

THE JOURNAL OF

OSTOMY

NEW ZEALAND



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N.Z. OSTOMATE

3-2019

ISSUE 112

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N.Z. OSTOMATE

**THE JOURNAL OF
OSTOMY NEW ZEALAND**

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FNZOS MISSION STATEMENT

To enable member Societies to best work together with families, medical professionals and Health Authorities to ensure that, in New Zealand, all Ostomates and persons with related surgeries receive, free of charge, care and equipment that will enable them to lead normal lives of optimal quality.

FROM YOUR EDITOR

Welcome to your final copy of the magazine for 2019. I am not sure where the year has gone but here we are at the end of another month already. I have just returned from a wonderful conference weekend filled with a great variety of speakers that was this year hosted by Waikato members who did an amazing job. We welcome Robyn Tourell back as Secretary and Richard McNair as Treasurer. The Training Day and AGM will be held in Wellington on Saturday 15th August 2020 so if you are planning a holiday in the North Island around that time why not plan a stop in Wellington and attend this one day event. Hawkes Bay Ostomy Support group have kindly put their hand up to host the 2021 conference and AGM with planning underway and the Ostomy New Zealand Board look forward to supporting them in any way we can.

Society Memberships

There are ongoing concerns in some societies where membership numbers have fallen. This is a problem across the country but one that Board members are aware of and are doing their very best to address.

Contact Phone Number

There is now a toll-free phone number available enabling anyone to access information about local societies and Ostomy New Zealand inquiries at any time. 0508 678 669 (0508 OSTOMY)

Facebook Group for NZ Ostomates

A reminder that if you would like some online company where you can engage in conversation about having an ostomy, or to share experiences, you

might like to join the closed Facebook Group set up specifically for Ostomates in NZ. At OstoMATESNZ <https://www.facebook.com/groups/237390785093/>

Website

A huge amount of time and effort has been put in by Kallia Patching over recent months re-developing the website to make it more attractive, user friendly and easy to negotiate resulting in an amazing site that went live at the conference in Hamilton..

Go to www.ostomy.org.nz and have a look for yourself.

Appliance Supplies

We are very fortunate to have such wonderful support services available to ostomates in New Zealand with the supply of free appliances. Regular reminders do need to be given however about the importance of not becoming complacent by stockpiling appliances as they do have a use by date and need to be stored correctly. If you find that you don't need a supply one month, please call your stomaltherapist or USL if that is where they come from and put your supply on hold for a month or so.

Friends of Ostomates Worldwide New Zealand

We are very grateful to Barry Maughan & Richard McNair who have set up Friends of Ostomates Worldwide New Zealand and are now sending surplus supplies to countries who are less fortunate than ourselves meaning that supplies are able to be used where they are most needed and appreciated.

Team OKK Ride for Ostomates

As you will all be aware the profile and awareness of ostomates in New Zealand has been lifted in recent months thanks to Kallia Patching and her very dedicated team who put in a huge effort with preparations over a 12 month period leading up to and completing an 8 day ride through New Zealand in support of holding camps for young ostomates. We look forward to the camps for young ostomates coming to fruition. As Youth Coordinator Kallia has made contact with many younger ostomates throughout New Zealand and as they are our future she will be keeping those contacts up to date with happenings in Ostomy New Zealand. If you are in the younger age group or know someone who is that would benefit from a chat, please get in touch with Kallia who is only too willing to offer a listening ear at any time. Kallias contact details can be found on page 38 of this magazine.

Changes of Address and Society Contacts

Please remember to contact both the Ostomy New Zealand Secretary and the Magazine Editor to advise of any changes to ensure that you are kept up to date with any events, correspondence and magazines.

NZ Ostomate Magazine

The magazine continues to be produced 3 times each year with good support from supply companies in the form of advertising. Both the Stomaltherapy Nurses Assn of NZ & the Crohns & Colitis Society of NZ are invited to

contribute to each issue of the magazine as I believe we are a partnership and should therefore be able to be of benefit to each other by regular updates and the sharing of stories. It still saddens me however, to hear reports that magazines and newsletters are only going to financial members in some areas denying ostomates and their family members of the opportunity to read some very positive stories that are being shared and to raise awareness that there is support available in all areas of New Zealand.. "How can we expect to attract new members if they are not being given the opportunity to receive information"? Each magazine takes approximately 120 hours to produce and I would like to think it was reaching all ostomates. Printing costs are a major part of producing the magazine so if you know of or are a part of a business or Service group that could offer some sponsorship towards these costs please let either me or a Board member know and we can discuss it further. I am always on the lookout for articles for the magazine so how about putting pen to paper while relaxing over the holiday season and get your story to me ready for the next issue.

As this is the final issue of the magazine for 2019, on behalf of Board members of Ostomy New Zealand. I would like to wish all readers, family and friends a Happy Christmas and a safe and healthy New Year.

Jill Newton
President Ostomy New Zealand
Editor NZ Ostomate Magazine

CAROL'S STORY

I have been a voluntary Catholic assistant chaplain for almost 16 years at our regional hospital. (The Hawke's Bay Fallen Soldiers" Memorial Hospital). I was commissioned by Bishop Peter on 3 April 2003. I believe a chaplain must have the four C's -Christ, comfort, compassion and confidentiality. These I live by in my chaplaincy as I tend mostly to my Catholic patients. All chaplains in our hospital wear a cross to show they are Christian Chaplains. I usually wear a wooden cross given to me by a dear nun friend, Sister Marcienne. It once belonged to a saintly nun, Sister Michael. Also I am very proud of a cross on a bar which my husband Dave made for me. Every day the Ecumenical chaplains and our main Catholic Chaplain Deidre Russ get a full list of every patient in the hospital. Each name has the ward and bed number. Often the patient has a religion named too. When a patient is admitted there are two lines on the admission sheet that states -

"Do you want to see a chaplain?" "If so, what is your religion?" Some fill it in; most don't.

But it is one way to ensure you will get a visit from a chaplain.

One day I counted how many religions were on the list -13! They ranged from Hindu to Church of England, Ratana and atheist. Many just write "Christian."

All chaplains wear ID cards giving them access to all wards including IC (Intensive Care).

Being a voluntary chaplain, I do not abuse this and if going into IC I go through the waiting room and ring the bell and ask if it is okay to speak to the patient. This also applies if I wish to go into maternity. I ask if the mother is free to see me" I always follow the nurse's instructions. In the general wards, if the curtains are drawn I do not see the patient -it could be they are having a procedure, bed bath or a well needed rest. If in doubt, I check with the nurse. Before visiting any patient, I pray to the Holy Spirit to guide me.

Very early in my role as chaplain, I was asked to visit a beautiful old Maori man from Wairoa, who was dying. Every so often he would say "I can still smell it now." He told me his story of how he was in the Battle of Monte Cassino. He was to help bring in the mules, to help the wounded and I suspect pull the guns. He said: "The Nuns were in the Benedictine Abbey above and firing at will at us. The soldiers and mules had nowhere to go and both were literally blown to bits. "I still smell it now - I will never forget the smell."

History shows that 343 New Zealand forces killed; 1211 wounded; 42 captured. That dear dying man could still smell it - his dead fellow soldiers and the dead mules.

On another occasion, again very early in my chaplaincy days, I was going to the rehabilitation ward when the receptionist called me over. "Carol, would you visit Mr X in Room 12. He will not talk to the nurses -he only grunts." "Ok", I said. "Is he a Catholic?" "Who knows, he only grunts." I went down to Room 12 and found an elderly man, fully dressed, sitting on the side of the bed with his hands beside him.

I quickly prayed for guidance. "Good morning," Grunt! I noticed his hands were big and thickish. "I asked: "You're not a farmer are you?" "Yes come in and sit down." On my way back from the ward, the receptionist called "You were a long time with Mr X." "Did he talk to you?" "Yes" I said, He talked about his farm and his childhood memories of the farm. And I told him how I had to help milk the cows when I was a child." She replied "Thank you. That was the breakthrough we needed." I am very grateful to Deidre who will often leave me a message; Mrs X Room 2, very deaf or Mr X loves to talk about his dogs. These wee tips help me as most patients are strangers. Since our hospital often has patients from Waipukurau or Wairoa, plus locals from both Hastings and Napier, I sometimes start a conversation with "Are you local?" Usually they are. One day I asked a patient if he was local. "Yes he said, "I am from New Plymouth!!! I have often held the hands of patients who are dying, while often waiting for family members to arrive. Sometimes there is no family to come so I will pray with them. Sometimes I've sat with a dying patient but death can still be a few days away. If the family is there I tell them to speak normally-tell stories, tell jokes -hearing is the last sense to go. Normal speaking, not hushed voices which allows the patient to share their last memories with their family. I never touch the head of a patient- you never know how they are feeling or what medication they are on. But holding hands is okay. I never ask why the patient is in hospital. If they choose to tell me, we will mention that complaint as we pray together. I was walking down the corridor of a ward one day when a nurse called to me "Carol, would you please come and see Mr X. He has just been told he has six weeks to live and has asked to see a chaplain- so you'll do!" When Mr X saw my badge he asked me to sit down next to him. "I hear you have been given bad news," I said. "No, good news. Not everyone gets to know how long they have left." "Is there anything worrying you?" I asked. "Yes, my wife." I offered to sit with him until she arrived. "Oh no, dear. She died two years ago." He went on and told me as a young fellow he used to go to Sunday School and he believed "his Jean" was in heaven after she died. "She was the best wife and mother in the world. About a year ago, two young fellows came to my door, I told them my Jean had died. I was shocked when they told me to forget her -my lovely Jean - the best woman in the world. Forget her - never!" They said "she's gone, poof, just like that." I took his hands and looked him straight in the eye. Dear, dear, Mr X. Never forget your lovely Jean. She is in heaven waiting for you. And it is your faith and hope in eternity that will bring you both together again. This I truly believe. Six weeks later, almost to the day I had been speaking to him, I read his death notice in the paper. It ended: "With Jean again." As chaplains, we are also on call if needed for the nurses and staff.

A nurse asked me to speak to a cleaner, who seemed very upset. I found Deb in Ward 2, and it transpired that she was very close to her Dad. She wanted to see him as he was very ill. But her stepmother would not allow her. That morning the stepmother had rung Deb to say he had died and she was not to go to the funeral. So I took Deb to a quiet room where she could have a good cry and tell me stories of her Dad and then we prayed together. Each time I met Deb from then on, I got a hug. Often patients can receive Holy Communion on a Sunday. One Friday I visited

CAROL'S STORY

a lovely old man. After a chat and a prayer, I asked if he would like to receive Holy Communion on Sunday. "Girlie, I have not been to confession for years. I said that is between you and God, but if you'd like Communion on Sunday, I will organise it for you. His face just lit up: "Yes please." "Girlie "is just one of the names I've been called. I've been called mother or sister when patients have thought I was a nun. But Girlie is the one I won't forget. Although I see my Catholic patients, I have been stopped many, many times by a wee voice saying- "Have you got time to talk to me?" One time in rehab I heard a tiny, frail, lady asking if I had time to talk to her. "Would you like a prayer? I asked. "Not yet, she said and then proceeded to tell me her life history starting with her great grandparents coming out to New Zealand in a sailing ship. She wanted to share her life with someone who had time to listen. By the time she got to her grandchildren it had taken three quarters of an hour. Then she said, "I'll have that prayer now." Yes listening is something chaplains learn to do to. From time to time, a patient will tell me - "I don't know how to pray." I tell them not to worry, God understands. "You can always, say, (even under your breath), "Jesus I love you, thank you for loving me." Recently I was speaking to a former patient who told me that I had told her that prayer when she was in hospital. She thanked me and said she now taught that prayer to her grandchildren and if she is very tired she will say it too. In the maternity ward we are not allowed to touch a baby but we can pray over it and for the parents. Only once has a mother said to me "Carol, would you like to hold the baby? I took it and put it over my shoulder and it burped! Memories of my boys when they were babies came flooding back. In my work as chaplain there are always extra special moments of great joy among the sadness. Many Catholic patients take their rosary beads into hospital. If they are left on their table, it is surprising how many nurses realize the faith value of them. If I



miss a patient because they are perhaps having an x-ray, are in theatre or showering, I leave a card on their table to let them know I have called.

**I make this my prayer for all you readers today -
"The light of God surrounds me,**

**The love of God enfolds me, the power of God
protects me, the presence of God watches over me,
Wherever I am, God is.**

Carol

NEW
wide
sizes

"I was determined to play cricket again. The seal gave me confidence."

Kevin, ileostomy since 2015



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Kevin uses **Brava Protective Seal Wide** to enhance appliance fit and protect against leakage.

What's right for you?

There can be many reasons for leakage. Kevin had difficulty in getting his baseplate to fit securely, particularly when playing cricket. He uses Brava Protective Seal to seal the gap between his stoma and baseplate.

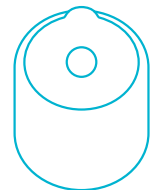
The seal is easy to shape for a snug fit around the stoma and helps to absorb any extra moisture. It is also easy to remove and leaves minimal residue.

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LETTER TO THE EDITOR

Dear Jill,

I have been an ostomate for 5 years now and have always had trouble with gassing.

I have read all about foods etc and tried to limit the foods which cause the gas.

I started off using the closed pouches but found open end ones of better value and have sent you the 2 types of pouch. You will note the closed ones have a place to use as a gas release position. I used to degas the closed end pouch before going to bed. I often get up to go to the toilet during the night and the pouch would be blown up so I would pierce it, let the air out and go back to bed.

For the open end pouches I have punched a hole in the same place as closed end type and this has made life easier as the gas automatically releases.

I am lucky in that I have an outside sink with taps and a shower and I put a hose on the tap and wash out contents of the bag into the sink and down the drain.

Cheers

GH Fernihough - Te Atatu Peninsula.

DON'T EVER THINK YOU ARE ALONE

As a new ostomate, you may be wondering just how long it takes to get used to everything. The answer is that everyone is different. Websites

and magazine articles can be very helpful and there is a lot of information about stoma management and ostomy products to be gained from them.

On the other hand, to get a real-life perspective on "what it's like to live with an ostomy", you need to talk with others who are living that life. The real value of a support group is that you have the opportunity to meet many people who have had a broad range of experiences dealing with the same issues that you have. It helps to know that someone else has had the same anxieties, the same concerns, the same questions, the same problems. Don't ever think you are alone!

WHEN TO CALL A DOCTOR OR NURSE

1. If cramps last more than two or three hours.
2. If you get a deep cut in your stoma or bleeding at the juncture of the skin and stoma.
3. If you have excessive bleeding from the stoma opening or a moderate amount in the pouch after emptying.
4. If you have a strong odour lasting more than a week.
5. If you have severe skin irritation or deep ulcers.
6. If you have severe watery discharge lasting more than five or six hours.
7. If you have an unusual change in the size or appearance of your stoma.

JOHN O'NEILL AWARD 2019

Our winner of the John O'Neill award for excellence by an ostomate for 2019 was born in Stratford, Taranaki in September 1932. She attended schools in Taranaki and Waikato, returning to New Plymouth with her parents, where she worked for three years in a cafeteria, before moving on to become a nurse Aid and training as a maternity nurse. It was during this time she met & married her beloved husband, returning to farming. Seven children later, the family moved back to New Plymouth where she was also a part time nurse, and in 1965 they bought a catering business.



After 20 years and many major surgeries, our winner became an ostomate in 1982.

1983 she became Secretary/Treasurer of the Taranaki Ostomy Society.

1986 she organised a 1 day training seminar at the Taranaki Base hospital.

1988.....she was President of Taranaki, newsletter editor, ostomy visitor and liaison person with training.

1991.....she organised a 1 day seminar in South Taranaki. That same year she was nominated as "A Woman of Spirit" for her ostomy work to the society, receiving an award from Dame Cath Tizard.

1992.....she assisted in the organisation of the FNZOS conference, followed by those in 2007 and 2017. She has attended every conference since 1982.

1992.....she was nominated onto Federation.

1994.....she was a delegate to IOA Congress in Adelaide and became President of SPOA, a position she held for 3 years.

1995.....she was Vice President of Federation.

1997.....she was the NZ Delegate to IOA conference in Calgary Canada.

2001 – 2007 she was President of FNZOS.

2006 she attended regular meetings of SPOA & FNZOS in Rotorua.

2008.....she went onto the FNZOS committee, and has assisted with 5 youth camps over the years.

2017.....she received a Life Membership with Ostomy Taranaki

We feel that FRANCES DOREEN BUTLER has gone well beyond the call of duty and it is our great pleasure to present her with the JOHN O'NEILL AWARD.

WHAT'S NORMAL FOR YOUR STOMA

Colour should be a healthy red. Usually the stoma is the same colour as the inside of your intestine. If the colour darkens, the blood supply might be pinched off.

Make sure your skin barrier or wafer is not too tight. This can vary according to the barrier type, as some require a small gap between your stoma and the barrier material, while others are intended for a snug fit where the wafer material actually touches your stoma.

If, in the unlikely occasion, the stoma turns black, seek treatment at once. Go to the emergency room if you cannot locate your doctor.

Note: Blockages should be evaluated by a physician to determine if it is from food impaction... or from other reasons, such as a kink in the bowel or adhesions/scar tissue.

Possibility of a little blood when cleaned. This is to be expected. Do not be alarmed. Just be gentle when cleaning your stoma.

Ileostomy stomas will flow intermittently and stool will be semisolid. If you notice that the stoma is not functioning after several hours and if you develop pain, you might be slightly clogged. Try sipping warm tea and try getting in a knee-chest position on the bed or on the floor. (Have your shoulders on the floor and your hips in the air. Gently rock back and forth in this position, in an attempt to dislodge any food that might be caught).

If you do not begin to function after a

couple of hours and have nausea or pain in the abdomen, call your physician. If you cannot locate your physician readily, go to an emergency room. In the meantime, your stoma might begin to swell. Remove any pouch with a tight barrier/wafer and replace it with a flexible one with slightly larger stoma opening. Colostomies located in the descending or sigmoid colon. Colostomy stomas should function according to what your bowel habits were before surgery (daily, twice daily, three times weekly, etc.). Some individuals manage their colostomy with diet and some prefer irrigation (process to wash out a storage area in the colon).

Pouching systems may vary according to your management method. (Open-end drainable, or closed end security pouch). Urinary Diversions. Urinary diversions function almost constantly (with slow, light output) the urine should be yellow, adequate in volume and will contain some mucus. If the urine becomes too concentrated or dark, try increasing your fluid intake. If the mucus becomes more excessive than usual, you might have an infection. (It will probably also have a stronger odour and you may have a slight fever). Consult your physician if this happens.

Copied from INSIGHTS The Newsletter of the Ostomy Assn of Southern New Jersey.



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the truth about peristomal skin itching.

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

*In a recent study, more CeraPlus skin barrier users were **very satisfied** with prevention of itching.***



* Consumer Survey of Pruritus, 2016 Hollister Data on file. **As compared to Hollister non-ceramide skin barriers. Colwell J, Pittman J, Raizman R, Salvadarena 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.

SHELLEY'S STORY

My story begins in Taranaki where I was born in 1951. My parents adopted me when I was 10 days old, and I grew up in a household with my Mother, Father and Grandmother. I don't recall feeling lonely as a child, as I had cousins and friends around most of the time. Many people would have described me as having a sunny disposition.

My teen years, after discovering from a kid at school that I was adopted, were fraught with anxiety and identity crises. That was about the time my constipation became an issue. Bear in mind that in those days support or assistance for a teen with emotional issues was non-existent. "Pull your socks up and grow up" was about the best I got!

When I was 19 after my forgettable teen years, I had a massive nervous breakdown. At last someone heard me and I was admitted to Ashburn Hall in Dunedin, where I was treated for several months by a dear little doctor we called Polly Lind. She walked through the journey of my life thus far, enabling me to reach decisions and courage and determination.

My chronic constipation was still a concern, however did not worry me as much (although, in retrospect, the damage had been done). In my 20's I developed fissures and fistulas, requiring hospital treatment and after-care.

After several years and a move to another city I met and married a man with a ready-made family. I really thought this was my destiny and we

would be so very happy. My dream of a happy family was not to be.

My beautiful son was born into that marriage – a marriage that was not a happy one, fraught with tension, more anal fistula surgery and violence. After years of abuse and marriage counselling I finally gained the courage to leave – to go it alone with my young son and stand on my own two feet.

For several years this is exactly what we did, and were surviving very well, using our own resources to create a happy existence for us both.

This all may seem irrelevant to my story regarding becoming an Ostomate, however, I ask you to bear with me and understand that the accumulative affects are all contributing factors to my journey.

Quite by accident, (at his Father's funeral!) I met my soulmate and now my husband. This man allowed me to be me, was compassionate and embraced both myself and my son. Our lives together have had their ups and downs, however, at the end of the day, our kids have all grown up and we are together – best friends, having each other's backs, and looking forward to growing old together with much love and friendship.

We spent many years together in Australia, and finally my bowel issues prevailed and I needed surgery yet again in 1996. It was discovered that I did indeed have rectal cancer.

This was removed and followed by treatment. However, this surgery rendered me incontinent. My life centred around discovering where the nearest toilets were throughout Sydney. I became known as Mrs W.C.

In 2003 we moved back to New Plymouth to care for my Mother, who was elderly and extremely unwell. We got ourselves jobs, bought a house and prepared to settle near to her. My bowel issues continued with incontinence ruling my life. Depression, that big black dog, became my daily companion.

Eventually, at my husband's insistence I made it to a General surgeon, who suggested we go for an interim option, which would offer me 'some level of comfort'. I was so desperate for a solution and a chance to reclaim my life, that I rejected this and opted for a full colostomy. And so my Ostomy journey began in 2007.

I had pancaking and many teething issues, including hernias.

During a surgical procedure for the latter my bowel was perforated and it became another life-threatening situation. The following year was spent in and out of hospital with ongoing infections. I was no longer employable and ACC rejected my case for compensation.

However, I was determined to get to the bottom of these infections and doggedly insisted that the surgeon forget the many keyhole surgeries, bite the bullet and 'go for it!' And so he

operated, opening me from hip to hip, discovering a piece of infected bowel that had been there for almost a year. What a relief!

My message to you is this – you know your body better than anyone. Don't allow yourself to be fobbed off, and remember that the squeaking wheel always gets the oil – or the screaming baby always gets the boob!

Time to reinvent myself and I rose like Phoenix from the ashes. Thus began my journey of paying back, using some of my previous grief counselling skills to volunteer, helping to make people feel better, and feel good about themselves and to give them hope for a brighter future.

Consequently I joined my local Ostomy Society, becoming Secretary and now President and have been fortunate enough to be elected onto the national executive of Ostomy New Zealand.

I am passionate about being there before, during and post Ostomy surgery, for the patient and their carers/family and it is so very rewarding to see patients emerge, keen to embrace life and everything in it.

Sure, I have the odd 'poo-nami' and smell-a-thon, but life is good. There is a bright future waiting out there for us all.

Shelley McDougall
New Plymouth

MORE OSTOMY FRIENDLY RECIPES FOR TWO FROM THE GIRLS

Carrots with Spiced Butter

Ingredients

2 large carrots
10 g butter
2 tsp honey
2 spring onions
Half teaspoon allspice (or ground cinnamon)

Method

1. Peel and trim the carrots, then cut into wedges about 1cm thick and 5cm long
2. Boil the carrots in water until tender – about 10 minutes. Drain and keep aside
3. Heat butter in the same saucepan, add the honey. Spring onions and allspice. Cook. Stirring, until melted
4. Return carrots to the saucepan and toss to combine, then serve and eat when the rest of the meal is ready.

Spicy Green Beans

Ingredients

1 tsp olive oil
Half an onion, sliced finely
1 tsp brown mustard seeds
1 tsp cumin seeds
1 tsp grated ginger
1 garlic clove, crushed
Eighth teaspoon turmeric powder
Eighth teaspoon chilli powder (optional)
Salt and pepper to taste
Frozen (or fresh) green beans enough for 2

Heat the oil in a fry pan and cook onion and spices on medium heat until soft. Cook beans as usual and add to the pan and continue cooking if you like the beans very soft, or toss in the spice mixture and serve with your main dish.

Things I've Learned

I've learned.... that I can't choose how I feel, but I can choose what I do about
I've learned.... that love, not time, heals all wounds.

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CONFERENCE & AGM HELD IN HAMILTON 9TH, 10TH 11TH AUGUST 2019

Once again members of the Waikato Society treated everyone to a magnificent weekend of education, fun and fellowship.

Barry Maughan opened the conference and introduced the Mayor of Hamilton Andrew King who gave a brief outline of the district and officially opened the conference.

This was followed by a polished performance by talented members of the Waikato Diocesan School Kapahaka Group.

Simi Lolohea a colorectal surgeon at Waikato hospital followed with an entertaining talk about his experiences doing surgery in the poorer parts of Tonga. Simi goes to the Island two or three times a year where he has built a house and mixes his time between doing surgery and “socializing” with the locals.

Richard McNair gave an update of the happenings in the South Pacific stomy Association, International stomy Association and the Friends of stomates World Wide New Zealand that has been set for the distribution of surplus supplies to ostomates in overseas countries who are less fortunate than ourselves.

The Trade Suppliers introduced themselves and told a little bit about their products before Morning tea was served.

Kallia Patching then gave a very informative talk about her life before, leading up to and following ostomy surgery with highlights of the recent cycle tour of New Zealand she had competed in with particular emphasis on raising awareness of ostomates along with raising funds to support young ostomates attending camps.

Rachel Tiberi who is the Marketing Manager for Coloplast in Australia and New Zealand presented the Coloplast Award to the Western Bays stomy Society whose entry won 1st place in the Coloplast Award run in conjunction with World stomy Day 2 18.

Debbie Strode who was a Stomaltherepist in Waikato for many years before travelling overseas to work in some very poor conditions amongst mostly Muslims in Arab countries told us of some of her experiences – a mixture of both good and bad. With no ostomy or cancer societies and due to cultural factors people mostly presented when they were in the late stages of their disease as bodily functions are not talked about. An enjoyable and rewarding experience.

Toby Cunliffe-Steel - a prominent athlete and survivor shared his many experiences and misfortunes both on the water as an international rower and on the land and showed that adversity can lead to success. A very gutsy young man who has certainly had his share of highs and lows and risen above them all. This concluded the morning session and beautiful lunch was served.

The afternoon programme began with workshop sessions - Colostomy. Ileostomy. Urostomy. Young Ostomates and Partners/Supporters. These workshops gave participants the opportunity to ask questions, discuss problems and share experiences. The positive outcome of these sessions certainly gave an indication that

it is something to be repeated at future conferences.

Judy Warren - Project Manager of the Midland Cancer Network outlined the current progress of the Bowel Cancer Screening Programme which will eventually be rolled out through all OHBs throughout New Zealand.

Jason Ly gave a very informative and well-illustrated talk about "Everything you need to know" about Parastomal Hernias and the different treatments available.

Patron of Ostomy New Zealand Mr Graeme Roadley who is a surgeon in Timaru then presented Breaking down Barriers holding the audience's attention before Dstamy New Zealand President Jill Newton gave a full report of updates and happenings of the Board over the past 12 months. Our wonderful new website was officially launched.

The Jahn O'Neill Award for Excellence by an Dstamate was presented to Mrs Frances Butler, a very worthy recipient who has been a very active, hardworking and dedicated member of the Ostomy world for 37 years.

The raffles were drawn and the conference closed by President of Waikato Ostomy Society Mr Brian Gardon.

Participants then had a couple of hours free time before meeting for pre-dinner drinks and an evening of socializing, dancing and catching up with friends.

The Annual General Meeting was held on Sunday morning with Robyn Gall, Lee King, Brent Silcock and David Barnes standing down from the Board. And Robyn Taurell filling the position of Secretary. Following the Annual General Meeting Richard McNair offered to fill the position of Treasurer for the ensuing year. Welcome back Robyn and Richard.

Waikato members did an outstanding job in presenting us with a full and stimulating weekend with everyone buzzing with enthusiasm. Thank you to Waikato for a great weekend.

There will be a Training Day and AGM held in Wellington on Saturday 15th August 2020 and the 2021 Conference and AGM will be held in Havelock North on 13th - 15th August 2021.



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BITS & PIECES

Resolutions of an Ostomate

I RESOLVE:

1. To remember my own early days and realize that no question by a new ostomate is silly.
2. *To not begrudge the time necessary for my personal stoma care.*
3. To value the cooperation of my family.
4. *To appreciate the fact that I am one of the lucky ones.*
5. To try to do the things I want to do but think I can't.
6. *To be patient.*
7. To LIVE all day, every day.
8. *To help others whenever I can.*
9. To urge my fellow ostomates to see people, go places, and do things.
10. *To give full credit to modern medicine.*
11. To be grateful for my present good health.

Short cuts - While we convince ourselves that we are doing the right thing or taking a "logical" shortcut, we might inadvertently get ourselves into trouble. Here are some instances to think about: -

- **Using alcohol to clean the skin around the stoma:** Alcohol is a powerful drying agent. Prolonged contact with the skin can have serious consequences.
- **Wearing the appliance for as long as you can until it leaks:** The object is to change the appliance before leakage occurs. This way your skin gets the best protection and care.
- **Ignoring skin problems:** All the skin problems are easier to treat if the treatment is started early.
- **When you feel you are living with a condition that you cannot correct yourself, consult your doctor or Stomatherapist.**

Helpful Tips for traveling with Medications and/or Ostomy Supplies:

- Keep your medicines (and emergency pouches) with you—not in the checked luggage.
- Bring more than enough medicine and/or ostomy supplies for your trip.
- Keep a list of all your medicines and/or ostomy supplies with you.
- Don't store ostomy supplies in your car, especially under the hot summer sun.

FIGHTING STRESS.. WITH LOVE & COMPASSION

Stress is inescapable in today's world and even simple issues like being in noisy traffic can give you stress

When you're stressed, your heart speeds up and your cholesterol and sugar levels rise. The possible results are backaches, stomach problems, increased sensitivity to pain and, of course, heart attacks. However you can effectively combat stress by learning to handle it better.

An active social life relieves stress, studies have shown that people with many social involvements have far fewer health problems than people who are isolated. If you interact with people regularly and feel like you belong -- in communities clubs, discussion groups or even work -- you are much more likely to be healthy and will probably live longer.

Scientists aren't exactly sure why social contact is good for you, but they suspect that it may be due to a "buffering effect." When you are supported by concerned friends and family, life's pressures are eased.

Volunteering seems to be especially good as it decreases your awareness of your own problems and increases your sense of commitment, challenge and self-esteem... all positive emotions that help counteract the effects of stress.

The hyper Ileostomate

If your ileostomy gets hyper or overactive it can be due to a variety of causes.

- If the small bowel is inflamed the output will be profuse.
- If there is narrowing of the small bowel close to the stoma, where the ileostomy goes through the abdominal wall, a pressure backup can lead to explosive high output.

Any food that has a laxative effect should be eliminated or, at best, kept to a minimum. People with lactose intolerance will have high output if they use any kind of milk product, including powdered milk, which is found in many ready-to-eat foods.

Excessive drinking of fluids will also increase the ileostomy output.

Someone who has had a gall bladder removed may have increased output. The ostomate should work with his physician to evaluate the problem. Dietary changes may be made strictly under Doctor validation.

Osto Facts - copied from Osto-Hope the newsletter of the Ostomy Association of India, 74, Jerbai Wadia Road, Bhoiwada, Parel, Mumbai-400012

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HYDRATION FOR OSTOMATES



When the summer months are upon us, it is a great time of year with lots of social engagements, fun and frivolity. And winter is a great time for staying indoors, keeping warm and enjoying some rest and relaxation. Both seasons bring their individual joys and pleasures. However, whether the weather is warm, cold or in-between, it is important for all ostomates to engage in one important activity – drinking!

I'm sure you'd like me to now start discussing the merits of an ice cold beer versus a good red wine, but unfortunately that is not what I am referring to (which I think you knew all along!) Instead, of course, I am referring to the health promoting activity of drinking more water to hydrate the body and facilitate a myriad of essential functions within the body.

Different parts of the gastrointestinal (GI) tract perform different functions, with the small intestine mainly digesting and absorbing nutrients from the foods that are eaten, and the large intestine (or colon) mainly absorbing water back into the body. In a person with full intestinal function who hasn't had any stomal surgery, approximately 2.5 litres of fluid are lost from the body each day via the lungs (breathing), the skin (sweating), the kidneys (via urination) and the intestines.

Of this 2.5 litres, only 100 mls is usually lost via the intestines. However, for an ostomate who has had part of their intestinal tract removed, the amount of fluid lost from the intestine can be a lot more than 100mls depending on which part of the intestinal tract has been removed, and the consistency and quantity of the output. It is therefore imperative to replace this extra fluid on a daily basis.

For a person with an ileostomy who has had all the large intestine removed and perhaps some of the small intestine too, the need for additional fluids is imperative. The tissue (colon) that normally performs the major function of absorbing water from the GI tract is no longer present, and output can be very loose as a result. If it is very liquid and resembles water, then it is critical to replenish this fluid frequently.

However, if the output has a thicker consistency and is more like a paste, then less fluid is lost from the body and the need to replace it is not quite as great. Over time, the small intestine does begin to compensate for some of the functions of the large intestine by absorbing more water, but it takes time for this adaptation to occur.

For people with a colostomy, who may have had only a small part of the large intestine removed, the ability to absorb water may not have been affected very much and there may not be such a great need to compensate for reduced fluid absorption. However, if constipation and motility issues are a problem, then increased fluid intake can be an easy strategy to begin addressing this issue.

Hydration is very important for all people with a stoma, and this includes people with a urostomy as well. A greater fluid intake is needed in this case to create a strong urinary flow that can flush out any harmful bacteria that may be lingering in the urinary tract and potentially cause infection. Extra fluid is also needed to flush out any mucous that is secreted by the intestinal tissue that was used to form the urinary conduit.

Fluid intake is usually via both moist foods (approx. 700ml per day) and ingested liquids (usually approximately 1600 ml per day), with around 200 ml of fluid being produced within the body itself via metabolic processes. Therefore, fluid intake usually totals approximately 2.5 litres per day, which would normally equal fluid lost from the body when intestinal tissue is intact and maintain a positive fluid balance.

However, as previously mentioned, if the output from the gastrointestinal tract is higher than 100 ml or a strong urinary flow is required, which is often the case for different types of ostomates, then the fluid intake needs to be much higher than this.

It is important for individuals to keep an eye on fluid intake compared to fluid losses to prevent dehydration. Some of the most common indications of negative fluid balance are dry mouth, headaches, irritability, fatigue, poor concentration, constipation and dry skin. Low blood pressure and fainting spells can also be indicative that fluid levels in the body are low.

An important fact to be aware of in order to maintain hydration is that the thirst mechanism becomes less reliable with advancing age. By this I mean that the sensation of thirst starts to weaken, and it isn't triggered as often as it used to be. Therefore, as aging progresses, it is important not to rely on the sensation of thirst to indicate when it is necessary to consume fluid.

A more useful tool can be to use a visual reminder to drink. This can take the form of a jug on the kitchen bench that is filled up each morning, and emptied by lunchtime and again in the late afternoon.

That way you know you are regularly consuming an amount of fluid that will facilitate hydration. It also enables you to know how much fluid you are drinking every day. Setting a target of eight good sized glasses of water per day is also an option.

Another important consideration in maintaining fluid balance is that excessive amounts of fluids such as alcohol, tea and coffee may not be hydrating and fluid replenishing, but actually dehydrating and fluid depleting.

When it comes to replacing fluid in the body, water is best. For those who are not fond of the taste of water, adding some fresh lime or lemon juice, or a dash of apple, orange or pineapple juice can improve the taste a little. This can also help with absorption. Switching to herbal teas can also help to rehydrate the body. If having to get up to go to the toilet during the night is a problem, drink more fluid earlier in the day and less after 3 pm.

Fluid intake can also be boosted by eating watery foods such as watermelon, mango, juicy peaches and nectarines, and grapes. Just be aware that they may also loosen stools and therefore increase output, so keep the quantity moderate. Milk drinks and soups can also add to the total fluid intake for the day if tolerated.

In relation to hydration, a woman with an ileostomy made a very valid comment to me one day. She said, "It's not on the hot days over 30°C when you are at greater risk of dehydration, because you are conscious of consuming more fluid on those days. It is when the temperature is between 25° and 30°C that you are more likely to forget to drink extra fluid." And she is right!

But the same can be said for the winter months. Cold weather certainly reduces the amount of fluid lost from the body via sweat, but overheated rooms can be generally drying on skin and mucous membranes, necessitating an increased fluid intake to re-hydrate them.

So my advice all year round is to drink up! Let's toast to a positive fluid balance throughout all the seasons and better health for everyone!

Wishing you good health and happy days,
Margaret.

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

ALLY BAIN IS COMING TO NZ



In the United States, “Ally’s Law” is a household word. It refers to a law guaranteeing access to employee restrooms for people with ostomies, Crohn’s disease, and ulcerative colitis. It is named after a fourteen year old girl in the U.S. with Crohn’s Disease, Allyson Bain. Ally was in a large store in a mall in Chicago, doubled over in pain, urgently needing a toilet. She was refused access, despite pleading with the manager. Ally had an accident in the store and vowed that this should never happen to anyone else. Ally went to see her representative in the legislature, Kathleen Ryg, and together they were successful in getting the first “Ally’s Law” passed in the state of Illinois. Sixteen other states have since followed suit, all passing their own “Ally’s Laws”.

Unfortunately, what happened to Ally happens all the time. What was different in her case was her courage to speak publicly about her experience and advocating tirelessly for change. In the process she has made a difference in the lives of countless thousands of people.

In New Zealand there is another courageous fourteen year old, Nicole

Thornton. Nicole’s petition for an Ally’s Law in New Zealand is still under consideration in Parliament, but has met opposition from business owners and organizations.

Nevertheless, as a direct result of her petition, the Ministry of Health is considering measures to expand access to toilets and raise awareness about the needs of ostomates and those with IBD.

Last year Nicole and Kate Montgomery (one of Camp Purple’s volunteers) spoke passionately and convincingly about the need for change at a public hearing of the Health Select Committee.

Allyson Bain is now a lawyer working for the American Civil Liberties Union in Chicago. She is still advocating for people’s rights and has been in contact with Nicole, supporting her efforts for change.

In November, in partnership with CCNZ, Ally will be coming to New Zealand. With Nicole, she will be addressing the Annual Scientific Meeting of the NZ Society of Gastroenterology on patient advocacy. Her address will likely be a highlight of the meeting. A second speaking engagement is currently being arranged in Australia.

**Richard E. Stein, MD, FRACP, FACC,
AGAF**

**Chairman, Crohn’s & Colitis NZ
Charitable Trust**



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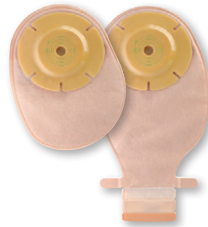


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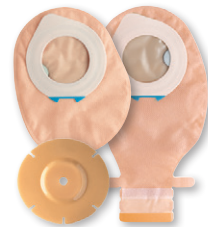
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VARIETY IS THE SPICE OF LIFE

We exercise for many reasons but in general, we should be doing something every day that will improve the efficiency of our heart and lungs. This is aerobic activity, activity that requires oxygen to produce energy. To be aerobic in nature, the activity must be of an intensity that can be maintained for a period of time - preferably more than twenty to thirty minutes. If this sounds too much for you, then use this as your goal and build up slowly. Select an activity that uses the large muscles of the body in continuous, rhythmical movement and one that you can maintain comfortably at a consistent level of intensity. Think about the following when selecting an activity that you will be able to maintain and enjoy:

- Continuous energy expenditure, not dependent on skill level - walking, cycling, jogging, stair climbing, hiking, water jogging or walking
- Energy expenditure dependent on specific performance ability (skill) aerobic classes, bench stepping, swimming, aquacise, rowing
- Variable energy expenditure dependent on the performance demands of the sport - basketball, netball, soccer, racquet sports, volleyball

While any of the above activities are considered aerobic, some will offer more in the way of additional exercise benefits such as joint range of motion, upper and lower body movement, agility, balance and co-ordination. Maintaining intensity in the second two groups is dependent on your skill level and the nature of the sport or activity. Activities in the water can be beneficial for the beginner or those with mobility issues as the water will aid freedom of movement by decreasing joint stress.

Any activity, sport or exercise programme followed too rigorously without professional direction, has the potential to result in stress injuries. For maximum benefit over time without risk of injury, choose between two or three different activities and alternate between them. Start easy and build up only when you feel ready to. All the activity we perform each day contributes to our total energy expenditure, so the more active we are, the better. However, when factoring in work you perform at home or in the workplace, ask yourself this:

- Am I working at a level that makes me puff a little?
- Do I maintain a constant pace for 20-30 minutes?

If we want to make a positive difference to our health and wellbeing, then we should select from a variety of activities that we enjoy, that are constant, and will make us puff a little every day.

Lee King
Colostomate and Fitness Instructor/Advisor

HEALTH MISTAKES THAT ARE MADE EVERYDAY

- 1. *Not drinking enough water each day*** - You should consume at least eight glasses of liquids every day to replace what you are losing through urine, bowel movements, sweat and the moisture you expel when breathing out and if you are exercising excessively you should drink even more.. (Beer and soda drinks do not count as they act as diuretics).
- 2. *Not getting enough sleep*** – People who skimp on sleep have been found to suffer from a variety of ailments including daytime fatigue, cognitive dysfunction, diminished reaction time and even a heightened mortality rate.
- 3. *Skipping breakfast*** – Research shows that learning, memory and decision making can be impaired when you skip breakfast. Furthermore by skipping breakfast you can jump start your appetite resulting in overeating throughout the remainder of the day.
- 4. *Attempting to exercise through pain*** – Pain is the body's signal that something serious may be wrong. Unlike discomfort, when you are experiencing pain, you should stop exercising and address the cause of the pain. Attempting to continue exercising through the pain could subject you to aggravating your existing condition or suffering an injury.
- 5. *Not washing your hands properly*** – Good hygiene helps to prevent infections and the transmission of germs.
- 6. *Not having a physical check-up occasionally*** – A regular check-up gives you an opportunity to detect potential illnesses from cancer to heart disease early. Although a complete annual check-up is not necessarily needed for everyone, you should see your physician for a check-up as often as he or she recommends.
- 7. *Being too busy to relax*** – (Whoops that might be me!) Making time to relax is a positive step you can take to help reduce your stress level and improve your health. Studies have proven that as your level of stress grows, you become increasingly susceptible to physical illness and mental and emotional problems. Relaxing is an effective way to control your level of stress.
- 8. *Not getting enough calcium in the diet*** – Your bones are approximately 25% calcium by weight, an amount that represents about 99% of your body's calcium reserves. Accordingly, if you don't consume enough calcium, you can suffer from a reduced level of bone density which can result in a higher risk of fractures.

DIETARY MANAGEMENT FOR YOUR OSTOMY

Reprinted at the request of readers

The following are a guide only, most people return to their usual eating pattern after the initial healing process.

However, it is important to: -

- Eat regularly. You may prefer to have three smaller meals with snacks in between.
- Eat slowly and chew your food well.
- Eat a variety of foods from all four food groups – breads and cereals, milk and milk products, fruits and vegetables, meat and meat alternatives.
- At first, until your colostomy has settled into a routine, it may be best to avoid certain foods which can cause flatulence or blockages.
- New foods should be introduced gradually. If a food does not agree with you, avoid it for a few days and then try again.
- Maintain a healthy body weight. Any excessive weight loss or gain can alter the fit and adhesion of your appliance and can therefore cause problems with leakage.
- To prevent constipation, ensure an adequate intake of wholemeal breads and a high fibre breakfast cereal like Weetbix, Cornflakes or porridge and plenty of fruit and vegetables.

COMMON PROBLEMS	POSSIBLE CAUSES	SUGGESTED REMEDIES
Constipation	Too little fibre	Increase fruit, vegetable and cereal intake and drink at least 1.5 to 2 litres of fluid daily.
Diarrhoea	Excess intake of cabbage, beans, onions, raw fruit, rhubarb, spicy foods, cocoa or chocolate.	Try eating white bread, bananas, cheese, mashed potato or pumpkin, oat bran bread, rice or porridge. Metamucil may help thicken the stoma output.
Flatulence	Baked beans, legumes, lentils, beer, broccoli, cabbage, cauliflower, carbonated drinks, chewing gum or cucumber	Reduce the intake of food thought to cause flatulence. Let carbonated drinks go flat before drinking and avoid drinking with a straw. Chew your food well.
Odour	Eggs, fish and some cheeses.	Try yoghurt, parsley, cranberry juice or orange juices.

OSTOMY FOOD CHART

Reprinted at the request of readers

For individuals who have had ostomy surgery, it is important to know the effects of various foods on ileal output. The effects may vary with the remaining portion of functioning bowel. Listed below are some general guidelines of the effects of foods after ostomy surgery. Use trial and error to determine your individual tolerance. Do not be afraid to try foods that you like, but just try small amounts.

GAS PRODUCING

Alcoholic Beverages
Beans
Soy Products
Cabbage
Carbonated Beverages
Cauliflower
Cucumber
Chewing Gum
Onions
Radishes

ODOUR PRODUCING

Asparagus
Baked Beans
Broccoli
Eggs
Fish
Garlic
Onions
Peanut Butter
Strong Cheese
Some Vitamins

STOMA OBSTRUCTIVES

Apple peel
Raw cabbage
Celery
Corn
Coconuts
Mushrooms
Pineapple
Pop Corn
Seeds
Dried Fruits

ODOUR CONTROL

Cranberry Juice
Parsley
Tomatoe Juice
Yogurt
Buttermilk

CONSTIPATION RELIEF

Warm Coffee
Cooked Fruit
Fresh Fruits
Water
Fruit Juices

DIARRHOEA CONTROL

Apple Sauce
Bananas
Boiled Rice
Tapioca
Dry Toast

COLOUR CHANGES

Asparagus
Beets
Food Colouring
Iron Pills
Liquorice
Red Jellies
Tomato Sauce

INCREASED OUTPUT

Alcohol
Whole Grains
Bran Cereals
Prunes
Some raw Vegetables
Highly Spiced Foods
Some leafy Greens

USEFUL LINKS

NEW ZEALAND WEBSITE - <http://www.ostomy.org.nz> where you can download the NZ Ostomate Travel Certificate and find online copies of both the Living With Your Ostomy booklet and recent NZ Ostomate Magazines.

Interesting Websites: www.innovationbyyou.com and www.comfizz.com

The International Ostomy Association (IOA)
<http://www.ostomyinternational.org>

IOA is committed to the improvement of the quality of life of Ostomates and those with related surgeries, worldwide. The website has links to the regions ASPOA (Asia and South Pacific Region) EOA (European Ostomy Association) and OAA (Ostomy Association of the Americas). There are links to the 20/40 Focus of particular interest to those in the 20-40 age group.

IOA TODAY - An online quarterly newsletter bringing you Ostomy related information from around the world four times a year. Subscribe by connecting to website: <http://www.ostomyinternational.org/IOAToday>

APPLIANCE SUPPLY COMPANIES – All companies have useful information booklets and DVDs available and offer a FREE helpline.

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Crohn's and Colitis New Zealand

<http://www.crohnsandcolitis.org.nz/> They also have a site where appropriate toilet facilities can be found for those times when visiting in another town and you need to go now!! <http://www.toiletmap.co.nz/>

Other Useful Links:

www.libertymed.co.nz

www.Cavilon.co.nz

www.bellybandz.nz

www.nutritionforostomates.com.au

www.convatec.co.nz

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MEMBERSHIP/SUBSCRIPTIONS FOR THE 2019/2020 YEAR

If you are not a member of your local Ostomy Society and would like to join, please complete the form below and send it to the Society Treasurer whose contact details can be found on pages 36 to 37, or by contacting The Secretary, Ostomy New Zealand, Mrs Robyn Tourell, 98 Highcliff Road, Andersons Bay, Dunedin. 9013. By contacting one of the persons listed in your area, you can find out the amount of the Annual Subscription as these do vary for some Societies. As a member of an Ostomy Society you will enjoy the opportunity of being able to meet with other members at information evenings and social occasions if you wish to do so, along with developing lifetime friendships. You are encouraged to join a Society whether or not you wish to attend meetings as member numbers are needed nationally to allow us to get the best voice at Government level in order to provide the best service to all Ostomates throughout N.Z.

The Secretary,
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(Please advise the Ostomy New Zealand Secretary AND the Editor of any changes)

Affiliated Societies and their Executive Officers and the Federation Executive members are welcome to forward their address to the Editor for publication.

I would request that these addresses be very clearly written as to content to avert error in publication.

Editor, N.Z. Ostomate

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