

OSTOMY

AUTUMN 2019

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TO CONTRIBUTE ARTICLES/FEEDBACK

Email to the editor (Manager) at info@ostomynsw.org.au

DEADLINES

Winter edition	6th May 2019
Spring edition	5th August 2019
Summer edition	4th November 2019
Autumn Edition	5th February 2020

PHONE: 02 9542 1300

ORDERS: WE ARE UNABLE TO ACCEPT PHONE ORDERS

Please email orders to: orders@ostomynsw.org.au

Please fax orders to: 02 9542 1400

Please post orders to: PO Box 3068,
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Warehouse Counter - Unit 6, 18 Monro Ave, Kirrawee

PAYMENTS

Payments can be paid by bank transfer (EFT) to:

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BSB: 112879 (St George Bank)

Account Number: 45 664 3389

Reference: Your Member Number and Surname

POSTAGE RATES

Standard NSW \$13; Interstate \$16

Express NSW \$20; Interstate \$30

Holiday/double orders NSW \$18; Interstate \$24

Holiday/double Express NSW \$25; Interstate \$35.

OSTOMY NSW LTD STN CLINIC – Janet Forsyth

Please phone 02 9542 1300 for appointment Second Tuesday of each month. Unit 6, 18 Monro Ave Kirrawee

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MY STOMA STORY

BY MARGARET

I am 77 years of age, widowed, have two children and five grandchildren. I was diagnosed with a bowel tumour in 1996 and had it successfully removed with a temporary colostomy, followed up with chemotherapy and radiation therapy for several months. I then had a re-join and back to normality!! I have been carefully monitored ever since by wonderful surgeons and staff who keep me sane and healthy.

I joined the local bowling club for recreation and got terribly addicted to the game, met lots of lovely ladies (and gentlemen) and am still trying to play the "perfect game".

Six years ago I started to lose weight and frequented the bathroom more often than usual. I visited my GP who referred me back to my colo-rectal surgeon and urologist for further endoscopies. After further discussions re my future health options, I participated in a couple of treatment trials. These did not help relieve my symptoms and after a short time it was back to discussions with the specialists.

Later that year I had another operation with a permanent colostomy this time. I was in hospital for approximately three weeks, where I gained weight and slowly progressed back to my "normal" self. It took about three months to slowly get back on my feet with the help the superb medical specialists and their staff, together with a beautiful stomal therapist who treated me like a best friend.

I returned to bowling not long after that and am still enjoying the game. I can now travel on public transport and visit shopping centres without looking for the nearest toilet facilities, which is wonderful.

In January last year on a Saturday morning I awoke not feeling too well and felt some abdominal pain and swelling. I started vomiting and thought it was "something I ate"! I just relaxed all day in my lounge recliner chair and had a cup of tea, which didn't stay down too long either. I just assumed I would feel better the next day – but I wasn't. My daughter phoned me as usual on the Sunday and I told her I wasn't feeling all that well and she offered to come over. I said no – I'll just "sleep it off". The next morning she arrived early and had one look at me then called the ambulance and I found myself in the emergency department of the local hospital. Needless to say, I was in trouble both from my daughter and ambulance officers for not doing this sooner!!

I was admitted overnight with pathology and CT tests taken and with fluid intake monitoring as I was very dehydrated and nauseous. I came home the next day with no official diagnosis as I had recovered enough to enjoy a light breakfast and the pain was gone after about 24-hour bed rest.

So back to my specialists with further endoscopies, which showed nothing out of the norm. I got back

to my old self without any further hiccups.

Then six months later, the same symptoms again. This time, my daughter phoned my specialist immediately, who referred me straight into hospital, where I had further CT and pathology done. My abdomen was very painful and swollen and I had no stoma output whatsoever, with vomiting as before. I was dehydrated again and put on a fluid drip with painkillers and antibiotics. I was diagnosed with probable blockage due to adhesions from previous surgeries over the years. Bed rest and plenty of fluids was required and after two days I came home again feeling back to normal. I have remained symptom-free ever since.

I always read the Ostomy NSW Newsletter and in the Spring 2018 edition, I was surprised to read in "Hello from the Clinic" page by Sr Janet Forsyth, CNC Stomal therapist, the article about Stoma Blockage. I thought she was writing about me as the symptoms were exactly what I had experienced. All I can say is having had the symptoms twice, I commend this as a "must read" one for all Ostomates and thank her for the article.

I have been a volunteer at Ostomy NSW Kirrawee for nearly five years and thoroughly enjoy my day with the pleasant and efficient staff each week.

Caption: Margaret with ONL Manager Stephen Lardner



FOCUS ON VOLUNTEERS – MARGARET'S STORY FOOTNOTE...

Margaret is a member of our association having joined ONL in December 2013. She volunteers her time every Monday to assist our team and provide support for our members. Margaret works from early in the morning from 9am (getting up at 6am to be on time) and works until well into the afternoon, leaving around 4pm. While she is working she answers the phone, responding to member enquiries and serves our members at our counter. She enters your orders into our mainframe system and completes other administration tasks. These include filing, printing orders, sending mailouts and folding raffle tickets.

Margaret is a great character to have around. Her personality is bright and infectious and her mannerism when dealing with members is very professional. This is a reflection on the roles she had when in paid employment. Margaret has worked for large corporates, medical

professionals and lawyers prior to retiring in 1996. Margaret's contribution to our not-for-profit charity is exceptional; we enjoy her company and her work is at a high standard.

In May 2018 we had the great pleasure of nominating her for a Hughes Community Award. In November we learnt that Margaret was successful with her award, which was presented by the local Federal Member for Hughes, the honourable Craig Kelly MP. The ceremony was held at Woronora RSL in December 2018.

Margaret is one of our twenty-eight volunteers who provide service to our members to give back some valuable time and assistance. Research shows volunteers live happier and healthier lives. So, enjoy your volunteering and all the benefits that come with it! (Source: Volunteering Australia). Thank you volunteers for helping make Ostomy NSW the business we are and helping make Australia the happiest place on earth!

REGIONAL INFORMATION MEETINGS 2019

BANKSTOWN AREA – NEW!!

Dates: Wednesday 6 March 2019
Time: 10:00-12:00 – morning tea
Address: Revesby Workers Club, 2B Brett St, Revesby NSW 2212, Ph 02 9772 2100
Access: Close to public transport and lots of free parking
About: A stoma support group hosted by Bankstown Hospital STNs for you and your family - everyone welcome.
RSVP: Please RSVP for catering purposes to your Bankstown Hospital STN or Clare Jacobs on 0400 921 901 or aucldo@coloplast.com for further information.

St George area

Dates: Tuesday 19th March, Tues 16th April, Tues 21st May, Tues 18th June
 (3rd Tuesday of every month)
Time: 10:00-12:00 – morning tea
Address: Ramsgate RSL (meet in front foyer) Cnr Ramsgate Rd & Chuter Ave
 Sans Souci NSW
Access: Close to public transport and free parking
About: Everyone welcome – please RSVP for catering purposes to your STN or Clare Jacobs on 0400 921 901.

REGIONAL INFORMATION MEETINGS 2019

SHOALHAVEN SUPPORT GROUP

Dates: Wednesday 8th May, Wed 26th June (Ulladulla), Wed 7th August, Wed 6th November
Time: 2pm
Address: Nowra Community Health Centre, 5 - 7 Lawrence avenue Nowra.
About: The STN is Brenda Christiansen. Ph. 02 44246300
e. brenda.christiansen@health.nsw.gov.au

Nepean Education Stoma Support Group

Dates: 22 February 2019
10 May 2019
26 July 2019
27 September 2019
29 November 2019
Time: 2-3:30pm – afternoon tea
Address: 63 Derby St, Penrith (University of Sydney Medical School)
Access: The building is opposite Nepean Hospital's Emergency Department. Enter via the side path to the Clinical School's Outpatient waiting room.
Please wait until 2:00 pm when you will be directed to the meeting room.
Car Parking: Either on the street or in the multi-story car park on Somerset Street, Kingswood (free for pensioners for the first 3 hours)
About: Family and friends are most welcome. Any enquiries please contact Naomi Houston on 4734 1245

GOULBURN COMMUNITY STOMA SERVICE

Dates: First Wednesday of each month
Time: 9am to 3pm
Address: Goulburn Base Hospital. 130 Goldsmith street, Goulburn, NSW 2580.
Enter via the emergency dept and ask at reception for the stoma clinic.
About: The STN is Kelly Taylor RN STN m. 0402 250 475
e. kelly@communitystomaservice.com
Kelly will provide individual consultations by appointment.

SOUTH WEST SYDNEY STOMA SUPPORT GROUP

Dates: Thursday 18th April, Thurs 20th June, Thurs 22nd August, Thurs 17th October, Thurs 12th December
Time: 1pm to 3pm
Address: Camden Hospital, Heritage Auditorium. 61 Menangle Road Camden.
Contact: Erin or Lu on (02) 8738 4308

LIVERPOOL AREA SUPPORT GROUP – NEW!!

Dates: Thursday 28th March, Thur 30th May, Thur 18th July, Thur 26th Sept, Thur 28th Nov.
Time: 1Pm To 3Pm
Address: Cabra Vale Diggers Club, 1 Bartley St Canley Vale 2166
Contact: Erin Or Lu On (02) 8738 4308



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OSTOMY AUSTRALIA MANAGING EDITOR

Do you have a desire to support your fellow ONL members by ensuring that the national journal continues to meet our needs for information and connection? Do you have experience in journalism, publishing or public relation? Or maybe you have a background in administration, teaching, project management or IT?

The Australian Council of Stoma Associations invites expressions of interest for the position of Managing Editor of Ostomy Australia, ACSA's national journal.

The role involves producing and man-

aging the national distribution of the journal to 21 associations, three times a year. As presently structured, the position encompasses editorial, advertising and administrative functions.

The position is honorary, but attracts an honorarium of \$1500 per issue. ACSA also provides a mobile telephone service and reimburses the editor for relevant expenses.

If this sounds like you, there is detailed information about the role on the ACSA website at:

<http://australianstoma.com.au> (See the link from the home page)





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percent of people with stomas surveyed reported peristomal itching.*

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

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Ostomy Care
Healthy skin. Positive outcomes.

IT'S NEARLY ANNUAL FEE TIME

Annual membership fees for the 2019-2020 financial year are due by 30th June 2019 and prior to your July order being dispatched.

As ostomates, we are lucky to have our stoma appliances fully subsidised by the Australian Government. The value of our supplies can be worth hundreds of dollars each month for a typical member. This subsidisation is only possible because the supplies are distributed by member organisations like Ostomy NSW in each state.

While the supplies are fully subsidised, the Australian Stoma Appliance Scheme requires each member to pay a very small annual access fee that is retained

by ostomy associations to contribute to the cost of running the organisation.

ONL also has a per-order charge to cover the actual cost of postage of orders. See inside the front cover of this journal for the current rates.

As charitable organisations we have tight resources so it's critical that we receive any revenue that is due to us. You can help us by paying your annual fee before July. You can also check your account balance on your packing slip that comes with your order. If it is low or in the negative, please make a payment as soon as possible. You can find out how to make a payment inside the front cover.

Visiting the ONL office by car or foot

If you are coming to the office to pick up your supplies or attend the STN clinic we recommend that you enter from the rear door at Unit 6, 18 Monro Ave for the next few months. Currently there is major road work occurring on the Princes Highway and it is causing some access challenges for both car and pedestrian access. Car access into the driveway is problematic and there is currently no footpath access for the entire block on Princes Hwy and pedestrians are detoured to Monro Ave. Here's how to find us:

- Turn off the highway at Oak Rd and turn right into Monro Ave or
- Turn off the highway into Waratah St and drive one block then turn left at the roundabout into Bath St and right into Monro Ave (Bunnings is on your right)
- No 18 is about half way along, with a sign at the gate where Ostomy NSW is listed. We are at the top of the drive in the blue building next door to an automotive business.
- There is some limited 10-minute parking outside our back door.

Easter closures

Please note Easter Trading Days:

Friday 19th April – Closed

Monday 22nd April – Closed

Thursday 25th April – Closed

Friday 26th April – Closed

We only open for two days during the week after Easter Sunday.

Please be prepared and order early in April.

When did you last see your



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- ☒ Other problems

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THE RESULTS ARE IN – BLADDER CANCER AUSTRALIA SURVEY 2018

In the Winter 2018 edition of Ostomy journal we let you know about an opportunity to participate in the PEEK Bladder Cancer Australia Survey 2018

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across different disease using a protocol that will allow for comparisons over time (both quantitative and qualitative components).

CCDR thanks each and every person that participated in the Bladder Cancer survey. The results are now available and if you would like to see them you will find them on the Centre for Community-driven Research website at this location:

www.cc-dr.org/au/peek/complete/2018aublic/

In short, there were 50 participants

in the study. The most common symptoms they reported at the time of diagnosis were blood in the urine followed by problems emptying or frequent emptying of the bladder. The most common treatments that participants had after diagnosis were surgery, BCG treatment and chemotherapy. Participants rated their quality of life after treatment in the range of distressing or a little distressing. Participants appreciated professionalism and compassion in their care. There was a focus on the information needs of people going through diagnosis and treatment and a desire for readily available, understandable, comprehensive information that can help people prepare for their treatment and beyond.

CCDR is now conducting a PEEK survey on Crohn's disease and ulcerative colitis and again invites affected members of ONL to participate. For details see the invitation to participate in this journal.



Crohn's disease & ulcerative colitis Australian Study 2019

AUSTRALIAN CROHN'S DISEASE & ULCERATIVE COLITIS PATIENT VOICE INITIATIVE

If you are currently or have previously been treated for Crohn's disease or ulcerative colitis you are invited to take part in a research study.

The Centre for Community-Driven Research is a non-profit organisation conducting the Australian Crohn's Disease & Ulcerative Colitis Patient Voice Initiative.

This is a study to help us understand the experience of people diagnosed with these conditions and what they would like to see from future treatment, care and support. The study involves an online questionnaire and telephone interview with one of our lovely nurses. This will be the first study of its kind in Australia.

TO REGISTER OR FOR MORE INFORMATION

Online www.cc-dr.org/au/peek/recruiting

Email administration@cc-dr.org

Phone (02) 8294 6760

HERNIAS AND YOU



End stoma Hernia

Carmen George, STN, Omnigon

Earlier this month I was shown a quote from J Byron-Gathright a well-known North American Colo-proctologist. He is quoted as saying

"It doesn't matter if God himself made your ostomy, if you have it for long enough you have 100% risk of a parastomal hernia" (1996).

Who can get one?

Certainly anyone with a stoma is at risk of developing a parastomal hernia. This is technically speaking an 'incisional hernia'. Incisional because to create the stoma a surgical incision/cut is involved, even if the main part of the surgery is done by key-hole (laparoscopic) surgery. The actual creation of the stoma involves making openings through all the layers of the abdominal wall thereby creating an area of weakness. The hernia itself is formed by loops of bowel protruding through that weakness and forming the bulge alongside or around the stoma.

You may be at more risk.

In acknowledging that anyone with a stoma is at risk of getting a parastomal hernia some are more prone than others. For example, anyone who has had a hernia before, anywhere, is at higher risk. If you are over 70, obese, doing minimal activity then you are at much more risk of developing a parastomal hernia than if you are 45 years old do regular exercise and are within a healthy weight range for height.

Even the reason you have had your stoma created can put you at higher risk. So if your surgery was emergency and you have a large stoma you are at more risk than if you had keyhole surgery and an ileostomy.

Further if you already have a breathing disorder or are a smoker you also go into the higher risk group.

Most parastomal hernias develop in the first 12 months after surgery so these first months are the risky time.

Prevention is better than cure

As discussed, anyone with a stoma is at some risk of developing a parastomal hernia. Ideally you should have been warned that this is one of the possible complications of having stoma surgery. Surgery that results in a stoma is often lifesaving or life enabling surgery so the probability of a hernia developing down the track might not have had any impact on the decision to have a stoma.

Being fit for surgery is also not often an option in emergency situations.

There is evidence now to show that an early intervention program with **advice on exercise and the wearing of support garments** reduces the incidence of parastomal hernia.

This same study found that developing a parastomal hernia reduced the quality of life for people with a stoma.

Prevention and management strategies

Seek advice on what exercises are good for you to do and do them

Loose excess weight if you can

Wear an appropriate sized support garment or belt for general support and especially when doing exercise

Give up smoking

Source: North J.

Early Intervention, parastomal hernia and quality of life: a research study.

British Journal of Nursing, 2014 (Stoma supplement) Vol 23, No 5

Abdominal exercises for hernia prevention

You may have been taught these exercises while you were in hospital for

your stoma surgery. It's recommended to keep them up and incorporate them into a life-long daily routine.

Start all abdominal exercises by lying with your head on a pillow, knees bent and feet flat on your bed or the floor.

1. Abdominal exercise

Gently place your hands on your lower tummy. Breathe in through your nose and as you breathe out, gently pull your tummy button down towards your spine. Feel the muscles tighten, try to hold for a count of 3 and then relax. Breathe in and out normally.

2. Pelvic tilting

Place your hands in the hollow of your back. Tighten your tummy muscles (as for exercise 1), flatten your lower back onto your hands, and tilt your bottom. Breathe normally. Hold for 3 seconds and release gently.

3. Knee rolling

Tighten your tummy muscles (as for exercise 1) and gently lower both knees to one side as far as is comfortable. Bring them back to the middle and relax. Repeat to the other side. This exercise has the added benefit of releasing trapped wind.

Aim to do these exercises three times a day with five repetitions each. Increase the repetitions as you feel able.

Source: Oxford Radcliffes Hospitals 2013

OSTOMINGLE- SUPPORTING SYDNEY'S YOUNGER OSTOMATES

Renee Constantin

As we go through life's ups and downs we all need support, from heartbreak to chronic illness, everyone needs a shoulder to cry on and an ear to turn to for guidance and understanding.

I first experienced IBD symptoms while I was studying for my HSC exams. My stubbornness and determination to succeed meant that I struggled quietly through bloody stools and stomach pains until I could no longer hide the daily painkillers and heat packs. The next six years are a blur of lengthy hospital stays, handfuls of medication, trial procedures and infusions peppered with a few wonderful moments of (semi) remission where I traveled and lived my life like a normal uni student. Half way through 2015 however, the conversation of creating an ileostomy became real and I began preparing for a surgery that would turn my life around.

At the end of 2015, as a young newlywed, just back from my honeymoon, my life as an ostomate began and following the advice of my stoma therapy nurse, I started an Instagram account (@pouch_by_pouch) as a sort of journal, to help chronicle the ups and downs of my ostomy journey. It ended up being one of my greatest sources of strength, as writing down and exploring my experiences has

become extremely cathartic and emotionally freeing. The feed also gave me a way of giving back to the online ostomy community, who had welcomed me with open arms, judgment free and ready to help during the months of preparation leading up to my surgery. But ultimately, I still felt alone and physically disconnected from other ostomates.

In 2016, I unfortunately had a small bowel obstruction that resulted in emer-

gency surgeries, sepsis, a temporary jejunostomy, a ton of infections and TPN that meant another wonderful hospital stay from April to August. During those months in hospital I had the chance to meet a lady who was newly diagnosed with colon cancer.

As she lay in the bed next to mine, my parents and I overheard her receive the news from her doctor that depending on what they found during her surgery, she may wake up with a stoma bag. She was devastated and petrified, and began to audibly cry as soon as the doctors had walked away. My mother went over, opened our dividing curtain, and sat on the bed of this complete stranger and hugged her for what felt like hours before introducing her to me.

For the next few days as she waited for her surgery, she picked my brain on everything stoma related, she tried on one



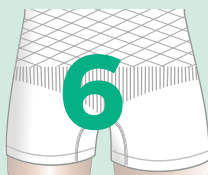


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of my spare bags, learnt all the tips and tricks I had once asked about and had picked up along the way and mentally prepared herself for waking up with a stoma. The two weeks that we spent as bed buddies was incredible for us both. Two complete strangers joined by a shared experience, leaning on each other, learning from one another and ultimately giving support in a way that only another ostomate could give.

Since then, the desire to physically reach out to the ostomy community has grown and this dream has finally become a reality in 2019, with the formation of a Sydney

based ostomy support group aimed at young ostomates. Aptly named Ostomingle, the group gives ostomates a chance to meet in familiar and comfortable settings, just as they would any other group of friends, and mingle. March 2nd marks the first meeting following a similar meet-up of Sydney based ostomates in November of last year at Bondi Beach. Meeting this wonderful group of young women drove home the need for a group such as Ostomingle as many of the established support groups focus on much younger or older ostomates, and I am thrilled to finally bring my dream to fruition.

ostomingle

LOOKING FOR SOME YOUNG, LIKE-MINDED OSTO-MATES?

Ostomingle is a group of ostomates 18 and over who come together over a meal to share their ostomy experiences, ask questions and learn from one another.

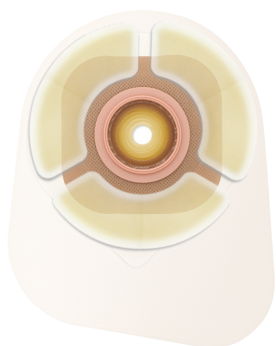
Each meet up will be held at a different venue around Sydney so we can mingle around town.

2nd March | 1st June | 7th September | 7th December

FOR FURTHER INFORMATION:

www.ostomingle.com | ostomingle@gmail.com

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Hello From The Clinic

Skin Care

There are several things that can affect management of your stoma. Some of the more common ones being weight gain or weight loss and herniation. Over a period of time your stoma may reduce in size thus requiring a change in the size of the opening in your pouch. Sometimes it may be necessary to change the type of pouch you are wearing. Many problems can be alleviated with some minor adjustments to stoma management or skin care.

Stomas essentially involve the maintenance of a permanently open breach of the skin and therefore the site requires expert skin care. The crucial skill in managing the skin comes mainly at the point of cleansing and changing as it is at this point that skin integrity is at risk. The skin around your stoma, also called peristomal skin should look and feel like the skin on the rest of your abdomen. As with most situations, prevention is better than cure when it comes

to peristomal skin care. You may have concerns that your skin will become irritated due to urine or faeces, or from having a pouching system on the skin all the time. Finding the product that gives you the best fit for your stoma and abdomen is most important to prevent any potential leakages that may irritate the skin.

Your Stomal Therapy Nurse will advise and assist you with the best choice and teach you to use ostomy products correctly to decrease the chance of skin irritation. A big proportion of people with a stoma are likely to experience some type of skin problem at some time and often are unable to identify if in fact they have a problem. Sometimes your skin may look pinker, redder or darker immediately after removing your pouch but this should fade away in a few minutes. If the redness persists or becomes itchy it may be a reaction to the adhesive on your stoma pouch or other products that you may be using on your skin. A visit to your

Stomal Therapist is required to determine the cause. Be gentle removing your pouch from the skin to avoid skin tears; carefully press the skin away from the adhesive with one hand whilst gently pulling the adhesive away from the skin with the other hand. Removing the pouch from top to bottom usually works best and helps prevent any spills on the skin.

Basic rules of skin care are Keep it simple! and that means the fewer products used on the skin the better. Wash the skin with warm water and a soft cloth and dry well before applying a new pouch. It is ok to shower without your pouch on and for many people this is the preferred option. Cleaning peristomal skin with baby wipes is best avoided as they can leave a residue build up that may impair the adhesive quality of your pouch. Remover wipes or skin barrier films should only be used sparingly and only if they are really needed. Most people do not require daily use of these products.

P.S. Just a friendly reminder to all that the cold weather and the flu season are approaching so don't forget your flu injections and

remain aware that it is not unusual for people to become more dehydrated in the winter months than it is in summer. In winter you often lose the body's natural thirst response and don't drink as often as you should. You also tend to be rugged up in all your winter gear whilst living, and playing in heated environments. You still sweat and lose body fluid even when it's cold outside, so drink up and keep well!



Good wishes to all, see you at the clinic!

**Phone 95421300
for an appointment.
Janet Forsyth RN MACN JP
CNC Stomaltherapy**



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