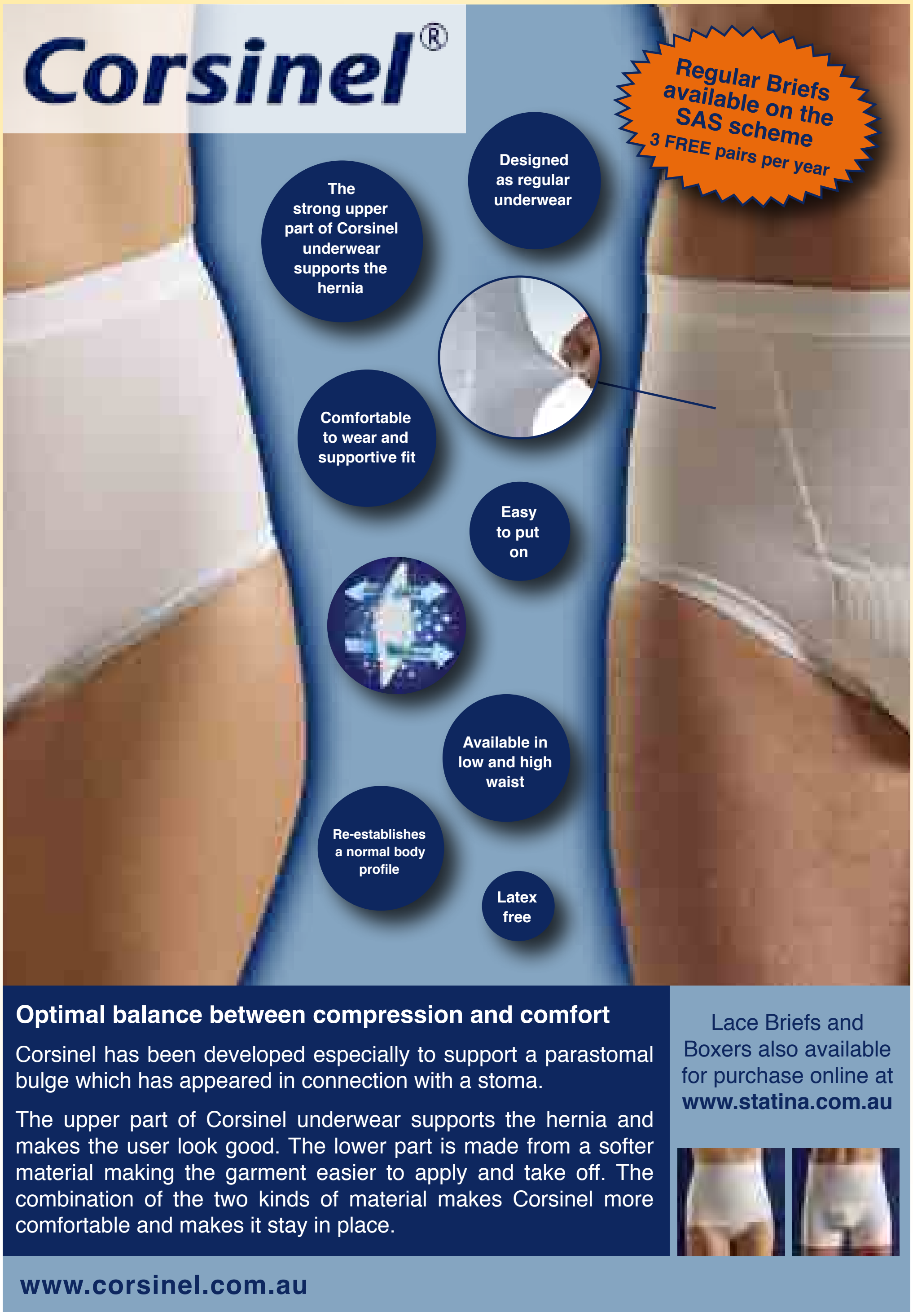
I found out that I had rectal cancer just a month before my 70th birthday. After many tests, I had an operation to remove the cancer and a temporary ostomy bag was fitted in November 2006. I then started on my long journey of chemotherapy and radiotherapy. It took me many weeks after completing these therapies before I started to feel fit again. A few months later I had another operation to remove the temporary stoma but at this stage things went really wrong as it was discovered that I had a perforated bowel and I had to be rushed to Frankston Hospital by ambulance for another emergency operation. The doctors thought that the radiotherapy may have caused the perforation. I was fitted with a permanent ostomy bag in February 2008.

About three months after my last operation I began to slowly get back to doing the activities that I had long enjoyed before my cancer treatment – tennis, golf, gardening and walking my dog, Tasha. I also enjoyed some new experiences including a hiking trip to New Zealand with my daughter, a camping trip in the Kimberley (at the age of seventy-two and I had never before slept in a tent!), a family live-aboard snorkelling and diving boat trip on Ningaloo Reef, Western Australia (I didn't do any diving but saw some amazing sights while snorkelling on the reef), swimming with the dolphins and seals in Port Phillip Bay near where I live. The list goes on!

So now, at the age of seventy-seven, I am still playing competition tennis and golf every week as well as walking my daughter's dog, Marni, every morning (unfortunately my dog Tasha passed away at the age of fourteen in 2009), gardening, mowing, going on more hiking trips with my daughter (our last one was to Phillip Island in September 2013) as well as swimming and snorkelling in the warmer weather.

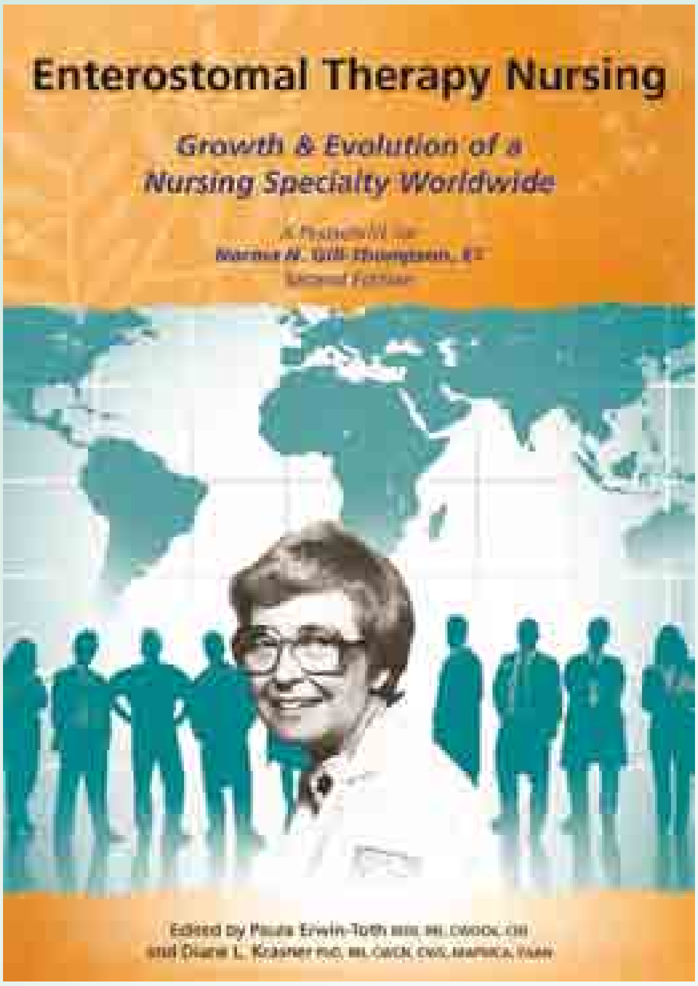
It feels so great to be able to live a normal life again, and even though I have been nervous about travelling with my ostomy bag and all the associated "stuff" that has to travel with me now, I haven't let it stop me at all.

I would encourage everyone with an ostomy bag to just "get out there and do it"! ●



Can you help Norma fulfil her dream?

Submitted by: ***Carmen George****,*
Chairperson Norma N. Gill Foundation
World Council of Enterostomal Therapists



Norma Gill was a young woman in her early thirties when she had surgery to remove her large intestine, rectum and anus, and have a permanent ileostomy created. Norma firmly believed that surgery resulting in a stoma 'should be a stepping stone to an improved quality of life rather than a sentence to a life of depression, isolation, rejection and shame.'

Norma devoted her life to revolutionising care for people with stomas worldwide.

Born in 1920, Norma's surgery for debilitating ulcerative colitis was performed in 1954 by Rupert Turnbull, one of the surgical visionaries at the Cleveland Clinic in the USA. At that time there was no such profession as a Stomal Therapy Nurse (STN) - also called an Enterostomal Therapist (ET) - to help Norma adjust to her surgery and find the correct leak-proof, odour-proof appliance for her to manage her ileostomy.

There were no adhesive bags with filters, no skin friendly barriers, no seals, no adhesive couplings, and no integral closures - just cumbersome rubber apparatus that was not disposable and soon became smelly, whilst giving little or no protection to the skin around the stoma.

Norma set about rehabilitating herself before starting a one-woman campaign to help people undergoing this surgery in her home town - and eventually the whole world. Although Norma wasn't a nurse, she became the world's first ET.

Around the world pioneer surgeons of her day were performing life-saving surgery which resulted in patients being cured of their disease but left with colostomies and ileostomies. Norma, through her connections with the surgeons who performed this surgery, was able to educate and support nurses around the world as they learnt about helping patients with stomas.

In 1976 the International Ostomy Association (IOA), an association of people with stomas, held its first meeting in London. Norma invited her network of ET nurses from Australia, South Africa, Sweden, Mexico, Canada, England, Ireland, Israel and USA. Industry, with its fledgling new stoma products, was also at the meeting, along with the renowned surgeons of the day. It was here, at this meeting, where the idea of forming a professional group to teach health professionals how to care for and rehabilitate people with stomas was born. The World Council of Enterostomal Therapists (WCET) was conceived and the first meeting of this group of health professionals and ostomates (who were Enterostomal Therapists) from all around the world was planned for 1978 in Milan, Italy. The mission statement of WCET is 'to lead the global advancement of specialised professional nursing care for people with ostomy, wound or continence needs.' The WCET's vision statement takes this further and says that specialised nursing care should be available to all people with ostomy wound and continence needs, and that specialty education for nurses in this field is provided so that they are able to fulfil this vision.

This was Norma's dream - that every person with a stoma has a trained health professional available to help them.

In many countries there are no Stomal Therapy Nurses but this does not stop surgeons from performing lifesaving surgery that results in a stoma formation. Most of the work of WCET is about supporting and helping to educate nurses in developing nations in Enterostomal Therapy Nursing (ETN).

The Norma N. Gill Foundation (NNGF) is the charitable arm of the WCET. In the past year, the NNGF provided scholarships for five of a team of ten Australian nurses who volunteered their time and expertise to go to Kenya for four weeks to teach in the first African Stomal Therapy Nurse education program. The NNGF has given many scholarships to nurses from Tanzania, Philippines, Indonesia, Iran, China, Thailand and Nepal to further their education and to support them to give appropriate care for people with stomas.

We welcome all donations to the NNGF fund, which will faithfully work towards fulfilling Norma's dream. To donate please go to the WCET website www.wcetn.org and click on the Norma Gill Foundation tab and then on the NNGF Donation tab - you will then see the Donate button. Alternatively, please contact me at nngf@wcetn.org if you would prefer to do a direct bank transfer. By donating to this Foundation your money goes directly towards the education of nurses in developing nations to provide appropriate care to people with stomas.

Thank you for reading this short story about Norma and about her dream for people with stomas around the world. Please help us fulfil Norma's vision. ●

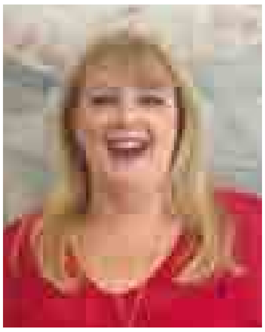
Stoma issues? Please call…

Coloplast Customer Care Team has been fully trained to deal with specific ostomy issues… With over 27 years ostomy experience!

Leakage?

Call Shari

Shari has been working with Coloplast for over 7 years. She is the Customer Care Team Leader and she specialises in dealing with people that have concerns around leakage.



Security?

Call Julie

Julie is our longest serving Customer Care Team member. With over 10 years experience she speaks to people just like you every day that have concerns around pouch security.

Filter issues?

Call Shirley

Shirley has been with Coloplast for almost 5 years now. She is trained specifically on filters and ways to best deal with ballooning and pancaking.

Skin protection?

Call Karen

Karen has over 5 years of experience dealing with people that have concerns around keeping their skin protected.

For trusted, reliable advice call **1800 653 317** or email **au.care@coloplast.com**

www.coloplast.com.au

Coloplast

Nutrition for Ostomates

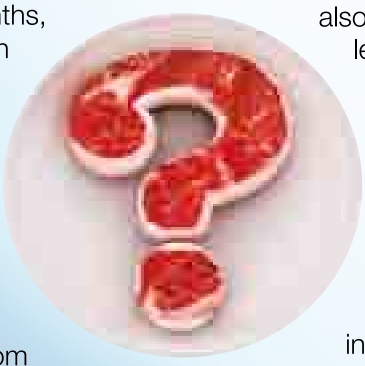
*Submitted by **Margaret Allan**, VIC*

Margaret Allan is a qualified Nutritionist. She advises Ostomates and the general public on diet and health-related matters.
Margaret is based in Melbourne and is available for clinical and telephone consultations by appointment. She can be contacted via email on margaret@foodfirst.com.au

In this article Margaret provides a nutritional case study and discusses the progress of a particular patient, with permission from the individual.

The summer months are here and, whilst it is a great time of year with lots of fun, frivolity and relaxation, there are also some important considerations for Ostomates in staying healthy during this time. And one of them is to remain hydrated during the warmer weather.

Sue, a lovely sixty-nine-year-old lady, contacted me in November 2013 seeking dietary assistance, primarily for fatigue. She had been an Ostomate since 2004 as a result of Ulcerative Colitis, and initially experienced no issues. She was very well and enjoyed a full and varied diet. In the latter part of 2005 Sue had her ileostomy reversed and a J-Pouch formed. However, due to a series of complications over a period of nine months, it became necessary to have the J-Pouch removed and a permanent ileostomy was formed in 2006. This resulted in the loss of the portion of ileum that had been used to form the J-Pouch.



At the time of contacting me Sue was experiencing excessive fatigue that she could not shake, a need to constantly graze else she would feel odd, weak and unwell out of the blue, and with diarrhoea possibly from a food that had disagreed with her recently. Her output was a liquid paste and she was emptying her bag approximately eight to ten times a day. In her own words, she felt "wretched".

Throughout most of her life Sue had had a thin stature, but had gained some weight more recently, possibly due to her constant grazing. She always had the feeling of being a bit hungry. Her hair had also become more lacklustre in recent years and her eyes felt scratchy. She was not on any medications but her doctor had recently recommended Vitamin D and an iron supplement because blood tests had shown she was low in these. She had also self-prescribed B vitamins to help with her energy, magnesium to assist with cramps, and fish oil.

Sue's diet consisted of fresh, organic food as much as possible but, because she was grazing erratically rather than eating regular meals, she was not eating a great quantity of food. There was also an emphasis on carbohydrate foods such as bread, cereal, crackers, rice, vegetable soup and salad, and not a lot of protein foods such as meat, fish, chicken, eggs or dairy. She felt she could only digest meat well when she was relaxed, e.g. when out for dinner with friends, and so tended to avoid these foods when feeling anxious as they felt too heavy in her stomach.

Sue consumed strong coffee each day and used it as a 'pick-me-up' as she got quite a kick out of it, but her tolerance of alcohol was low as she felt a little tipsy after one or two glasses of wine at night. She was also sensitive to strong smells such as perfumes and paint fumes and felt she was becoming more allergic over the last few years. Her water intake was also generally low for her stature.

My initial dietary recommendations for Sue included consuming more hydrating beverages, as water is needed to produce energy in the body and dehydration can contribute to fatigue. I felt that her fatigue may also have been due to fluctuating blood sugar levels and recommended that she consume a protein food with each meal or snack to balance her blood sugar levels throughout the day. I also wrote a letter to her GP requesting blood tests to help determine if specific nutrient deficiencies were contributing to her fatigue as well.

I then provided Sue with some recipes to support my recommendations, and information on the Glycaemic Index (GI) of carbohydrate foods and their effect on blood sugar balance. I also referred her to the Hydration for Ostomates article that was printed in the December 2013 issue of the *Ostomy* AUSTRALIA Journal.

When discussing her progress in the follow-up consultation, Sue reported that she had endeavoured to consume more protein, but was struggling with this as it was still not sitting well in her stomach. Many people find that, as they age, their ability to digest protein foods, especially meats such as steak and chops etc, is reduced and so they start to avoid them, which can have health implications.

For this reason I generally tend to recommend more digestible protein foods such as scrambled eggs, omelettes, fish and slow cooked meats such as lamb-shank soup in these circumstances. Sue had made a casserole of slow-cooked beef and found this to be quite good with no issues regarding digestion.

She had also started making a beef tea (a link to the recipe is provided at the end of this article) and was finding considerable benefit in this as a restorative.

Continued page 36

Twice as secure as any other 2 piece pouch system

Flair® 2 Dual Security System

CLIP + **STICK**

Unique Clip + Stick locking system

It's locked on, so <u>no more</u> unexpected pouch "pop off"

- ✓ Double the ease of application
- ✓ Double your comfort
- ✓ Double the flexibility
- ✓ Double the protection

flair 2®

For more information and samples, please contact our Customer Service Team on:

Freecall 1800 819 274
or samples@omnigon.com.au
www.omnigon.com.au

omnigon
Your healthcare partner

Continued from page 34

To assist her with digestion of protein foods and to help her enjoy a fuller diet, I recommended Sue sip some apple cider vinegar mixed in water before meals, and continue with slow-cooked recipes. Apple cider vinegar is not appropriate for everyone but was suitable in this particular instance.

In our next consultation Sue reported feeling a bit better. She felt the extra protein in her diet was helping and she was not experiencing the 'weak and woozy' feeling as often as previously. She was sipping the apple cider vinegar before meals and the food was sitting more comfortably in her stomach. Fatigue was still an issue though.

When Sue's blood test results came through, I was interested to see some anomalies considering her dietary intake and surgical history. Her GP had stated that everything was fine, but her test results showed some nutrients were higher than I would expect in her case. Based on these test results I adjusted her supplement regime which included ceasing the B vitamins. I have now referred her for a genetic test in order to determine if a genetic abnormality is affecting the expression of genes and enzymes that affect how her body stores and utilises certain nutrients.

In an earlier consultation Sue had queried whether it was appropriate to consume salt with her food or even take salt tablets considering her stomal output and fatigue. Generally it is recommended that ileostomates in particular consume more salt in their diet to replace stomal losses, however I wanted to see the results of her blood test before making any recommendations. The test results indicated her electrolyte balance was normal and her blood pressure was low so I advised her that it was suitable for her to add salt to her diet and consume a salt tablet occasionally if necessary.

In our most recent consultation Sue reported that she is focussing more on low GI foods and finding benefit in this. She is not experiencing as much hunger and feels these foods fill her up more. It can be tricky for many ostomates to consume low GI foods because the fibre content is higher and they may increase output. However Sue is enjoying barley and spelt cereal for breakfast, some dried fruit, yoghurt, sourdough bread, nuts (such as peanuts, walnuts and cashews) and corn-chips. She is making a point of chewing all her food very well (as she has always done) and is only eating a small quantity at a time, and has not experienced any issues.

As advised, Sue has also ceased the B vitamin complex she had self-prescribed, and feels her energy is returning as a result. Her eyes did not feel as scratchy as previously and she looks better. She feels sharper in her mind and is not experiencing any attacks of hunger, which she now realises were quite debilitating. Her stoma output has reduced as well, which may be due to the soluble fibre in the low GI diet slowing down transit time and increasing nutrient absorption.

Sue attributes a lot of her improvement to the increased protein in her diet and the lower GI foods filling her up more. Looking back, Sue says she can now see that she was consuming too much coffee and her diet had become unbalanced. She recently made the comment to me that she had accepted her symptoms for years in the belief that they were inevitable, when in fact they can be corrected.

On another note, just prior to Christmas Sue reported a skin rash under her ostomy appliance with small red bumps that was causing her some concern. Upon questioning she admitted she had not seen a Stomal Therapy Nurse (STN) since being discharged from hospital many years previously. I advised her that it is good practice to see a STN at least once a year for a 'check-up' to ensure that her appliance is fitting correctly and is still the best option for her. Next time I spoke with her she reported that she had indeed seen a STN who had recommended an additional product to protect her skin and her skin rash had resolved as a result. She was very happy.

I am very pleased with Sue's progress and the work she has put into changing her dietary intake and habits. I look forward to continuing to work with her as necessary to ensure continued improvement.

Wishing you good health and happy days,

Margaret ●

Link to beef tea recipe: https://groups.google.com/forum/#!msg/alt.survival/WMHyDSUoZAg/G6cnKFYs9U4J

Footnote from Sue: I have struggled with issues like fatigue and falling hair for years, and was not given any dietary advice when I left hospital. So speaking with Margaret has been very helpful in that many of my questions have been answered and she has provided specific advice that is suitable for me.

This article contains specific dietary advice tailored to the personal circumstances and medical/surgical history of the individual. It is not intended as general dietary advice.

NEW

Change your life with SecuPlast® Aloe Rings

DESIGNED TO HELP STOP LEAKS AND SORE SKIN

Introducing the latest advance in skin protection

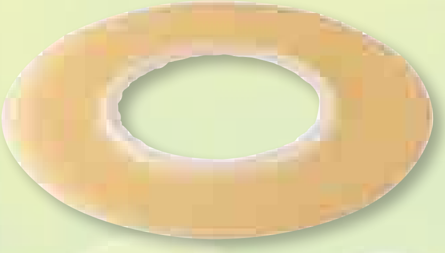
SecuPlast® Aloe Rings are infused with Aloe Vera, are only 1.8mm thick, **moderately stretchable** and **adhere without warming.**

Infused with Aloe Vera

to help **soothe, moisturise and protect** sensitive peristomal skin

Strong gel formation

providing further **skin protection** and **easy removal** with no residue



Absorbs and swells,

hugging the stoma

Can be stretched to fit moderately oval stomas

FOR FREE SAMPLES call **TOLL FREE 1800 784 737 (NZ 0800 100 146)**
or visit **www.ainscorp.com.au**

AinsCorp

BRITISH SKIN FOUNDATION
Recognising Salts research into healthy stoma skin

SKIN HEALTH ALLIANCE
DERMATOLOGICALLY ACCREDITED

SALTS HEALTHCARE
www.salts.co.uk

Sailing the Sydney to Hobart Yacht Race with a Stoma

Submitted by:
Roger McMillan

When surgeons removed my large bowel and colon to cure ulcerative colitis in October 2003, I vowed not to let the resulting ostomy bag restrict my activities. So when I was offered the media position on a 68-foot yacht for the 2013 Rolex Sydney Hobart race, it was a no-brainer.

The Sydney Hobart is not a race for the faint-hearted at the best of times. It is generally considered the toughest of the world's ocean races and in 1998 six people died and five yachts sank when an East Australian Low (a severe weather bomb) struck the fleet in Bass Strait. The 628 nautical mile journey didn't worry me, and nor did the chance of severe weather, but I did have to do some serious thinking about how to handle the practical side of sailing with a stoma.

Fit and Well

As I said, I was determined from the moment I got out of hospital not to let the change of circumstances ruin my life. I did a 1.2 kilometre open water swim (very slowly) five weeks after the operation and have since won my age group in three of them. I've also done a triathlon and a 10 kilometre fun-run. I generally swim three times a week, covering 2.5 to 3 kilometre each session, and ride a bike to the shops or train station rather than driving. So fitness wasn't a problem.

During my three-year illness, I read a sailing magazine that described how to build a yacht from a kit, so that went straight on my 'to do' list. With the help of a friend who is an expert welder, I built a 37-foot aluminium sloop which was launched in 2008 and I sailed it, mostly single-handed, from Busselton in Western Australia to Sydney via the Great Australian Bight.

Arriving during the global financial crisis, I decided I needed a job so I scanned the internet for a deck-hand position at a marina somewhere in Queensland. Instead I found an advertisement for the Editor's position at the Australian Sailing magazine. Right place, right time!

So that's why I was invited to sail on one of the fourteen Clipper boats which were taking part in the great race for the first time. There were two of the older 68-foot boats, which are ten years old and have been around the world four times, but the bulk of the Clipper fleet are twelve brand new 70-foot boats which are halfway through their first circumnavigation.

The Clipper Race is a unique event. The brainchild of Sir Robin Knox-Johnston, who was the first man ever to sail solo, non-stop and unassisted around the world, the Clipper offers 'ordinary people' the chance to cross the world's oceans. Some do just one leg, but most pay around $70,000 for the chance to become a circumnavigator.

They are a wonderful group of people, all pulling together to achieve something special in their lives, and they exude a powerful sense of 'can do'. The oldest person in the current race is a seventy-three-year-old British woman who was a violinist with the Royal Philharmonic Orchestra.

Sir Robin himself is seventy-four and was navigating one of the older boats, which is why I picked that one. It was a once-in-a-lifetime chance to sail with an absolute legend.

The Issues

The first task as an Ostomate was to convince my doctor, and then the Clipper organisers, that there was no reason why I couldn't do the Sydney-Hobart. I pointed out that I had sailed around five thousand miles without a problem, and they agreed to let me sail.

I was also required to attend a training day on Sydney Harbour, where I was able to persuade the skipper that I knew what I was doing aboard a racing yacht, and was given the green light.

The race starts on Boxing Day, so Christmas was quiet. I was organised and calm, and had a great night's sleep. On waking, the first task was to make sure my ostomy bag was carefully and properly applied. I use a two-piece bag and I taped all four sides with five centimetre wide stretch-tape which I also use when swimming.

Normally I change the bag every second day. I have extended it to three days when I don't swim, but have had a couple of accidents when I've left it that long. We were expecting the race to take three days, and I thought if I kept it dry the tape might just do the trick.

Using the Toilet

Excess weight is always an issue on a racing yacht, so the toilet, or 'head' as it is called at sea, doesn't have a door. Instead there is a long curtain that covers the opening, with a zip down each side.

We were doing four-hour watches. The crew is split into two groups, with half the crew sailing the boat while the other half rested down below. So every four hours, I went into the head, zipped down the curtains and emptied the bag.

For the first two days it was not too bad. We had the wind behind us so the boat was fairly level, although it was pitching around a bit as it surfed down the swells. The problem began about forty hours after the start when the wind swung round to the south-west and built to over forty knots.

Now the boat was on an angle of between thirty and forty-five degrees and I had to brace myself in the tiny cubicle, wet-weather trousers around my ankles, while trying to wipe the bag clean (never a one-handed operation) and avoid being violently thrown into the hand-basin.


The Clipper 68 during pre-start manoeuvres on Sydney Harbour

We weren't eating very much owing to the rough conditions, so my output was down, but I still wasn't prepared to leave it eight hours without emptying. So every four hours, in I went!

The gale force winds refused to abate and our three day journey turned into nearly four. While sailing up the Derwent River I took some photographs of the crew and they all looked at the end of their tethers.

Down Below

The major problem was lack of sleep. The noise of water rushing past a yacht that is doing 8-9 knots is loud at the best of times but it was compounded by the ear-splitting crash as she leapt off the top of the four metre swell and bashed her hull back down onto the surface of the sea. Then there was the banging of ropes on the deck, the creaking of the hull under extreme stress and the yells of the on-deck crew as they tried to put a reef in the mainsail or change one of the headsails.

On top of the noise, everything was soaking wet. I was lying in my wet bunk in a wet sleeping bag, wearing wet clothes that I hadn't changed for over three days, with water hitting me in the face from a leak in the hatch above my head. My sides were sore from bracing myself against the bunk and I was tossed from side to side by the motion of the craft.

And it was cold. Brutal, freezing cold and it was cutting through even three layers of clothing. The wind was coming straight off the Antarctic ice-shelf that had trapped a research ship a few days before.

No, it wasn't fun. And there was no chance – absolutely no chance – of changing an ostomy appliance under those conditions. Fortunately, the stretch-tape did its job and for the first time ever, I had gone four days with the same bag.

The hot shower at Constitution Dock may have been 'shared facilities' but I didn't care. I stood under the hot water and luxuriated in it, before retiring to the toilet (which wasn't moving) and attaching a new bag.

Will I do another ocean race? While freezing to death twenty miles offshore in a howling gale, the answer would have been a resounding 'no'. But after listening to the cheers of the crowd, downing a cold beer and having a hot shower, the pain recedes. I promised myself never to let my stoma stop me. If someone suggests I should do the other great race, the Fastnet in Great Britain, who knows?

In October 2003 my sister was told I would be dead within four days if the surgeons didn't operate. They gave me a second chance at life, and it wouldn't be right just to waste it. ●

For more information about the Clipper Round World Race go to www.clipper-ventures.com

Smile A' While

Submitted by: **Valerie von Willisen**, WA

TODAY ONLY

(Author unknown)

Today we have higher buildings and wider highways,
but shorter temperaments and narrower points of view.
We spend more but enjoy less.
We have bigger houses, but smaller families.
We have higher incomes but less morals.
We have more medicines but less health.
We have much more food but less nutrition.
We have more compromises but less time.
We have more knowledge but less judgement.
We have multiplied our possessions but reduced our values.
We talk much, we love only a little and we hate too much.
We have conquered the outer space but not our inner space.
We have reached the moon and came back but we find it
troublesome to cross our own street and meet our neighbours.
These are times with more liberty but less joy.

That's why I propose that, as of today, you do not keep anything for a special occasion, because every day you live is a special occasion.

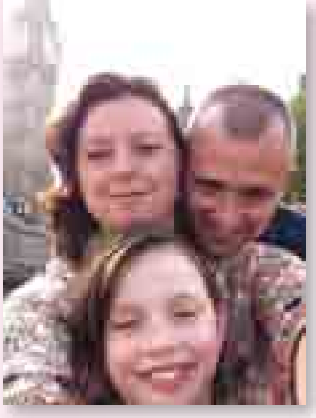
Search for knowledge, read more, sit on your front porch and admire the view without paying attention to your needs.

Spend more time with your family and friends, eat your favourite foods, and most importantly take time out to smell the roses.

Our Story – Janelle and Greg Solomon

Co-Founders of Mitrofanoff Support Australia

Submitted by: **Paula Lawrence**



Ten years ago our daughter, Lilah, was born with Bladder Exstrophy, a condition where the bladder is unformed and attached to the outside of the abdomen wall. She has since had twenty surgical procedures and many visits to the emergency department for bladder infections and retention.

In mid-2012 yet another bladder stone developed and needed to be surgically removed. My husband and I needed to find a way to improve our daughter's health, kidney function and self-esteem, plus her ability to participate in school and sports.

I began looking for information on the Mitrofanoff (Mi-trof-an-off) procedure, an operation our surgeon had mentioned previously. I found many sites discussing the procedure and explaining the operation in detail – but they were all based in Europe.

I needed something closer to home, someone who would understand what we were going through, and could help us decide if this was the right decision for our daughter. I found a YouTube clip of Kyla Rogers, the founder of a United Kingdom-based support organisation for Mitrofanoff patients. I felt I had found someone who could provide the answers about what life was really like after the procedure. We have since become good friends and Kyla was sponsored by Hunter Urology to travel to Australia to launch Mitrofanoff Support Australia (MSA) and become one of our Ambassadors. Kyla's story and our interview with Fran Kelly (ABC) is on our website.

Our daughter's Mitrofanoff surgery was completed in Melbourne in December 2012. The preparation we undertook with our daughter transformed her from someone who dreaded hospital visits to a little girl who skipped through the hospital foyer on her way to having her Mitrofanoff surgery.

Through our experiences, we knew we needed to establish an organisation that could raise awareness of the procedure and provide support to others.

MSA was established in October 2013 with an emphasis on support, providing tailored information and a social platform for people, their families and carers, who have undergone or are considering the Mitrofanoff procedure.

Our website (www.mitrofanoffaustralia.org.au) features information and resources in sections that have been tailored to children, teens, men, women, paraplegics, families and carers. We have worked with surgeons, play therapists and relaxation experts to provide resources and information to assist with the transition to Mitrofanoff and to improve recovery.

Our website also features Ambassadors for each group and they have kindly shared their stories so that others may take comfort in their experience or be inspired to live full and active lives. Please take a look and read or watch Gobi Ranganathan's story (a Gold Medal winning member of Team England's Para-Badminton squad) or any of our other wonderful Ambassadors.

Almost half of the Mitrofanoff surgeries in Australia are performed on children. Our experience with our daughter and her emotional and physical reactions to the thought of a large surgery prompted the extensive range of tools and information for children and parents on our website under Families and Carers. Our children's tools have been developed by Natasha Hund, Play Therapist and there are links to find play therapists in your area.

The children who undertake this surgery are special and we are thrilled to be working with the Ostomy Association of South Australia, which provides specially designed Gastronaut® hand-puppets for these determined little people. These wonderful puppets are designed for each child with a stoma and are now available for children with a Mitrofanoff. The puppets are a great resource for children, parents and play therapists in assisting children to learn to catheterise through a tube and to express any fears or concerns they may have. Gastronaut® hand-puppets are available free of charge to eligible children through the Ostomy Association of South Australia via email colosa@colostomysa.org.au or phone 08 8235 2727 or fax 08 8355 1073. Check out the range of Gastronauts® at www.thebowelmovement.info

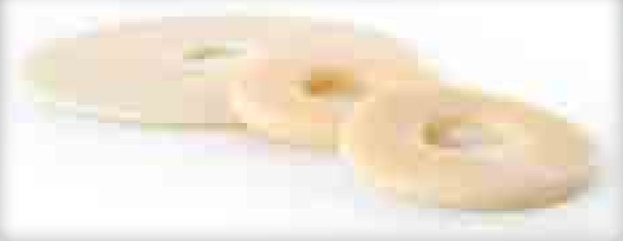
I hope you will take a look at the MSA website and consider supporting our work financially or joining us at upcoming events. We have partnered with the Parnell Fund (www.parnellfund.org) in the UK to undertake joint fundraising events throughout the year, so there's plenty to get involved in. ●

WHAT IS THE MITROFANOFF PROCEDURE?

The Mitrofanoff procedure was developed in France by Dr Paul Mitrofanoff in 1976.

The procedure creates a tube for voiding the bladder, which is made from the appendix or bowel. One end of the tube is embedded into the bladder-wall to create a continent valve, while the other end connects to a stoma which is discretely hidden in the navel or low in the pelvic region below the bikini line. The bladder is voided every three to four hours by intermittent self-catheterisation via the Mitrofanoff tube. The surgery is often combined with more complicated procedures, to either enlarge the bladder or to create a urinary reservoir. The bladder neck is often tied off from the urethra ensuring the patient remains dry.

We brought you the Eakin® Seal in 1990 and changed the face of Stomacare in Australia!



We NOW bring you the Eakin® Pelican Flat Closed Pouch!

- ✓ A perfectly designed round skin barrier gives you maximum security and skin protection during multiple pouch changes
- ✓ A split fabric cover that allows you to view your stoma when positioning your pouch
- ✓ An advanced filter system that controls odour and stops you worrying
- ✓ The most comfortable silky-soft water-proof fabric cover - gentle against your skin
- ✓ Available in Mini, Standard and Maxi sizes – broad pouch capacity for every need

eakin®™

Brought to you by the company that established the benchmark for skin protection.

For more information and samples, please contact our Customer Service Team on:

Freecall 1800 819 274
or samples@omnigon.com.au
www.omnigon.com.au

omnigon
Your healthcare partner

National Directory of Ostomy Support Groups

NEW SOUTH WALES

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

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

CENTRAL COAST
Meet: 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 3:30 pm
13th Feb - 10th Apr - 12th Jun - 14th Aug - 9th Oct - 11th Dec
Venue: Club Coffs, West High Street, Coffs Harbour.
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

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

GRAFTON & 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 69635267 or 0429 635 267
Email: ann.bar@bigpond.com
Karan: 0434 785 309

HASTINGS MACLEAY
Meet: The Old Hospital in Room 4 at 10am to 12noon on the third Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.
Inquiries:
Noel (President) 0407 932 647 or
Jenny (Secretary) (02) 6586 0270

ILLAWARRA
Meet: 10.00am to 12 noon on Wednesdays 12th Feb - 2nd Apr - 11th Jun - 13th Aug - 15th Oct - 10th Dec (Christmas Party) in the Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525. For further information contact Helen Richards CNC STN on (02) 4225 5046 (Monday only) or Julia Kittscha CNC STN on
0414 421 021

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

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

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

SHOALHAVEN
Meet: 2.00pm on 3rd Feb - 5th May - 4th Aug - 17th Nov
Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra.
Contact: Margaret or Tracey on
(02) 4424 6300

SYDNEY – LIVERPOOL / CAMPBELLTOWN AREA
Meets Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).
20th Feb - 17th Apr - 19th Jun - 21st Aug - 16th Oct
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

SYDNEY - PENRITH AREA
Meets: Feb - Apr - Jun - Aug - Oct commencing 2.00pm.
Tresillian Meeting Room, Tresillian, Penrith (next to Nepean Specialist Centre and Nepean Private Hospital). Parking is at Nepean Private Hospital or on Barber Ave.
Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

SYDNEY - SOUTH-WEST AREA
Meet: Saturdays 3pm - 5pm on 8th Mar - 17th May - 9th Aug and 5:30pm -6:00pm on 22nd Nov (followed by Christmas Dinner)
The Macarthur Room, Revesby Workers Club, 2b Brett St. Revesby (closest parking at front of Club)
Contact: Ann-Maree McDonald STN
Phone: (02) 9722 7196

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

SYDNEY - ST. GEORGE / SOUTH EAST AREA
Meet: 11.00am first Wed. each month Feb through to Dec
Community Centre, Premier Street. Kogarah
Contacts: June: (02) 9311 0201
Allan: (02) 9556 3268

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

VICTORIA

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

BENALLA / WANGARATTA
Meets 2.00pm on the third Monday of each second month.
Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug – Dec and Benalla Community Health Service,
45 Coster Street, Benalla in
Feb - Jun – Oct.
Contact: Rex Nankervis
(03) 5762 2080
Email: rexmarn@bigpond.com

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

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

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

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

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

WAVERLEY
Meetings are held every two months on a Wednesday from 2pm-4pm at Ostomy Association of Melbourne Centre, 71/170 Forster Road, Mount Waverley
Contact Ron Butler via email to
crocite@gmail.com or
enquires@oam.org.au

WESTERN AUSTRALIA

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

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

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

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

QUEENSLAND

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

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

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

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

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

ROCKHAMPTON
Meet: 1.30pm third Saturday, Feb - May - Aug - Nov.
Venue: Community Health Centre, Bolsover St. Rockhampton
Contact: Frank & Marge Noy
Phone: (07) 4921 0728

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

SUNSHINE COAST
Meets at Headland Bowls Club, Syd Lingard Drive, Buderim
Meetings commence at 10am on the third Monday of even numbered months.
Enquiries: Winifred Preston:
(07) 5476 6313
presto70@bigpond.net.au
Don Lindsay: (07) 5477 0864
lindsaymar@optusnet.com.au

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

TASMANIA

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

SOUTH AUSTRALIA

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

FLEURIEU
Meet: 3rd Mar - 30th Jun - 20th Oct from 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor.
Please contact Sue McKay STN for further information on 0412 692 418

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

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

YOUNG OSTOMATES UNITED (YOU)
Tel: Helen (03) 9796 6623 or Karen 0452 513 191
Web: www.youinc.org.au
Email: helshae@hotmail.com
Facebook:
Young Ostomates United

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

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

Stoma Appliance Scheme Product Suppliers

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

Dansac
PO Box 575, Port Melbourne, Victoria 3207
Phone: +61 3 9673 4144
Email: customerservice@dansac.com.au
Website: www.dansac.com.au

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

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

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

Hollister
PO Box 599, Port Melbourne, Victoria 3207
Freecall: 1800 335 911
Email: customerservice@hollister.com.au
Website: www.hollister.com/anz/

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

Omnigon Pty Ltd
PO Box 171, Moonee Ponds, Victoria 3039
Freecall: 1800 819 274
Email: info@omnigon.com.au
Website: www.omnigon.com.au

3M Australia
Locked Bag 19, North Ryde NSW 1670
Phone: 136 136
Website: www.3m.com.au

Statina Healthcare Australia
3/30 Leighton Place, Hornsby, NSW 2077
Toll Free Number: 1300 365 404
Email: sales@statina.com.au
Website: www.statina.com.au


dansac
NOVALIFE