



THE JOURNAL OF  
**OSTOMY**  
NEW ZEALAND

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- Registration form at back of magazine -

LIVING WITH FRED AND  
CANCER

YES, YOU FART MORE  
ON PLANES

MY JOURNEY -  
TO THE BRINK AND BACK

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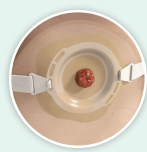
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## NZ OSTOMATE MAGAZINE - The Journal of Ostomy New Zealand

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**Ostomy NZ 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.*

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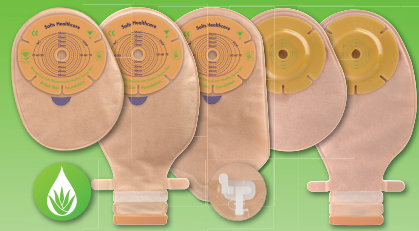
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## PRESIDENT REPORT - March 2023

As I'm sitting here thinking about what I could write about in this message, all I could think about was what is happening to our beautiful Country and how much it must be affecting everyone.

The last few Months/weeks have been a shocking time as we witness the devastating news of the flooding up North and the Cyclone Gabrielle on many of our regions. There is so much work to do in the clean-up and the rebuilding and it is heartening to see communities working together with the whole Country behind them. My deepest sympathy goes out to everyone who has lost loved ones at this very sad time.

I know that it these events have affected many of our fellow Ostomates. I am hoping that you can still get your supplies. It is a reminder to us all to have an emergency bag packed of all your supplies and Medication as we never know when we might need them, the last thing we need to do is worry about where everything is. Of course, it is easy for me to say as I have not been in an emergency where I have had to leave my house and lose everything I own, so I don't know how I would react if it happened to me. Please know that my heart goes out to all who has been affected by everything that is happening.

Our Conference is in 6 months' time it is coming up fast, our Executive is working very hard behind the scenes to make it an enjoyable Conference, there is more about it later in the Magazine. It would be a lovely time to meet up again as we have not had a Conference for two years, it is always great to see old friends and to meet new ones.

I would like to thank Brent H, David, Brent S, Robyn and Michael, for the ongoing support they give me and each other while serving on the Executive, it is a honour to work alongside them.

Please everyone take care of yourselves and each other.

**Jan Haines**  
FNZOS  
President



## Living with Fred and cancer - A year of my life

No!!! this is not a tale about my husband, it is about a bag that is attached to my bowel on the outside of my skin. It is called an Ileostomy.

Now how did this all come about? It all started on the 23rd Dec 2002 when I went for a colonoscopy to see what was going on with my bowel. I had been having some trouble and had left it for to long convincing myself it was only haemorrhoids or perhaps polyps. We were not prepared for what we were told. To say we were shocked and stunned would be putting it mildly, more accurate to say we were floored. The look on my husband's face is hard to describe, I still don't know what went through his mind as my own had stopped functioning the minute the surgeon had said it was a "Nasty". So that was that! I had a cancerous tumour. It then got worse with the surgeon saying we now have to do a MIR to see if it has spread, with every breath I took my world was crumbling around me. Is this it thought! How can I be so sick and not know it! I wanted to ask questions, but what ones? and did I really want to know!!! What I wanted to do was run away from it all, yes! that was the answer, if I could get far enough away it couldn't catch me this terrible thing. He told us nothing else and we were sent home to wait for an appointment for the MIR. We walked out of the hospital in a daze. How my husband drove us home safely is a miracle in it self, we couldn't talk, what was going through his mind is probably the same as what was going through mine. Are we not going to grow old together?? That was our plan, how dare this disease come along and upset our apple cart. Those first few days were almost a blur, I think I did everything by automation, it was xmas after all, you know, everybody happy, presents, xmas dinner, family. What lay ahead for me? Everything or nothing.

The Mir came and went and the result was promising, so surgery was to go ahead as planned for the 10th Jan. Now here is a word of warning, don't get sick at xmas, things shut down, Doctors go on well deserved breaks, and no

amount of insurance can get you seen too any sooner. So not only are you desperate to get it all over with, it cannot be done, and just because you now know what you have, it is not sitting there passively waiting to get cut out, it is still growing inside you, this alien thing trying to take your life. So now you fight back!!!

Six weeks have now passed, and my life with "Fred" is moving along quite nicely. I had a few problems with leaking, and bags not sticking, which only happened last week. It gave me a wake up call as Fred has to be seen to straight away and I thought I was just perfect at doing all the necessary things, and actually thought this Ileostomy bag was no big deal.

Now don't get me wrong, it is no big deal. Just think of the alternatives if some "bright spark" away back when had not come up with this wonderful idea, where would I be today? Perhaps not sitting here trying my best with 2 fingers to type this little "ditty" Fred is now part of me for who knows how long, so acceptance is the only way to get on with your life and that is the big word LIFE. Will I be sorry to see him go?? I don't think so, but he is here, so he fits in with my life style, not the other way around, that way you are still in charge, and that feels good. I actually managed to wear a dress the other day, that was sort of fitting, and Fred behaved and didn't blow up with wind and for once was not too noticeable. I think for us to give this bag a name is a positive way of accepting it all. It is part of your life but you must keep your sense of humour, as there will be times it will be sorely tested. I am back at work now and my work mates are very good, in the situation where "Fred" starts to grumble and growl we just say "my tummy is rumbling I must be hungry!"

I had my follow up visit with the surgeon last week and he seemed pleased enough with my progress. He will talk to the oncologist and see if Fred will come off before I start the chemotherapy or after. So I wait with baited breath on their decision. I would like the chemo to start and get

the op after it is all over. I just want to get cracking with all that they are throwing at me so I can be my old self again. I feel really good, and the dragging feeling I have had for 4 wks is all but gone. So I don't have to take Panadol now, and that makes me feel like I am the calling the shots.

I got my hair cut short yesterday, and I coloured it last night so I think I look ok, perhaps a few more wrinkles than I had 3 mths ago, but I suppose there has to be some sign that I have been under the weather!!!! The weight loss has not helped. Why?oh? why? When you lose weight it falls off your face first, and not the places that you would prefer!!!! Our shopping list has changed a bit from all fat free to "fat fat" please!!!!. Do you know how hard it is to find food with some "fat" in it??? Near impossible!!! But we struggle on, maybe I should live on a diet of chocolate, now I could go for that, "I LOVE CHOC!"

When I first came out of the hospital I could not look at a lot of food which I love, and choc was one of them, now that would have been the "straw that broke the camels back", imagine a life with no choc, and lets face it, we all know that choc releases the endorphins in your brain that makes you happy. Don't laugh I read that somewhere, and if its in print it must be true!!!! So I am real happy to say my appetite for choc is "back", just like "Shwarzzenegger" you know who I mean, "ARNIE".

Not a good night last night, my demons visited me about 1.30am. When it happens as it does, I find for me to get up, and have a Milo and put on the TV, is better than lying in bed, doing your best not to toss and turn. Complete distraction is the answer. Things always seem worse in the wee small hours, and lets face it the news on CNN at the moment about the state of the world, soon takes your mind off yourself!!!!

I probably will be a lot calmer when I find out this week, if I am starting chemo, or having the operation to reverse "Fred". I just want to get cracking. The sooner is all started the sooner I will be nearer to being myself again completely!!! Although minus a few bits of bowel and colon. Well I got the answer from the surgeon and Fred will stay on till I get the all clear from the oncologist, and then it is about 6 wks after that. So it looks like 7 mths or so, I am ok with that

as I feel really good at the moment and will be able (I think) to tackle the chemotherapy and radiotherapy. It is all a bit daunting, but I will be able to ask questions at the orientation appointment I am going to this Thurs.

Fred has been a bit naughty these last few days, and I have had trouble with leaking around the stoma. No point in getting in a flap over it, just clean yourself up, and get on with what you were doing. I have made up 2 bags with all that I would need if I had an accident while at work or when we were out. I leave one at work and the other comes with me when I go out socially. Its lovely when I change the bag and have a shower, I feel so clean. I would love to have a bath, but that would be like a military operation, to juggle when you last ate, and to depend on Fred to not drip into the lovely bubble bath. Whereas with the shower if he does his "thing" it will be flushed away, no harm done, but in the bath!!!! Oh no, not so nice.

I have been for my orientation visit, and the chemo starts on the 8th April. It is a 6mth treatment. That was a bit of a shock, I thought it might only have been 3mths. You see I don't think I am sick so it's a reality check. I have 10wks of once a wk chemo, and 5wks of daily radiotherapy, and at the same time daily doses of chemo, then it is another 10 wks of the chemo again.

I have to admit to not been to enthusiastic about the daily chemo thing, as I have to have a shunt in my arm, that runs up the-main artery and down towards the heart, with a bag like-a bum bag that the chemo feeds from. There is no taking this off for the 5wks, but the shunt frightens me.

Why am I being so silly about this I cannot say? So I have decided to get through the next 10wks and worry about the bit in the middle when I get to it. To waste these days with worries I can do nothing about at this stage is not going to do me or the people around me any good. So I will be like that song "don't worry be happy"

Do you think when I go for the tattoos for the radiotherapy I can ask for them to be in the shape of "Happy Faces"!!!! They will probably go into a big speech about how this is a precise procedure and spoil the moment !!



I had a down day yesterday, but that is ok, it's allowed, and now today I am fine. You only have to read the Women's Weekly to see there is people out there, worse off than you are! Sometimes these magazines are all doom and gloom, so delete them from your reading material!!!!

Had a gins night out last night. All the girls from work came and we went for a meal. It was a great night we had lots of laughs, so how can you be down when you have workmates like that!!!! It was arranged to cheer Sarah and myself from the office, (who is going through her own health problems) up, and it certainly did!!! The support they have all given me has been fantastic, and I don't say that lightly, after all I have only worked there for 11 mths. Now we mustn't forget about the men, they have been great as well. We have a lot of laughs at work, and that makes you feel really good. It is a fun place to be.

The chemo has now started, and I must admit it was no where as bad as I thought it would be. I have had 2 treatments now, and so far have felt ok!!! I had a headache last week, but I thought it was from the smell of the paint that Peter was putting on the feature wall. But I got it again this week so it must be the chemo. So if that is all I suffer I will consider myself pretty darn lucky. The treatment goes in the back of my hand and takes about 10mins to go in. Don't feel too much maybe just a little cold feeling but it is alright. I also have to go for weekly blood tests, the day before the chemo, so for the next 6mths I have this ritual to do, and then the rest of my life, "God willing" "Fred" was 3mths old last week, so if the next 6 go as quick as the last 3 I will be happy. "Fred" and I have settled into our routine and to be honest it is all ok. I have some minutes when I think I am fed up with this bag, but I tell myself its not for ever he will be all gone by xmas, and he will have been but a bump in the road of life.

At lot of things have happened in the last few months. It is now mid October and Fred is still with me. I was on the chemo for 8 weeks, and then I got the shunt put in my ann, so the chemo could drip in hourly for the next 6 weeks to be at the same time as the daily radiotherapy, but unfortunately after 2 weeks of it I had a terrible reaction and ended up in hospital very sick, with

my white blood cells to low and terrible pains so had to be put on morphine. I was in for 4 days and the shunt had to be taken out. It was decided that I wouldn't have anymore chemo but after a 1-week rest I had to continue with the daily radiotherapy and finish the 6 wks. That has been all over now for 2months and on the 23rd of this month I go for my first check up with the oncologist. It has been 3mths since he has seen me. I have put on some weight only 2 kilos but for me it is a big step forward, and I must be eating more as most nights now I have to get up and empty 'Fred' I used to be able to go all night, so I would say he gets emptied about 6 to 7 times in 24hrs. It is ok he is so much part of me I forget all about him at times. I wear what clothes I want now and have found ways of hiding him , it's amazing what you can adjust to when you have to.

It has been quite a while since I have added anything to my story. It is now mid Jan 2004 I had my check up with the oncologist in Oct and he was pleased, said everything with the blood test look fine, and the 2 points that were highlighted were what he expects to see when you have been on chemo, he said see you in 6mths. We were happy when we came out, and I almost skipped back to the car. He was very surprised to hear that I still had Fred, said he had told the surgeon that he was finished with me 3mths ago, and could only put it down to the fact that he must be real busy, but said he would mention me to him next week when he would be seeing him (probably play golf together every week).

So the weeks have rolled on and my life with Fred has gone on with no major dramas. There is days when if I do to much crouching at work or even at home that the seal lifts around the bag which makes it leak. There has been one or two days where I have worn 3bags in one day, which in turn makes the skin, feel a bit tender and the last thing you want is a skin infection. I never really got upset usually just cleaned myself up, but once or twice if it was in the middle of Stargate, or one of the murder mysteries that I love I will admit to saying a few choice words and Peter would come running.

I didn't really like him to see me with, or without, the bag either way, it is not a pretty sight, but it was skin coloured so I suppose that was an

added bonus. Fred himself is not too handsome either. I have, or I should say now, had, a loop stoma. He was about the length of your little finger and a bit fatter and of course was a lovely red just like the inside of your mouth. I am wandering now . I wanted to say how I have been back at the gym for 4mths now, and now, I know I am ok. I go to step and sculpt classes 4 times a week, and it feels so good. I am not as unfit as I thought I would be and Fred is not a problem .I just make sure I empty him before I go, and then I tuck him in my g-string and pull on my leggings, and you don't even know.

Anyway I decided that I didn't care if people looked at me, they don't know what I have been through and I am just so happy to still be here. People are going to think what they want so no amount of me getting stressed about it wilt change their minds, so I concentrate on the things I can change and the stuff I can't can go to hell in a wheelbarrow!!!!!! is the after effects that are worse. My bowel has to be retrained to do a job it has not done for over 1year, and at the time of writing this, is still an ongoing battle, and could be for a while, but I am impatient, I want to be up and running, it is a time thing and cannot be hurried. I think I have made the Guinness book of records for a roll of toilet paper used in 22hrs. My tum is still swollen - but not as bad as a week ago, it is my wee botty that is my main concern, I now know what babies feel like with nappy rash!!!!!!

So is my story over??? I think so, am I a success story???? Only time will tell. I feel good, so here it is one day at a time till it all becomes just a horrid memory. It is good that I at last got the phone call to go into the hospital for the reversal of the ileostomy on the 13 Jan. So it is all over 10/01/03 to 13/01/04. I have been home 10days now, and the operation was ok. Is it good we only remember the good things.

I must thank my family both here in NZ and Scotland for their faith in me and the fact that I would get through it all. As my Aunty Jenny would say you are a CARRICK, made of what I don't know, but whatever it is I think we should bottle it. My sister Margaret would agree I'm sure, that a sense of humour is needed in big supplies, a laugh at ourselves is what helps the ones around us to cope as we forget they are suffering as

well as us, although not in the physical way but mentally.

This wee ditty has not turned out quite what I had in mind, what the hell did I have in my mind, I don't know, should have paid more attention at school, Oh no!! That wouldn't have helped, I hated doing compositions anyway, so this is as good as it gets!!!!

**Regards Janette Topping Mccaughan  
nee Carrick 28/01/04.**

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## Bellybandz

I wish to take this opportunity to introduce myself and my business – NZ Ostomy Supplies Limited, Trading as Bellybandz.

My name is Suzanne O'Kell and I originally had an ileostomy and I now have a colonoscopy. This came about due to a medical misadventure some years ago and I have had many operations to try and rectify the damage.

My background is in Business Management and I have enjoyed a passion for sewing throughout my life.

When I got a stoma I set about finding a way to hold my bag in place with some degree of comfort and security. I had trial tested many different ideas and products over a period of time, all of which I had felt were unsatisfactory for one reason or another. Eventually I sat down and started to create my own product.

I was asked where I had sourced my bands from by a medical professional and she suggested to me that I should start a business and to supply bands to other ostomates. That was eight years ago.

I began in earnest to create a band that fitted my exacting standards, sourced my fabric from Turkey and sourced high quality double density lace and a top of the range elastic to add interest, support and comfort to my bands. My goal has been to produce something that is affordable and long wearing.

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## Profile Page - Syreeta Rogers

My father was a terrible asthmatic. As a 5 year old girl, we had a routine – on a certain day of the week, I used to help dad count out his pills and place them in the tiny pill containers and carefully close the lids.

I have a vivid memory of him teaching me the time so that I could wake him up from naps at certain times of the day and I used to have so much fun squeezing the medication into the chamber for regular nebulizing. I used to puff on his preventers occasionally to see what it felt like. I guess I was his nurse bringing him glasses of water and this and that. I wonder if this is where wanting to be a nurse came from. He died when he was 36 from a severe asthma attack - we lived in an extremely remote area in the Bay of islands, and paramedics were an hour away at least. It just took too long to get help. If that had happened today, he probably would have lived.

When I finished my nursing training, I was really confused about which path I should take. I got a job in a rest home and learned some really valuable skills that I still use today – conflict resolution, time management, and of course people skills. After having my son, I really wanted needed a change, and did a bit of work here and there for an agency and then eventually a short term contract for Hutt Valley DHB. A chance meeting in Pak n Save with Rochelle Pryce (yes that Rochelle), a wonderful friend who I studied with took me to where I found my passion – Surgical Nursing in Wellington. She encouraged me to put an application in and I eventually landed a job there. I loved it, night shifts and all. The challenges of the low blood pressures, post op care, complications – I really grew and flourished there. After a while, the sun, sea and sand of Australia called us to the Sunshine Coast. I worked in agency and mainly worked in Noosa – then got a job in a small private hospital doing General Surgery, Orthopedics and Urology. Private was way too fast paced for me, and I didn't feel that I had time to care in the way I could.

My next move was an amazing opportunity at the Sunshine Coast University Hospital. A brand

new 1.8 billion dollar build with a bed capacity of 1000. We were opening a new service "4C" a Regional Plastics Vascular and ENT ward. Prior to us opening, patients who needed these services were sent to the Royal Brisbane and Women's hospital, a hugely pressured service that already served over a million people. We spent the first three weeks unpacking beds and obs machines and setting up the ward the way we wanted. It was so exciting being a founding nurse in such an important and brand new service. Despite all of the excitement, I really wanted to go and work in "4B" the neighboring ward - General Surgery.

When we came back to New Zealand, I got a job in District Nursing at Hutt Valley DHB. An opportunity came up for an increase in FTE for a CNS Stomaltherapy, and after a really long deliberation I put my application in on the very last day. When I got the job I was really shocked, it did take a few weeks for it to sink in. What I love about my job is the ever changing nature of it. Sometimes Vicky Beban and I are in the ward, sometimes in the community, sometimes both. Whatever we do, we do it together. She truly is a great friend and mentor and has taken me under her wing. I feel that she gives me enough space to make decisions and learn from them, and guides me through the challenging situations. It's such a wonderful working relationship, and we have lots of laughs.

One thing I hope to bring to this job is some of my knowledge of Tikanga Maori. I speak Te Reo Maori quite well, something that not many of my colleagues know. We serve a population of about 17% of those who identify as Maori in the Hutt Valley area, and having someone who can relate and speak the language is a huge achievement for our DHB, breaking through those cultural barriers, and therefore delivering care which is culturally safe. I don't have too much spare time these days – I'm one of these "active relaxers" but when I do have extra time, I really love mountain biking, gardening, travelling and of course all that sun, sea and sand.

**Syreeta Rogers**  
Clinical Nurse Specialist – Stomal Therapy



## Yes, you fart more on planes - A guide to inflight flatulence

It was on a flight to New Zealand that a Danish scientist had a bit of a lightbulb moment. Noticing changes in the air of his water bottle, and feeling just a little bloated after the journey, Jacob Rosenberg began theorising about the human body's behaviour on something that happens to all of us, something we never speak about, and something we never want to hear or really smell for that matter: 'why do we seem to fart more on planes?'

Getting together with some fellow scientists, Rosenberg helped publish a study in the New Zealand Medical Journal in 2013 entitled, Flatulence on airplanes: just let it go. Whether a rather popular song out at the time from the movie Frozen played a part in the title is not known, but what is known is that the report proved to be a wild success.

International media jumped on it, with everyone from the BBC to the South China Morning Post looking for more details. Rosenberg, now working at the Department of Clinical Medicine at the University of Copenhagen, told Stuff Travel the interest was "quite extreme". "I was interviewed by numerous radio and TV stations and many individual web pages cited and discussed the

work. Thus, a few months after publication my name and flatulence was mentioned in more than 2 million web pages according to Google," said Rosenberg. "I have never seen anything like this with other publications. So we must have hit something of common interest and relevance."

Even today, Rosenberg continues to get questions about the study, but said that he is "quite OK" to field enquiries. "It just shows that the problem is relevant." And it's very pertinent now as we start travelling long-haul once again.

Why do we fart?

Let's start with the basics, why exactly do you break wind? Very simply, it is gas in our intestines that needs to get out, but how it builds up can come down to a range of factors.

As we go through our day we are swallowing in air doing basic activities like chewing food or drinking. This swallowed air, known as exogenous air, includes oxygen and nitrogen which gets absorbed into the bloodstream from the small intestine, but any excess needs to be expelled.

There are also plenty of bacteria doing their job in the colon of breaking down food which results

in something called endogenous air. Depending on what you have been eating, the makeup of this will mostly be hydrogen, but it could also contain methane, and the stuff that adds that certain 'je ne sais quoi' stink aroma, hydrogen sulphide. But only 1% of the roughly 1.5 litres of gas we emit each day actually smells.

As you are no doubt aware, some foods you eat tend to make a difference on your flatus quota for the day with high fibre foods and undigested carbohydrates in sugars like fructose and sorbitol, starchy products like potatoes, high-sulphur items like garlic and onions, and cruciferous vegetables including cauliflower and broccoli making the difference.

And speaking of quotas – the average person will knock out around 10 a day, although other studies say it's closer to 25, and there's no major difference in the frequency between men and women, except one gender may boast about it more. There is one exception though, women's tend to trump men's for the smell. And yes, there was a study to prove that.

Do we fart more on planes? In a word, yes.

As Rosenberg noted on that fateful flight to New Zealand, he saw changes to his water bottle. It had been "squeezed" after expanding in the low pressure and then crumpling back when the plane reached the airport.

"When we landed, my belly had grown. That led me to speculate what had happened. When I got back to work I discussed with two of my students, and we simply came up with the idea for the paper."

It's really down to physics. Pressurised cabins on aeroplanes are having an effect on the air inside you, so as the cabin pressure decreases, the air inside the bowel expands by up to 30% more than usual, and that needs to get out.

"Since there is only limited space in the large bowel, it is a natural consequence to fart," Rosenberg told the South China Morning Post.

Hold it in, or let it go?

Release ... the flatus! Modern planes with whisper quiet cabins have made the risk of dropping a loud one more of a potentially embarrassing problem, and with a healthy proportion of the air being constantly recycled it may make you think

twice, but there can be health risks for trying to maintain dignity.

As well as bloating, it can possibly lead to dyspepsia, which is pain in the upper abdomen, or even heartburn.

If you are worried about smells, most commercial planes these days are fitted with HEPA (High Efficiency Particulate Air) filters which can capture about 99.97% of airborne particles over 0.3 micron in size. The charcoal inside helps take out the odours. About 40% of a cabin's air goes through this HEPA filtration process with the rest being pumped in from outside the plane, and the air is completely refreshed pretty much every five minutes. Your seat will also absorb a lot of your air biscuits, so let the covers do the heavy lifting.

If you are particularly gassy then maybe invest in flatulence-filtering underwear. The Carbonana from Shreddies (not the cereal) has been created especially for long-haul travel, and is designed "to sit between the buttocks and absorb gasses before they escape your underwear".

What can be done to prevent it?

Well maybe put down those candied Brussels sprouts for a start. What you eat or drink before a journey can play a factor, but bear in mind that on a long-haul flight, it's going to happen. Nature always finds a way.

The day before a flight try to ease off products which are FODMAP foods (also known by the less catchy fermentable oligosaccharides, disaccharides, monosaccharides, and polyols). These include dairy products, cashews, garlic, onion, seeds, bread, crackers and some fruits. Probably best not to have any carbonated drinks before or during the flight and drink lots of water. Another tip; eat more slowly too.

It's also best to get up and move around, which is recommended anyway on those long flights, to help prevent any bloating, but spare a thought for anyone on an aisle seat at risk of crop-dusting.

Bottom line..

Next time you are flying long-haul, remember everyone else on that plane is in the same boat bowel-wise. If you are embarrassed, work your way to the toilet and release. Otherwise, don't fret and let it go.



## Blockages - Richard McNair



These are the Bains of an Ostomates life and as someone who has had a very large number over the years I felt that I had some experience to write about them! These only effect Colostomates & Ileostomates and there are three types of blockages.

1. Bowel Obstructions. These are when something like a large amount of poop gets stuck in your intestine and cannot get pushed out by the normal muscle movement.  
Note that non-ostomates can also get these. These can also be caused through scar tissue, twisted bowel or a tumour. Insufficient fluid intake is also a cause.
2. Bowel food blockage. These are caused by eating something that is too hard or too fibrous such as steamed vegetables, food that is too dry, etc.
3. Pseudo – obstruction. These can cause symptoms of a normal blockage without food or other reasons being present and are caused by muscle or nerves becoming paralytic.  
Note that these are only the common reasons – there are more, but only a doctor should diagnose these anyway.

Symptoms of all of these are intense pain in the intestines, bloating, gas coming back up the stomach, lack of a bowel movement and nausea. It is important that if you experience any of these symptoms that you get to the ED as soon as possible, do not be brave and think that if you wait they will go away, they probably will just get worse.

There are three ways that the problem could be addressed in the ED, just put you on a drip plus anti-nausea and pain meds. If the blockage is down near the stoma they may simply insert a Foley catheter into the stoma and squirt a bottle of fleet enema solution in that way to clear it. If the blockage is too far up for that you will end up having to have an NGT,

Naso Gastric Tube, inserted into the nose and down into the throat. Not nice but they can then pump fluid into the stomach in order to clear the blockage. Just make sure that you are given several of those plastic jugs that they have in the wards as when the blockage clears it will happen with a vengeance!

Now using my own case as an example: I have had an Ileostomy and have had removed, the colon, appendix, rectum, anus, and a large area of flesh inside of the pelvic region. This means that there is now far too much “spare” room inside the abdomen which allows the intestine to move around rather than stay put like it was designed to do. I almost certainly have adhesions between the outside of a couple of intestinal tubes and it is quite possible that one or more bits stick up above the other and so if a bit of harder food decides to “jam up” in this extension then a blockage will form.

Like most people, I thought that blockages were simply only caused by food but when I started having them with no obvious food cause, I started doing research into stress and was astounded to learn that we have more Neurons in the lining of our intestines than in the Spinal Cord and that stress is a major factor in bowel problems. Why is this not discussed when you are in hospital?

They never get past the fact that the problem is caused by food and I expect that this is because in the ED you get admitted as a potential surgical patient and so any mental aspect will be out of their frame of thought. Now I guess that stress can be caused by a number of things which in the ED it is hard for you to influence, and these could include other people and their interactions with you, outside organisations, family etc. I found the following item online which I thought was interesting.

Making The Gut Connection. Sometimes we just have to stop and rethink what is happening in our life and make the connection that whatever is going inside your body is a reflection of what is going on in your environment. This could be emotional stress, physical stress, or mental stress, or all three. If you are feeling stressed or feel blocked by life’s challenges this can result in your digestion and bowel become blocked as well. ‘We Have Two Brains Research’ has discovered that we have two brains, one in the head and the other in our gut, and they are connected via the vagus nerve that goes from your brain stem down to your abdomen. That is how you feel the butterfly effect in your stomach when you get nervous. When we are stressed, it changes the connections between your brain and your digestive system which contribute to complaints such as gastrointestinal disorders, including:

- Irritable bowel syndrome (IBS)
- Inflammatory bowel disease (IBD)

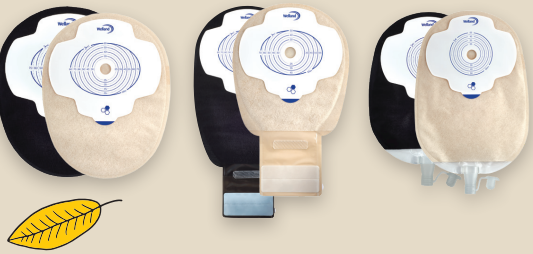
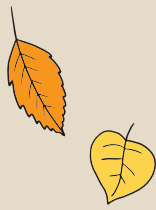
### Suggestions

- Put together a list of all of your medications.
- List any allergies.
- List any surgeries.
- List any other info that medical people should know, such as your doctor, next of kin, etc.
- If you have an Android phone (may also work for an iPhone) go to “Settings”, scroll down to “safety and emergency”, click on that and then on “Medical Info”, and then enter all of the above information. This can be accessed by emergency responders even if your phone is locked, I know, I have tried it!

It is important that you “own your own medical problems” by learning as much about them as possible for sometimes you may know more than the doctor treating you! Also if you understand what is happening inside your body then you are better placed to take care of yourself.

### Richard McNair

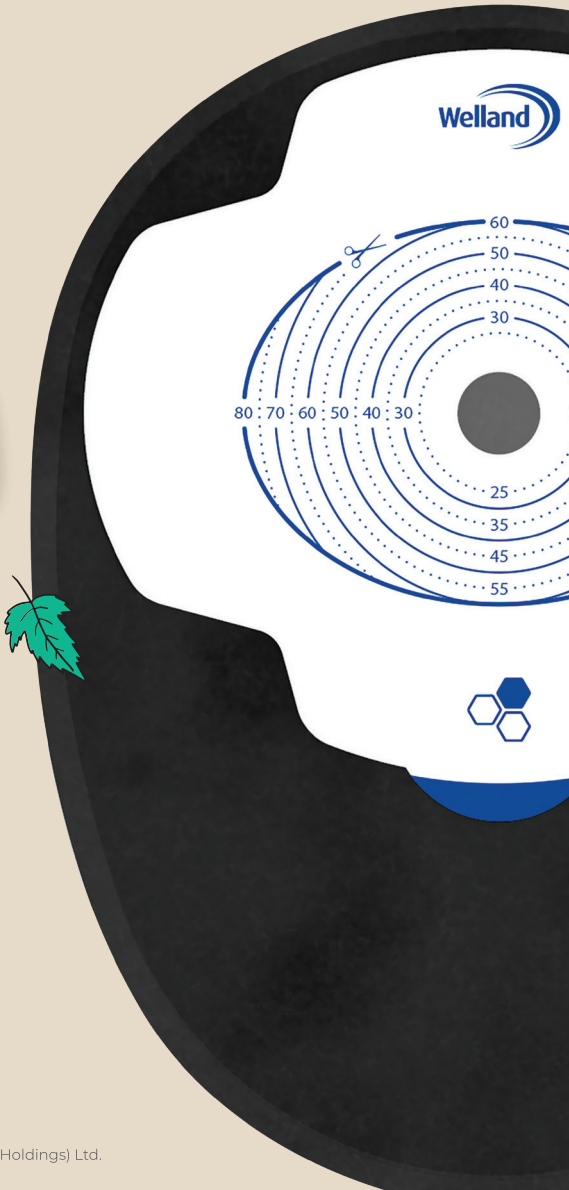
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## MY JOURNEY - To the Brink & Back Again Graeme Hamilton

My journey started early in 2017. I was taking longer and longer sitting on the toilet and reading the morning news on my phone. There was no pain, just an increasingly longer time required to complete the business. Over several weeks I could hear a caring voice in the background that grew louder.....

“Don’t you think that you should go and see the Doctor?”  
“You should go and see the Doctor?”  
“Go and see the Doctor?”

Being an older bullet-proof male, these instructions sometimes take a while to sink in! In late March of 2017, I finally went to my Taupo GP who did a routine examination and said I could expect to hear from Rotorua Hospital shortly. The response was rapid, and within three weeks I had been diagnosed and advised by the Gastroenterologist of a serious condition of a bowel tumour situated low down, that was cancerous and that maybe one lymph node was also involved. I also noted in my haze that the Colorectal Nurse Specialist was there to advise my Carer that my condition was indeed very serious and to lend her support at this critical time. I should add that while my Carer was always at these meetings, my thoughts were about my condition and not about her and her needs. At no stage did I consider that my condition might have been fatal although, the Carer knew that the odds were perhaps 50/50, and that I was very fortunate to be diagnosed, albeit at this late stage.

A CAT Scan and an MRI followed prior to a serious discussion with a Colorectal Surgeon, in-which it was stated that a permanent colostomy would result, in all likelihood, because of the location of the tumour so close to the anus. This advice notwithstanding, I wishfully argued at this early stage for the reversal option ad nauseaum, knowing that I was flying in the face of adversity! Then following my diagnosis as T3 N1 M0, the inter-hospital discussions of specialists decided on an upfront course of treatment of

chemotherapy and radiation combined for some 5.5 weeks in Hamilton’s Waikato Hospital, to be followed by a month of rest, and then the APR (Abdominoperineal Resection) operation would be undertaken at Rotorua Hospital.

As an engineer who likes to have his projects well documented, I realised at an early stage that the number of appointments with many different professionals at differing locations and times would be a challenge to keep track of. Therefore, I instigated a spreadsheet system to keep track of what was going on for me and around me, as I progressed on my journey. Today, this detailed “book”, as staff liked to refer to it, is some 12 x A4 sheets in length, and is an invaluable track record of a kaleidoscope of people and events at differing locations over the most critical of times. I was off to stay at Lions Lodge in Hamilton, where I was to be based for 5.5 weeks, for my pill-based chemo and daily radiation regime. This was a very caring and empathetic environment to be a part of, as one goes on this journey to where? The Lodge was a free temporary “home” for other cancer patients undergoing treatment at the nearby Waikato Hospital. At first, the experience was like a holiday staying at a 5\* motel (but without a TV). However, as the weeks passed, the effects of the treatment and fatigue gradually kicked in and my weight dropped.

The month to follow at home was one of putting up with extreme haemorrhoidal pain (perhaps from the radiation), sleeping, and eating, to regain strength for the upcoming operation. Ahead of the operation I met the Stoma Nurse who put an indelible X on my left-side stomach for my future stoma site. Perhaps the operation was going to happen after all!

The day of the operation of 31st August 2017, I was duly prepared and whisked off to theatre noting that the Colorectal Nurse Specialist was again beside my Carer at this stressful time. The intervening period is a gap but I was advise that Colorectal Surgeon took some seven hours for





my operation.

In the hospital I was a mass of bandages, stitches tubes, etc. There was considerable discussion with nurses on my new body exhaust system, and advice offered including some physio exercise. Care was excellent. My discharge to home occurred on the 6th day after the operation and of which I remember a few glimpses. My energy levels were low and my fatigue high. Along with this, I was coping with the significant adaption of my new front-side vs rear end plumbing. These were days when I slept a lot, and I often overlooked tasks which I had agreed to do around the house.

One heartening factor that was conveyed to me after the operation, was that no further chemo treatments were deemed necessary, so in a way this was a relief from further intervention and regular hospital visits. A challenge that arose for us on arrival home was how to quell the odour in the house that emanated from emptying the bag. This started me off on a web search of solutions for this and also on how to quell the expected noises that might issue forth. Websites cropped up in Australia, USA, Canada, UK where they all had approaches that were pertinent to their conditions, noting that some were transferable to our situation. On Facebook, I even found one clip of a young woman in USA who cheerfully shared her bag change with the universe and I thought that was very brave, cathartic, and helpful. After many experiments with a range of products, the odours seemed to lessen as my body settled, without needing so much intervention and trial of a range of different deodorants. To address the issue of sound control in a public setting, a family friend made me a sound absorbent bag cover from neoprene, but in reality this has not been an issue on an ongoing basis.

While I never thought of myself as being depressed, or doubtful about my ability to regain full health, I do recall that in the early days of my postoperative recovery through to January 2018, there were days where I seemed to lose motivation and direction, together with experiencing some gnawing intermittent lower back pain. During this period I had a couple of returns to hospital for checks on my condition as well as being under the constant watch of my

GP. My Carer added that during this period my level disposition was sometimes missing and my reasoning suffered from what she called "chemo brain"! Advice from the medical field encouraged me to eat small meals regularly and drink more fluids, together with the application of an antibiotic to assist with internal healing issues. With this period of frustration and intermittent pain behind me, I started moving onward and upward in the New Year, for which my Carer was also grateful.

Humour Does Help! I recall lying on a hospital bed one day in November 2017, mostly exposed, and a Surgeon doing the rounds with a group of doctors in training. The Surgeon managed to resolve my issues and stated that "You will have to use women's pads, do you hear" to which I replied "and will I have to wear a dress too?" and the Surgeon replied "No, no, You'll be all right". During this exchange, not a flicker of a smile was seen from the trainee doctors who were absolutely straight-faced with note-pads in hand!! Ostomates NZ Support Groups. Post surgery, a Rotorua staff-member suggested that I attend a meeting of the Rotorua Ostomates Group that would be a supportive group for dealing with the challenges of living with a colostomy.

Some months later, I was invited to a meeting in Taupo by the Stoma nurse where I met Richard McNair, WBOP Ostomates Society and Ostomy NZ, together with several other Ostomates from the Taupo/Turangī area. Following discussion, it was suggested that more regular meetings could be useful in support of the 50 or so Ostomates who were in the Taupo region, as well as ongoing new additions. Later, I was asked to organise an inaugural meeting in September 2018 and, by and large, meetings have been held almost monthly since that date. Guest speakers included: Stoma Nurse; Suppliers; Organisations including the Cancer Society, & Lake Taupo Hospice. The mixed group discussions were open, frank (not to mention humorous) and cover any topic that is a challenge to those present and where ideas are shared and solutions offered. This forum proved useful for new Ostomates as well as those further along the track who can learn of newly introduced products and services to ease life's challenges. Carers are equally welcome and have been helpful in contributing ideas. Some 10-15 persons attended these monthly meetings regularly, with

ages ranging from 30's to 90's, at least until Covid intervened. Efforts to reach out to Ostomates unaware of this support group included: -sending an explanatory letter to medical practices and chemists for the awareness of nurses and GPs; sharing knowledge with other specialist focus groups such as Diabetes NZ and Probus; a regular invitation in the regional Taupo Times newspaper, and on the web-based community support group, Neighbourly.

The Role of the Carer. Throughout this whole process the Carer is watching, helping, and wondering, about the outcome for the sickly person's future. This process alone is very stressful for the Carer, who has a parallel challenge that needs to be addressed and supported as required. One should not overlook this need, as it is often not possible for the sick person to see beyond the end of the bed!

Hindsight. About twice over the previous 7 years, I had experienced some blood in my faeces and, in retrospect, I should not have put that down to haemorrhoids but rather undertaken a FIT (faecal immunochemical test), which is now being made readily available to 60-74 year olds via the DHB's in NZ. This may well have led to a lesser invasive treatment such as a routine colonoscopy and removal of polyps, rather than the permanent colostomy that no doubt has saved my life. Also, over this same timeframe, I had been troubled by bad breath that seemed to defeat my GP and Dentist as to the cause and solution.

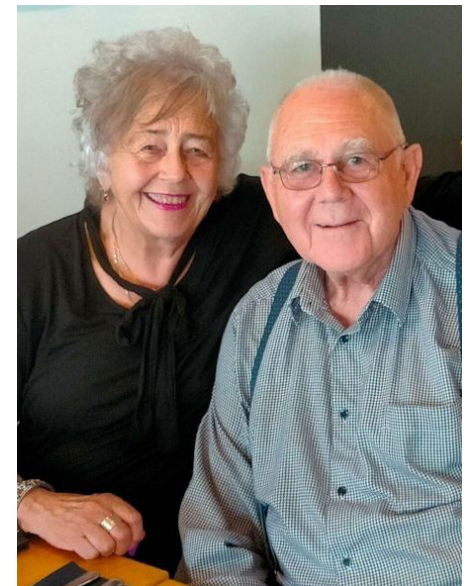
Today, I look back with gratitude on the coordinated treatment from so many sources provided to me over the period from early 2017, and at no financial cost to myself. The whole process was well coordinated and seamless over this time, and included the following range of services and locations: - Hospitals; Accommodation. Professionals: GPs, Colorectal Surgeons; Specialists in Oncology, Radiation & Anaesthetics; Senior Colorectal Specialist Nurses; Stoma Nurses; Dieticians; Psychologists; Nurses; Pharmacists; Physiotherapists; Radiographers; Theatre support; Hospital Staff. Transport: St John Ambulance, Inter Hospital Shuttle, and Local Driver Services to/from Hospital, MOH National Travel Assistance. Home Help: Nurse support in the initial return to home; District Health Nurse;

and Nurses in GP's office. Support Organisations: Cancer Support NZ; NZ Ostomy Society, Hospice NZ.

There is no doubt that my life has been spared by this operation, albeit with the challenge of some fatigue that continues to bug me ...but then again, could that be attributable to advancing years?

How do I feel about taking up the time and resources of so many caring and supportive people and organisations? I will be eternally grateful and feel compelled to continue to give back to the communities, in which I live, in one form or another.

To all who helped me on my journey, I say a big thank you, and to my carer I offer a special thank you. So there you have my story... Re-plumbed & ready to go!



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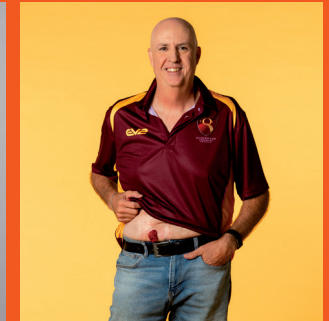
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## Useful Links

**FNZOS website:** <https://ostomy.org.nz/>

Contains the Travel Certificate, the Living With Your Ostomy and Caring for Ostomates booklets, and recent NZ Ostomate Magazines.

Up to date contact details for local societies.

### Suppliers

As well as listing their products and enabling you to request samples, these sites have useful information on living with an ostomy. Check their adverts for latest details.

Coloplast	0800 265 675	<a href="http://www.coloplast.com.au">www.coloplast.com.au</a>
Convatec	0800 441 763	<a href="http://www.convatec.co.nz">www.convatec.co.nz</a>
Dansac	0800 678 669	<a href="http://www.dansac.co.nz/en-nz/">www.dansac.co.nz/en-nz/</a>
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Omnigon	0800 440 027	<a href="http://www.omnigon.com.au">www.omnigon.com.au</a>
Salts	0800 100 146	<a href="http://www.ainscorp.com.au">www.ainscorp.com.au</a>

### Accessories, wipes etc

3M Cavilon	0800 808 182	<a href="http://www.cavilon.co.nz">www.cavilon.co.nz</a>
BellyBandz	021 296 1425	<a href="http://www.bellybandz.nz">www.bellybandz.nz</a>

### National Service Specification

<https://nsfl.health.govt.nz/system/files/documents/specifications/stormaltherapysvct3.docx>

### Specific Support

Crohns and Colitis:	<a href="http://www.crohnsandcolitis.org.nz">http://www.crohnsandcolitis.org.nz</a>
Map of accessible toilets:	<a href="http://www.toiletmap.co.nz">http://www.toiletmap.co.nz</a>
Cancer Society:	<a href="https://www.cancer.org.nz/">https://www.cancer.org.nz/</a>
Bowel Cancer NZ:	<a href="https://bowelcancernz.org.nz/">https://bowelcancernz.org.nz/</a>

### International

Colostomy UK:	<a href="http://www.colostomyuk.org/">http://www.colostomyuk.org/</a>
Ileostomy Support Group UK:	<a href="http://iasupport.org/">http://iasupport.org/</a>
Medical advice:	<a href="https://www.nhs.uk/conditions/ileostomy/">https://www.nhs.uk/conditions/ileostomy/</a>
Medical advice:	<a href="https://www.nhs.uk/conditions/colostomy/">https://www.nhs.uk/conditions/colostomy/</a>
International Ostomy Association:	<a href="http://www.ostomyinternational.org/">http://www.ostomyinternational.org/</a>
Nutrition of Ostomates:	<a href="https://www.nutritionforostomates.com.au/">https://www.nutritionforostomates.com.au/</a>

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### Membership

See the contact details for the member societies.

As a member you will have the opportunity to meet other members.

You are encouraged to join, whether or not you wish to attend meetings, to enable FNZOS to get the best voice at Government level to represent Ostomates. And while you might not feel the need for support yourself, you may well be able to assist others.



## Officers of Affiliated Societies

2022 FEDERATION OF NEW ZEALAND OSTOMY SOCIETIES INCORPORATED MEMBER SOCIETIES

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Pre	Darryl Nelson	d.jnelson@xtra.co.nz	03 307 0500	Ashburton

### AUCKLAND

Sec/Tre	Lynda McCarthy	aucklandostomy@gmail.com	027 621 2700	Auckland
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### CANTERBURY

Tre	Brent Silcock	brent@stalkertackle.co.nz	027 756 9682	Rangiora
Sec	Diane Bain	ostomycanterbury@gmail.com	027 416 4185	Christchurch

### HAWKE'S BAY

(Including Poverty Bay) hbosgi@gmail.com

Pre/Tre	Peter Ide	eyespid@hotmail.com	021 178 4144	Napier
	Hugh Thornton	hughandnorma@xtra.co.nz	027 877 1553	Havelock North

### MANAWATU

Tre/sec	Val Rodgers	vmrogers@hotmail.com	06 362 6766	Levin
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### NELSON

Pre	Eddie Shaw			Nelson
Sec/Tre	Janis Baker		03 547 3800	Nelson

### NORTH HARBOUR

Sec	Mandy Little	nhos@hotmail.co.nz	021 044 4067	Birkenhead
Tre	Christine Bibby	bibbychristine@gmail.com		

### NORTHLAND

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Pre	Terry O'Meara	terryomeara2@gmail.com	09 432 7351	Ruakaka

### OTAGO (incl Southland)

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Tre	Robyn Tourell	tourell.r@xtra.co.nz	027 477 4137	Dunedin
Pre	Phil Elliot	ffrostyphil@gmail.com	03 481 1847	Dunedin
	Maree Shepherd	c/- Otago	03 216 9933	Invercargill
	Pam Wilson	c/- Otago	021 101 8575	Invercargill

### SOUTH CANTERBURY

Pre	Ngairé Whytock	whyplumb9@gmail.com	021 236 7471	Timaru
Tre	Dave Whytock	whyplumb9@gmail.com		Timaru
Sec	Jill Newton	1949jilln@gmail.com	027 454 7388	Ashburton

### TARANAKI

Pre	Raewyn Rooney	rooteam@xtra.co.nz	027 463 6130	New Plymouth
Sec/Tre	Bernie Christian	bchristian@xtra.co.nz	06 278 6379	New Plymouth

### WAIKATO

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Tre	Michael Sumner	michael.sumner@xtra.co.nz	021 245 5064	Hamilton

### WAIRARAPA

Sec/Tre	Yvonne Etherington		06 377 7262	Masterton
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Pre	Brent Hamlin		027 561 2704	

### WEST COAST

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Pre	Dian Cheyne	lescheyne@gmail.com	07 543 0598	Tauranga

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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 the publication.

- *Editor, N.Z. Ostomate*

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## FNZOS Conference 2023

For Bookings please contact: Bealey Quarter - 0800 115 043 or email: groups@bealeyquarter.co.nz  
As all the rooms have been booked for the conference so you will need to call or email them and use the Reference number 174776 and the name it is booked under is FNZOS

The Studios are our modern motel accommodation, awarded a 4-star plus Silver Qualmark rating. Built-in 2019 these comfortable rooms are ideal for leisure and business travelers.



### The Studios - Double

Our Studio double rooms offer a king-sized bed made with quality linen, Smart TV, FREE unlimited Wi-Fi, air-conditioning, tea and coffee making facilities, microwave and a fridge. Ensuite bathroom with a shower and toilet and includes towels, hairdryer, soap and shampoo.



### The Studios - Twin

Our Studio twin rooms offer two full-sized single beds made with quality linen, Smart TV, FREE unlimited Wi-Fi, air-conditioning, tea and coffee making facilities, microwave and a fridge. Ensuite bathroom with a shower and toilet and includes towels, hairdryer, soap and shampoo.



The Studios – Double \$126 p/n please note same price for twin that can be made into a double



### The Courtyard – Garden Court Studio King + Single

These spacious and sunny rooms contain everything you need for a comfortable stay. A king-sized bed plus a single bed made with quality linen, Sky TV, FREE unlimited Wi-Fi, tea and coffee making facilities, and fridge. Ensuite bathroom with a shower and toilet and include towels, hairdryer, soap and shampoo.



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### The Lodge - Twin Ensuite

Our Lodge twin ensuite rooms offer two single-sized beds made with quality linen, Smart TV, FREE unlimited Wi-Fi, room fan, tea and coffee making facilities, fridge. Bathroom with a shower and toilet and include towels, hairdryer, soap and shampoo.



### The Lodge - Double Ensuite

Our Lodge double ensuite rooms offer one queen-sized bed made with quality linen, Smart TV, FREE unlimited Wi-Fi, room fan, tea and coffee making facilities, fridge. Bathroom with a shower and toilet and include towels, hairdryer, soap and shampoo.



Garden Court Studio King & Single \$130 p/n

Garden Court Studio King \$120 p/n

The Lodge rooms 2 singles or a double \$110 p/n

## FNZOS Conference 2023 - Registration Form

FNZOS CONFERENCE & AGM 8th-9th-10th September 2023  
The Richmond Club, 75 London St, Richmond, Christchurch.

Surname \_\_\_\_\_ First Name \_\_\_\_\_

Address \_\_\_\_\_

Email \_\_\_\_\_

Phone \_\_\_\_\_ Mobile \_\_\_\_\_

Society \_\_\_\_\_ Delegate: YES / NO

Preferred Name for Name-Tag \_\_\_\_\_

Partners Name-Tag \_\_\_\_\_

REGISTRATION	COST P/P Number	TOTAL
FULL REGISTRATION with DINNER & DANCE	\$170	\$
FULL REGISTRATION excl DINNER & DANCE	\$100	\$
Includes: Friday Evening, Saturday am & pm Tea/Coffee & Lunch, Sunday Light Lunch		
FRIDAY EVENING ONLY meet & greet with nibbles	\$20	\$
SATURDAY CONFERENCE ONLY	\$70	\$
Includes: Saturday am & pm Tea/Coffee & Lunch		
SATURDAY DINNER & DANCE	\$70	\$
SUNDAY LIGHT LUNCH	\$20	\$
TOTAL for PAYMENT		\$

Please indicate if you or your partner have any special dietary needs. Y/N

Please specify \_\_\_\_\_

RSVP by: Saturday, 7th August 2023

Post Registration Form to: B Hamlin, 68 Tutaipatu Ave, Pegasus 7612

Or E-mail to : [conference@ostomy.org.nz](mailto:conference@ostomy.org.nz)

INTERNET BANKING: **12-3011-0809378-04** Please include surname as reference

Receipt required? Y/N

Will be emailed if possible or available at registration desk

Registration desk opening times will be detailed in a further information pack emailed closer to the conference date.

Canterbury Ostomy Society will be offering transfers from and to the airport and bus depots.

Please indicate if you are likely to need transfers Y/N

We will email you seeking flight numbers etc closer to the date.

Transport from the Bealey Quarter to and from the conference venue will be provided so you do not need to book this in advance



# OSTOMY

NEW ZEALAND

