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**OSTOMY**  
NEW ZEALAND

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**2023 Conference and AGM**  
**Millennium Hotel Rotorua 8-10 September 2023**

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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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# Acting President Report 2022

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Welcome to my first report as your Acting President. Let me introduce myself. My name is Jan Haines and I have been an ileostomate for 39 years due to having Crohn's.

I was a young mum (25) with two lovely sons 4 and 2 years old. I went on to have two more sons 6 years after I became an Ostomate. I was very lucky I had a very supportive and loving husband to help me through my illness and to help with our boys.

I joined the Wellington Ostomy Association right back at the beginning of being an ostomate, then went on the committee within the year and I'm still on it all these years later. (I'm one of the old ones now) I really enjoy helping people whether it is on the phone or visiting them. I have been on the Federation for a while now and have loved my time on it.

I have done a lot of talks with 2nd year Student Nurses which I have really enjoyed, talking about living my life as an Ostomate and I think they got a lot out of it. I have always been very open about being an Ostomate "I am alive because I am an Ostomate and life is for living and I am living it".

I work full time as a Mental Health Support Worker. It is a very challenging job but it is my dream job as well.

In my down time I love being with my family. I have 7 grandchildren and 1 great grandson. I also love traveling around the world on Cruise ships (that is when we are allowed to do it again) . This was what my husband Chris and I had just started to do before he passed away 9 years ago and I have carried on with doing it. I have had hard times at Airports with having to show my "bag" as they wanted to know what was under my clothes. I act cool and calm and drop my pants and show them, they are more embarrassed than I am. You have to laugh otherwise you cry.

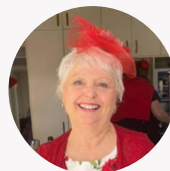
The reason why I am Acting President is because our President Kallia Patching resigned after 7 months due to personal reasons and as I was Vice President I automatically became Acting President. Robyn Tourell, our Secretary, also resigned due to ill health. This was very unfortunate for us all. We have picked ourselves up and have carried on as we all have the same goal to help all ostomates in any way that we can. The reason that we have come on board is because we care about what happens to everyone.

On the Executive we have Brent Hamlin as Treasurer, David Barnes as Acting Secretary and Brent Silcock on the committee. Since March we have added two new Executive members as we had some places to fill. They are Robyn Gall and Michael Sumner. We are very lucky to have a very hard working team and we all work very well together.

We have all been through very disruptive and challenging times. We have worked together and stayed strong for the better of all ostomates in New Zealand.

On behalf of our Executive we look forward to working with you in the best way we can.

**Jan Haines**  
**Acting President**  
**FNZOS**



# Jill Newton My Friend and Fellow Ostomate

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*This is Jill's Story to tell below*

## **My Journey To Ostomy and Achievements To Date**

What should have been a memorable experience in the early 70s resulted in a never-ending nightmare in one way, but a very worthwhile outcome with the birth of my second child. After a trouble free pregnancy, came a labor lasting just 30 minutes from the first twinge to the resulting birth of a beautiful daughter now 46 years old, but unfortunately, irreparable damage to my body.

I battled with total incontinence, unable to stay dry long enough to hang out the washing or do my own shopping and endured 18 surgical procedures with my longest stay at home during this time being just 3 weeks at time.

Having a Urostomy performed was suggested as a solution. I thought to myself that gone would be the days when the number of knickers on the clothes line each day would reach into double figures, I would now be able to have a leisurely wander around the supermarket and spend quality time with my family.

Four long months and several complications later, I returned to my home and family 200 kilometres away and began to rebuild my life. (My older son had also spent many weeks over the last 15 months in hospital with Intersuception requiring three lots of surgery followed by several bouts of gastroenteritis and then TB).

Progress was incredibly slow however, with a continuous battle with infection and ulceration around my stoma, until the surrounding tissue was so corroded that it looked from the inside out. My surgeon decided to attempt a reconstruction. However, this too proved to cause more trouble than enough (through no fault of the surgery) and an attempt was made to reconstruct the reconstruction, which I battled with for a period of time before having another Urostomy performed.

The lightest moment of that time came from my delightful daughter, who was by now in the infant

class at school and was having a morning talk when they had to tell the class about something they had to do at home that Mummy & Daddy didn't have to do. She told the class how unfair it was that she always had to go to the toilet to do a wee, and her Mum just did it in a plastic bag!!! (She was forgiven, but rumour was rife in a small town like Alexandra).

I should perhaps explain my definition of "Incredibly Slow" as you may have already guessed that I am an incredibly impatient person. It spans over many years, in which time I suffered gross discomfort, a loss of self-respect, many hours a day doubled over with pain and smelling like a walking sewer most of the time.

Things did look up for a while however, I began working again and got back to swimming, playing sport, cycling and walking, all of which I loved. I even competed in triathlons, but my health began to plummet yet again, with infections again being a huge problem, which of course meant more antibiotics and I learned that I would have to give up work. My whole world had crashed and suddenly I had nothing to look forward to – I was a nothing person with nowhere to go except to specialist and doctors waiting rooms.

Sure I had other interests, all with voluntary organizations, however I was on the wrong side of 45, too old for this benefit and too young for that one and told I was far too old to re-train for anything else, I didn't have much to look forward to really. I had also by this time had 3 lots of surgery for an achilles problem which had me in and out of hospital yet again & in plaster for the biggest part of 2 years. My life was truly shattered.

My health continued to be a problem however and I returned to hospital for a reconstruction of my already reconstructed reconstruction which laid me low yet again with infection, pain and discomfort continuing to be a problem for several months and Antibiotics becoming a regular part of my daily routine.

After thinking my life was at last on track I was tied

down again for a further 3 months in 2006 after having to undergo extensive spinal surgery and again in 2013 & mid 2014 when having to undergo knee surgery.

I have enjoyed an interesting and rewarding involvement with the New Zealand Ostomy Society in a variety of ways since my initial surgery in the early 70s. Having held various positions over those years including Chairperson of the Ashburton Branch, a position I held for almost 21 years having previously served as both Secretary and Treasurer and I have also held the position of Secretary of the South Canterbury Branch for the past 16 years.

I have been a member of the National Executive of the Federation of New Zealand Ostomy Societies for the past 18 years and am currently their National President. During this time I have organized a reprint of the FNZOS information booklet "Living With Your Ostomy", been involved in fundraising projects and helped with the running of very successful camps for young ostomates between the ages of 11 and 20.

I accepted the challenge as Editor of the NZ Ostomate magazine in 2003 and continue to look forward with enthusiasm to producing each issue and have been part of the organizing committee for the FNZOS Conferences and AGMs held in both Ashburton and Timaru.

I have been a volunteer lifeguard at the Ashburton Community Pool for 33 years, a volunteer with the Evening District Nurse for 34 years, and a member of Ashburton Town Watch for 24 years all of which I thoroughly enjoy. I am not good at being idle and swimming most days and regular walking takes care of my leisure time.

Although the last 45 years have been a trial in many ways, life must go on, and being one who WILL NOT be beaten, if a few pills a day, occasional Antibiotic treatments and the odd hour or so sitting in a hospital or doctors waiting rooms keep me functioning –

### **Life Is For Living, And I'm Living,**

I will pick up from here as Jill said in her story she did become the editor of the NZ Ostomate in 2003 and editor until 2021 and was a dedicated

editor of the magazine which is distributed to all Ostomate in New Zealand, as well as copies being sent to Australia, England, USA, India, Philippines. The magazine was very well run in the hands of this very capable lady who was still working and volunteering with other support groups along with Ostomy groups and President of the National Body of Ostomy NZ (Federation of New Zealand Ostomy Societies Inc) a big role on its own without running the magazine three times a year.

Jill certainly lived life to the full and still is even after recovering from a very bad cancer which made her have to take time for herself and she reluctantly had to give up the editor of the magazine and president of Ostomy NZ so that she could focus on getting through what life challenges had sent her way.

As always since I have known Jill which is a over 35 years she is a fighter and although things were very tough for her she has come through and can now see light at the end of the long tunnel she was in. Jill you will be missed at the head of the Ostomy Table and leader of the magazine but we hopefully we will see you at a conference in the future and we will be able to have the fun, laughter and not have the responsibility of the group on your shoulders.

My dear friend I wish to say from all the Ostomates New Zealand, World-wide to whom you have had contact, made friends with and travelled overseas with and represented New Zealand a very big Thank you , Un Merci, Grazia, Gamsahamnida, Arigatou, Hindi/Urdu, Thanks. It does not matter what language you use THANK YOU it does not seem enough for all the time and hard work you have put in over the years.

THANK YOU, THANK YOU, THANK YOU

**Your friend,  
Robyn**

# “Yip, I Have an Ileostomy, and it’s WONDERFUL” The Inspiring Kiwi Who is Making Her Invisible Illness, Visible!

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We’re putting the spotlight on Invisible Illnesses in this new series. Are you one of the many Kiwi women who suffers in silence?

In this series we’re talking to Kiwi women about their health battles with Invisible Illnesses, their journeys to being diagnosed and what’s given them relief along the way. Our hope is that by sharing these stories, they may help spread awareness of these illnesses to other women, giving some tools to help, inspiration to those who can sense something isn’t quite right with their health to continue to search for answers and ideally, get diagnosed sooner! If you’d like to contribute your story, please drop a line to [alice@capsulenz.com](mailto:alice@capsulenz.com).

Here, we talk to Cheyenne Welham who waited for a decade to finally be diagnosed with a relatively rare – but debilitating disorder. But she also – frustratingly – is one of the luckier ones, considering it takes an average of more than 14 years to get there...

When Cheyenne Welham was diagnosed with a rare and painful genetic connective-tissue disorder at just 24, she immediately burst into tears. But not for the reason you’d expect. “I cried A LOT,” she says. “But mostly out of relief! I wasn’t crazy and it wasn’t all in my head. There was finally an explanation for everything that I had experienced.”

Cheyenne diagnosis was Ehlers–Danlos Syndrome (EDS) – a condition that causes faulty collagen to be produced by the body. And, because collagen is found all throughout our bodies – we’re talking skin, muscles, tendons, ligaments, blood vessels, organs, gums and eyes – EDS can affect a number of different parts and systems of the body. Symptoms and severities can vary greatly – from having mildly loose joints to life-threatening complications.

There are 13 different types of EDS and Cheyenne suffers from Hypermobile EDS (hEDS),

which is thought to affect between 1 in 5,000 people. For the most part of her life, Cheyenne’s illness has been entirely invisible – something that’s made it particularly difficult when it comes to being treated by doctors and medical professionals, but also professionally and socially. It’s pretty darn tough being a teenager, or early 20-something, trying to explain to your friends why you can’t go out with them for the night, even though you look and sound fine.

But in the last few months things have changed somewhat on that front, and now Cheyenne does have an outward sign (if she chooses to share it!) that she’s not 100% well. Three months ago she underwent ileostomy surgeries and now sports a stoma bag. It’s surgery that she says has completely changed her life for the better. A stoma is basically an opening that is created on the abdomen, that can be connected to your digestive or urinary system to allow waste to be diverted out of your body. In an ileostomy, part of your small bowel (the ileum) is pulled through to create the stoma. You then wear a discreet pouch on your lower abdomen that is connected to the stoma.

Cheyenne’s attitude to her new accessory is phenomenal – yip, it’s a big change, but it’s improved things for her enormously, and she’s determined to not hide it away or be ashamed or worry what others think. She’s here to show how normal, clean and wonderful they are – and it’s everyone else who has a problem with hers who need to get over it!

There’s plenty we can learn about stomas (as well as perseverance and kindness!) from Cheyenne, but first, let’s go back a bit in time, to how things developed for her. Cheyenne says her very first symptoms showed up when she was just in primary school – but back then she – nor any of her doctors – had any idea that there was anything sinister going on.



“My shoulders would pop in-and-out and I took great delight in showing off this ‘party-trick’ to my classmates!” she says. “But it turned out that my ligaments were far too lax to hold the joints correctly in place – and I was subsequently banned from doing any more party tricks!”

Unfortunately it would soon become clear that her unusual joints – and little party trick – was actually just the tip of an iceberg of different symptoms – but at the time it was treated as a one off, isolated issue. But by the time she was in high school she was suffering from another round of symptoms – this time far more painful. Most of them showed up when she was 15 and mainly affected her gastrointestinal (GI) tract. Over the next 10 years things steadily went from bad, to worse.

“In the end I was dealing with bowel incontinence, diarrhoea, weight loss and lots of other fun stuff on the daily,” she says. “This really affected my mental health – as one would expect – I was terrified to leave the house for fear of having an accident. I definitely struggled a lot with depression and anxiety.”

Determined to feel better and get to the bottom of what was going on, Cheyenne saw a host of different doctors and specialists – undergoing multiple scans, blood test and colonoscopies in the process. Meanwhile, she was giving everything else she could think of, or was recommended give a go too. “I tried all the weird and wonderful diets, herbal remedies, acupuncture, chiropractor, Reiki etc,” she says. But still, she seemed to be getting nowhere – except extremely frustrated. “I was repeatedly told that it was IBS or that I was just ‘stressed,’” she tells. “I was even referred to a Psychologist at one point as a result. Sadly it isn’t uncommon, especially for young females, to have their concerns totally brushed off and disregarded. And in fact, doctors may fail to appreciate their female patients’ symptoms in part because medical research has historically focused on men.”

Then, just as she was about to give up hope, she went to a specialist GI clinic. “They finally did a particular type of X-ray that showed the tissues in my lower large intestine were strangely stretchy and weren’t functioning normally,” she tells. “Even the radiologist was confused at the findings! Finally, my wonderful GP (worth her weight in

gold) made the connection between what I’d experienced as a kid and what was shown in this scan, and then later I was diagnosed with EDS by a rheumatologist.”

Cheyenne was 24 when she was diagnosed – almost a full decade since she began suffering from debilitating symptoms. It was liberating to finally know that it wasn’t all in her head, but incredibly frustrating that she had to suffer so long before having a confirmed diagnosis. “I really regret that it took so long,” she says. “And unfortunately I’m not alone in this. The average time to diagnosis for EDS is 14 years. Sadly this is the case for so many and not just for EDS. Another similar yet terrifying statistic is that 1/10 females have Endometriosis but the average time for diagnosis is 8+ years.”



Battling something that other people can’t see certainly added to the difficulties in getting a diagnosis – but it also had a much wider impact on Cheyenne’s life. “I think people naturally struggle to believe or understand things they can’t see,” she says. “So life with an invisible illness can be such an isolating experience. It’s really hard for others to know what it’s truly like.” “The biggest thing for me is that even if I look okay it does not mean I’m feeling okay! I definitely used to put on a front when I was with other people (especially in a professional setting) and pretend that everything was fine when it wasn’t at all. Which actually made things worse for me in the long-run because when I did finally open up about what was really going

on, people found it very difficult to reconcile with my outward appearance and abilities.”

It's also made things pretty touch for Cheyenne, socially. “I used to have to cancel on plans with friends all the time because I was so unwell. I wish they would have understood that I was far, far more frustrated, guilty and upset about having to cancel than they would have been on the receiving end.” “Even now with my ileostomy I have the right to use the Disabled toilets in public but I'm always worried that someone will make a rude comment because I don't 'look' disabled (with my clothes on at least!). Luckily nobody has said anything yet but I'm sure that it will happen sooner or later.”

Cheyenne's ileostomy was her last resort option, which she finally came to in October last year. By that time, she'd exhausted every medication and therapy under the sun. “Literally everything had failed to fix my GI issues,” she says. “So by the time the doctors suggested an ileostomy, I was just so desperate for relief that I sort of welcomed the surgery. I was probably more nervous about what would happen if the ileostomy didn't work, than having one in the first place. She didn't know anyone else with a stoma bag at the time, but has since connected with a number of incredible ‘ostomates’ through social media (including the wonderful @katemontgom who everyone should follow!). “I really don't know how I would have coped without having seen other people around my age on Instagram with stoma bags,” says Cheyenne. “All the pamphlets that the doctors give you beforehand only feature older people and it doesn't really make us younger patients feel great about the bodily changes that lie ahead. We have the best and most supportive community on Instagram and I have no doubt that our community provides a lifeline for many.”

For Cheyenne, her ileostomy has been a true success story and she says that in the three or so months since her surgery, her life has completely changed for the better. “I'm so grateful for all the small things that I feel other people might take for granted,” she shares. “Like being able to leave the house with less anxiety, not having to plan out all the bathroom stops beforehand, being able to eat and drink in public and be more present when I'm with other people. I almost feel like I'm

just starting Life 2.0! “Don't get me wrong, there are some definite cons to having a stoma, but the benefits far exceed the downsides for me. So right now I'm really focussing on living life to the fullest and enjoying a lot of quality time with my family and friends now that I'm able to.”

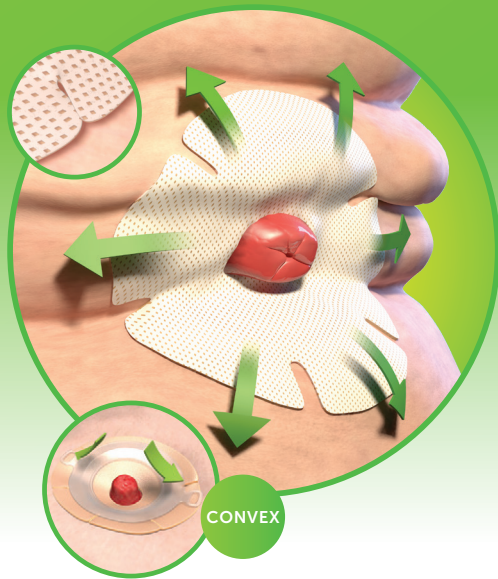
Cheyenne doesn't want to shy away from her ostomie, but it's also very easy to keep under wraps! And now, she doesn't want to constantly hide her stoma bag away, like it's something to be ashamed of. She's upfront about telling friends and family, and wants it to be something that's talked about and normalised more widely.

“Initially I was quite worried about telling people that I have a stoma because I was afraid of their reactions,” she admits. “But I've been quite surprised because most people that I tell actually respond with “Oh that's cool, my cousin/brother/Aunt etc. has one too!”. They're really much more common than you'd expect and nothing to be ashamed of at all.” But she knows not everyone is quite as welcoming and accepting. “Unfortunately there's a bit of “I'd rather die than sh\*t in a bag” rhetoric out there which is just so upsetting,” she says. “Hearing things like that really breaks my heart because having an ostomy has given me back my quality of life and I don't think that it holds me back at all.

Having a stoma has given me more freedom, confidence and opportunities in life that I didn't have before.” She says there are three key things that she also wishes people knew and understood about stoma bags: “**Yip, I Have an Ileostomy, and it's WONDERFUL**” “One: Stoma bags aren't just for old people, people of all ages can need one for many different reasons. “Two: There's nothing gross about it, and people with ostomies do not stink! “And Three: We can pretty much do everything that you can!”


But besides just talking about ileostomies and EDS – which she'd be stoked if you came away from reading this knowing a thing or two more about – if there's one thing that Cheyenne would love you to leave this remembering. And that's the saying: “Be kind, for everyone you meet is fighting a hard battle.” You can follow Cheyenne on Instagram at @cheyber\_space. And if you have your own story you'd like to share, please drop an email to [alice@capsulenz.com](mailto:alice@capsulenz.com).

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## From Then to Now

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I am writing this as I retire from my career in Stomal Therapy Nursing which began 39 years ago. I trained at Dunedin Hospital 48 years ago and things were very different than they are now. We worked in the hospital almost from the start of our training and by the time I was 18 I was doing night shifts on my own in a 30 bed ward with a staff nurse overseeing 3 wards who we could call on when needed.

I spent quite a bit of time working in the surgical ward and my love of stomal therapy probably started there. On nights we would change the stoma bags and there were always quite a few patients in. Back then it was common for people who had ulcerative colitis to have their entire colon removed and so had a permanent ileostomy. This was to done to prevent the risk of cancer as surveillance wasn't so good back then!

The bags we changed each night were nothing like what is available now as we made our own. A length of plastic sleeving was cut from a long roll and a double-sided plaster was put one third down and the hole to fit the stoma was cut in it. Rubber bands secured the top and bottom of the bag. Friars balsam was used on the skin prior to the placement of the bag. I have no idea what these people used when they went home but Ruth Wedlake worked with them while they were in hospital, she was an ostomate who went to the Cleveland Clinic and trained to be an Enterostomal Therapist under Norma Gill.

The one good thing was that the stomas were permanent and were well formed so there was no issue with leakage.

We shifted to Wellington next and I worked at National Health Statistics as a morbidity and mortality coder and then we shifted to Invercargill where I went to work in one of the surgical wards with Mrs Bernadette Hart as my charge nurse. She was a truly wonderful woman and I feel very privileged to have known her. We didn't have a stomal therapist back then and she used to see the stoma patients at the end of her working day.

Unfortunately she developed bowel cancer and I took on the role of seeing the ostomates. Most of the problems back then were skin issues as many of the bags still used plasters to adhere to the skin rather than the hydrocolloids we have today. When Mrs Hart died I was fortunate enough to be allowed to start the stomal therapy service in Southland as a memorial to her.

I loved my time in Southland, it was challenging but also innovative as new products were coming on the market. I would think nothing of using a wide range of products on one patient from a variety of companies. Stomahesive and Hollister wafers became available and I added them under a lot of the old adhesive type bags and macerated skin would heal within a week after years of problems. Cell phones were not heard of back then so when I ran out of petrol on the Bluff Road I had to stand in the middle of the road and wave down a car to help me!

Supplies had been dispensed to patients through the hospital pharmacy for years but then the decision was made to do this through our stores department so I would go down and pack up the monthly orders. I had about 220 patients back then and was paid for 16 hours per week but of course extra hours were common and I would never refuse when I was called out at all hours of day and night!

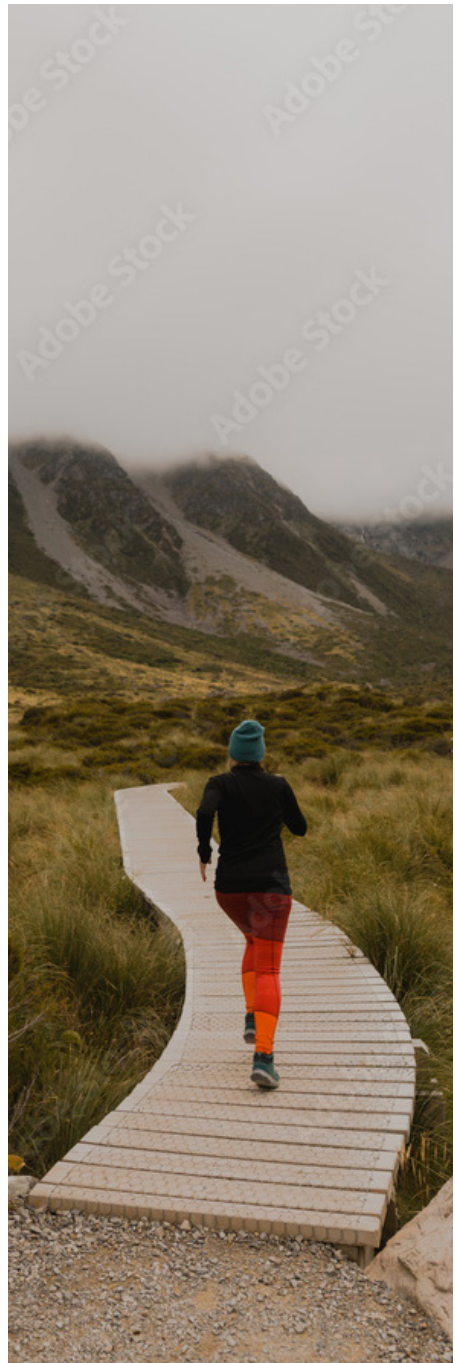
Eventually we moved to Christchurch and I joined Nurse Maude and it felt really odd to go from

being a sole practitioner into a team of four but I adapted. The hardest thing was not seeing the whole patient journey as we did a monthly rotation through the hospital, home visits and our clinic. The great thing about a team environment though is the ability to problem solve with other people in person instead of over the phone.

The years went by with changes to the type of surgeries done and the products available. I remember when integrated closures on the bottom of drainable bags were introduced. Before then there was a clip on the bottom and it was quite a common occurrence for these to be knocked off the cistern and flushed down the toilet when bags were being emptied. I also remember the introduction of convex bags which we also welcomed and are now almost more commonly used than flat bags. Temporary stomas are far more common now than permanent ones. Cell phones and GPS have also made a big difference to the job. The company representatives are extremely important as they made sure we knew what was available to help our patients.

It can be tiring and frustrating as a stomal therapist but there were so many positives that kept me going and I could see the improvements I could make to help people both physically and emotionally. I have met so many wonderful people over the years when they were at a very vulnerable time in their lives and saw how well the majority of people cope.

I look back on my career remembering the good times which far outweigh the bad. I have served on both the Southland Ostomy Society as secretary and also on the stomal therapy executive committee many times over the years in a variety of roles. I feel that I am leaving Nurse Maude at the right time as they have a wonderful talent there with 6 stoma nurses and I wish them all the best for the future and hope they all love the job as much as I did. Finally, I would like to thank the management team at Nurse Maude for being so supportive of the Stomal Therapy team.



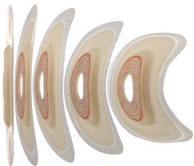
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## COLOSTOMY CORNER

*Share your experiences, tips, and ideas here. While this is aimed principally at colostomates, some ideas might be of help to others.*

### **David Barnes:**

Colostomy (full colon remaining) 2001 – rectal cancer – one piece closed

Well, that was a bit of surprise; when I had a massive bleed I thought the piles I'd had a year before had recurred, but no – rectal cancer! Diagnosed on my 48th birthday I thought I was a touch young for that, but actually I already knew 3 friends, 2 of them younger, with colorectal cancer, one of whom had a colostomy. Oddly I wasn't particularly worried, just wanted to know how long I'd got. Then it turned out I was one of the lucky ones, so the fact that I'd need a bag wasn't really a big deal – I could be fixed, and the people involved in the fixing were all amazing.

So, looking back the first 6 months were the hardest – recovering from the surgery and undergoing chemotherapy and radiotherapy tends to mess your digestion about just while you're getting the hang of the whole business, but it does improve almost immediately the treatment finishes. For temporary ostomates this is of course likely to be a large portion of the time you will have your colostomy, but it does get better – honest!

With all my colon remaining I can eat what I did before, fiery curries (no after-burn) and all. While I was having chemo I actually chose spicy food so I could taste it! The only real change I've made is to stop eating the nice heavy "healthy" muesli I used to eat – it just used to make its way through at the most inconvenient time in the evening.

I was put on to a one piece closed bag (or more accurately it was put on to me) from the start and that pretty much seems to suit - I wouldn't want anything that was stuck on for more than about 48 hours! The first couple of makes didn't stay on well for me, but then I was moved to some better ones. I found that Botox® injections around the stoma totally eliminate sweating for about 3 – 4 months, and for several years that saw me through the summer. The latest bags will now stay on me for up to 48 hours and I can change generally depending on when they're pretty full or when I choose to rather than because they're falling off. Changing to soft convexity meant I no longer needed to use Botox.

### **Tips**

I like to shower with the bag removed, so need to use tissues to clean up if necessary. I found that the most durable tissues were Kleenex Aloe Vera – the way they are impregnated means they stay in one piece when damp. I put a cup hook in the shower (above the height of the shower rose) and hook a box of tissues onto it so they're within reach. If you don't have easy access to the toilet from the shower, then another hook for a plastic bag for the used tissues is useful.

I wear braces to keep my trousers up rather than using a belt or a tight waistband (I buy an inch larger than I used to), this avoids undue pressure on the stoma and is also cooler.

If you are worried about being a bit smelly from time to time, try carrying around a small child in nappies on a regular basis No-one will ever suspect it is you! And gentlemen, you also get much better service in stores – all those shop assistants hiding away chatting about their social life magically appear when you're carrying a cute child.

# My Journey with Antiflams

All Ostomates should read this...

Approximately 8 months ago I damaged my shoulder working in the garden. At first I thought I had just pulled a muscle but after 2 weeks I thought a doctor visit was in order.

The doctor arranged physiotherapy and prescribed Tramadol for the pain, within 3 days I was vomiting and was then put onto antiflams with the same result.

Ostomates need to be aware that vomiting and even coughing can put a lot of strain on your stoma and can lead to bleeding of the stoma and can also cause hernia.

I was changed to a course of Panadol and Ibuprofen together, 4 tablets every 4 hours as I have an allergy to codeine. (are you aware that Ibuprofen is not recommended if you are over 65 also you don't want to know about the 34 possible side effects from this medication). This brings me to the point that if you have to go on to antiflams you need to make sure that your doctor fully understands your history before prescribing medication or changing your existing ones that could complicate your condition.

A close friend was prescribed a 20-day course of Celecoxib an Antiflam and near the end of the course came out in an extremely bad rash from top to toe. Yes, it was one of the side effects, but who reads them anyway. YOU SHOULD!

We are so used to ticking terms and conditions these days but as Ostomates you need to look at the information for medications.

The week before Christmas I also fell and tore the meniscus in my knee so I was visiting 2 different specialists for shoulder and knee. Then after X-rays Ultra sounds MRI and CT scans They find I had a Stage 2 frozen shoulder and should have had different treatment.

Now with cortisone injections I have relief from the pain and believe I am on the way to recovery I still take Panadol regularly which although not strong gives me temporary relief and hot

water bottles, wheat bags and aqua jogging at the Pool are all beneficial. Now they have discovered Sciatica in my right leg and I am taking Gabapentin for nerve pain.

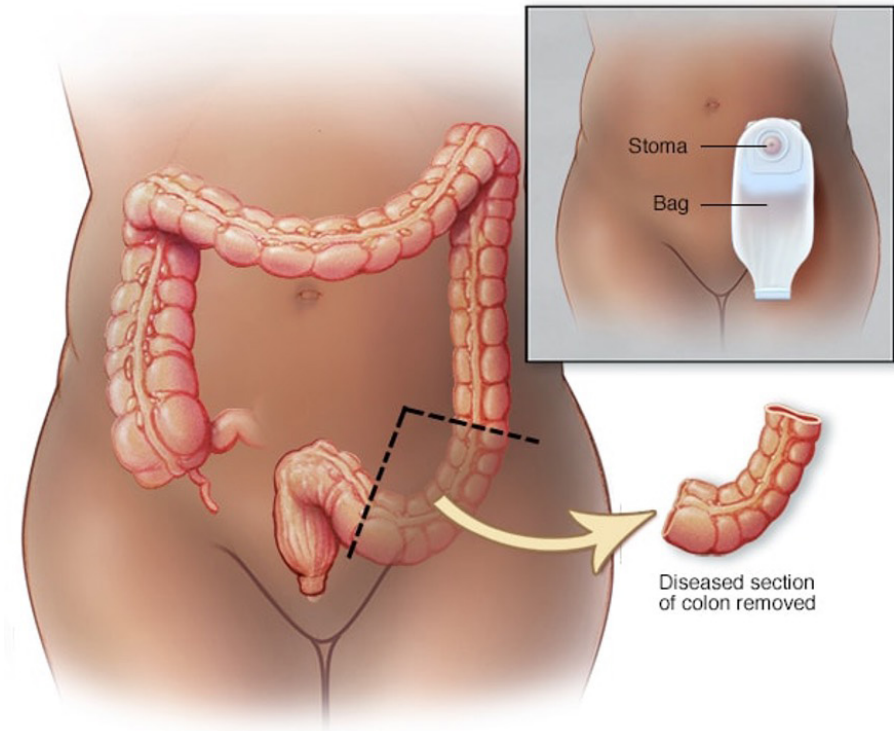
After all that the rest of me seems O K So take care all you Ostomates and don't work too hard in the garden (read the side effects instead.)

**Dian Cheyne**  
**President W B O P**





# Adapting to life after colostomy, ileostomy or urostomy



Learn all you can about life with an ostomy. Use this information to boost your self-esteem and help you adapt to your ostomy.

It takes time to become comfortable with an ostomy — a surgically created opening in your abdomen that allows waste or urine to leave your body.

Many questions may run through your mind as you plan your first ventures outside of your home. Can you go back to work after colostomy? Can you ride your bike if you have an ileostomy? Will everyone figure out you've had urostomy surgery just by looking at you?

## You can eat whatever you want if you have an ostomy

Have a favorite dish? If you've been given the OK from your doctor to resume your regular diet, eat what you like. If you have a colostomy or ileostomy, you'll find that various foods affect your digestive tract differently.

Just as some foods gave you gas before your surgery, you'll likely experience gas with certain foods now that you have an ostomy. While you may choose to eat gas-causing foods sparingly or only at times when the gas won't make you self-conscious — such as when you're at home, rather than at work — it doesn't mean you shouldn't ever

eat gas-causing foods.

Certain foods are more likely to cause gas, diarrhea, constipation, incomplete digestion or urine odor. But which ones have these effects will depend on your body.

If you're unsure how foods will affect you, consider trying them at home, one at a time, before eating them in public. Knowing how each food affects your digestion means you'll spend less time worrying about the food's effects and more time having fun with friends.

It may help to chew your food thoroughly and drink plenty of water.

### Common intestinal reactions to certain foods

- **Gas** - Asparagus, beans, beer, broccoli, Brussels sprouts, cabbage, carbonated beverages, cauliflower, onions, peas
- **Incomplete digestion** - Apple peels, cabbage, celery, coconut, corn, dried fruit, mushrooms, nuts, pineapple, popcorn, seeds, skins from fruits, skins from vegetables
- **Thickened stool** - Applesauce, bananas, cheese, pasta, rice, peanut butter (creamy), potato (without skin), tapioca
- **Thinned stool** - Fried foods, grape juice, high-sugar foods, prune juice, spicy foods
- **Increased odor** - Alcohol, asparagus, broccoli, dried beans, eggs, fish, garlic, onions, peas
- **Reduced odor** - Buttermilk, cranberry juice, parsley, yogurt

Source: Academy of Nutrition and Dietetics, United Ostomy Associations of America

If you have a urostomy, you might be concerned about urine odor. Certain foods can cause a stronger urine odor, but you can minimize that by drinking water or cranberry juice.

### Controlling urine odor

- **Increases odor** - Asparagus, fish, garlic, onions
- **Decreases odor** - Eight to 10 glasses of water, cranberry juice or other

noncaffeinated beverages daily

Source: United Ostomy Associations of America

### You can participate in sports if you have an ostomy

Unless your favorite hobby is a contact sport with lots of potential for injury, you'll be free to go back to the activities you enjoy after you heal from ostomy surgery. The main danger is injury to the opening where waste or urine leaves your body (stoma), which means rough sports may be out.

If you want to continue these pursuits, ask your doctor or ostomy nurse about special products you can use and precautions you can take to protect your stoma during these activities.

Check with your doctor before you begin lifting weights after your surgery. You may need to wait for your surgical incision to heal before lifting weights, to reduce your risk of complications. Once you're fully healed, your doctor or an ostomy nurse might recommend a device to support your abdomen when lifting weights.

If you're nervous that running, swimming or other athletic activity will loosen your ostomy bag and cause a leak, use a special belt or binder to hold your ostomy bag in place. Check with your local medical supply store or look online for specialty products for active people with ostomies.

### You can go back to work if you have an ostomy

You'll need time after your surgery to heal and recover, but you can eventually go back to work. You might choose to ease back into work or talk with your employer about a limited schedule until you feel more confident with your ostomy.

If your line of work involves manual labor or lots of lifting, your doctor may recommend ways to protect your stoma on the job.

Once your doctor says you're ready, consider going back to work. If you're nervous about caring for your ostomy at work, talk to your doctor or an ostomy nurse.

Don't let worrying get the best of you. Returning to work is a good way to transition back to a normal routine, and working again can make you feel good about yourself.

## **You can tell — or not tell — whomever you want about your ostomy**

It's up to you to decide who to tell about your ostomy surgery. It may make sense to tell the people closest to you. These people may be worried about your recovery, and explaining your ostomy may ease their fears. Talking with loved ones is also a healthy way to cope with your emotions.

Acquaintances may be curious about why you've been away from work or know that you were in the hospital and ask about your illness. Think ahead about what to say when questions arise. You could say you've had abdominal surgery or use another basic description without going into details if you're uncomfortable discussing your ostomy with people you don't know well.

Other people will need to know about your ostomy for practical purposes. If you don't have a desk or locker at work to store extra ostomy supplies, for instance, you might need to reveal some details of your ostomy to someone at work so that such arrangements can be made.

Some people keep their ostomy surgery private, and others prefer to tell anyone who asks. Who you tell is up to you, but you may find you're more willing to discuss the details as you become more comfortable caring for your ostomy.

## **You can hide your ostomy**

To you, the ostomy bag attached to you is very obvious. When you look in the mirror, you notice the bag under your clothes. You might think every gurgle and noise coming from your stoma is loud and heard by everyone in the room.

Most people won't notice your ostomy unless you tell them about it. As you get used to your ostomy, you'll figure out tips and ways to keep the bag concealed and the noises to a minimum. Here are some ideas to get you started:

- Empty your ostomy bag when it gets to be one-third full. That way it won't bulge under your clothes.
- Work with your ostomy nurse to find the ostomy pouching system that works best for you.

- If you're worried about the odor when emptying your ostomy bag, ask your ostomy nurse or visit your medical supply store for pouch deodorants or air sprays to minimize odor.

Ask a close friend or loved one whose opinion you trust whether your ostomy bag is visible under your clothes or if the sounds your ostomy makes are as loud as you think they are. Everyone's body makes noises and produces odors from time to time. While it can be embarrassing, don't let a fear of what could go wrong keep you from going about your day.

## **You can wear whatever you want if you have an ostomy**

No clothing is off-limits if you have an ostomy. However, your individual body contour and your stoma's location may make some clothes less comfortable. For instance, tight waistbands or belts might feel restrictive over your stoma. Be open to experimenting with different styles of clothes.

But don't let your ostomy keep you from wearing tightfitting clothes or even your bathing suit. Look into ostomy swimsuits and trunks, which can be found through specialty retailers.

## **You can go wherever you want if you have an ostomy**

It will take some pre-trip planning, but having an ostomy shouldn't prevent you from traveling. If you'll be traveling by airplane, bring extra ostomy supplies and pack them in both your carry-on and checked bags.

Consider carrying a statement from your doctor about your ostomy. This note might explain why you have an ostomy and ask airport security screeners to respect your privacy during searches.

## **You can have sex and intimate relationships if you have an ostomy**

You'll need time to recover after surgery. And depending on what type of ostomy surgery you have, you may experience some temporary sexual side effects, such as erectile dysfunction or vaginal dryness. But sexual intimacy can continue after you have an ostomy.

If you feel less attractive with your ostomy, take your return to intimacy slowly. Maybe you aren't ready to have sex right away. Discuss this with your partner. Suggest starting with touching and kissing. Your partner can help make you feel more comfortable and reassure you that you are just as attractive with an ostomy.

Take steps before intimacy to feel more confident. Empty and clean your ostomy pouch. Check the seal to make sure it's tight. Use an opaque pouch or try a pouch cover. Lingerie and cummerbunds made to conceal a pouch or hold it in place are available from specialty retailers. Ask your ostomy nurse about companies that sell these products.

Certain aspects of sex may change with an ostomy. You might find that some sexual positions put pressure on your ostomy and are uncomfortable. Experiment with new positions, such as lying on your side.

People with ostomies who are dating often worry about when to tell new companions about their ostomies. That's up to you. Some people feel more comfortable getting it out in the open right away, while others want to get to know and trust a potential partner first. Do what feels right for you. Know that rejection is possible, and give a new partner time to consider what an ostomy means to your relationship. Answer questions openly and honestly.

### **Talk to others with ostomies**

Get in touch with other people with ostomies — they sometimes refer to themselves as ostomates. Whether it's a support group in your community or online, getting advice from people who've been there is a great way to boost your confidence. You can ask questions that you might be embarrassed to ask your doctor or nurse. And you can get tips to help you adapt to life with an ostomy.



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# Camp Purple

Camp Purple Live is an annual summer camp that is free for the young attendees [between 9 and 17 years of age] who share a diagnosis of Inflammatory Bowel Disease. For most of the young campers, the chronic, unpredictable course of their disease has resulted in hospitalisations, invasive medical procedures, harsh drug regimens and, for some, major surgeries. As a result, most of the young people will have experienced extended absences from school and time away from their peers. The impact on their wellbeing and quality of life can be huge.

Camp Purple offers an avenue for managing the psychosocial wellbeing of young people with IBD by fostering social connections with those with both shared and differing experiences. This week-long camp, filled with fun activities, provides young people with IBD opportunities to be themselves, safe in the knowledge that those around them 'get them'. Having a great time is the focus of the camp experience, made possible by a caring group of volunteers and medical professionals who ensure a safe and accepting environment. Many hours go into planning fun and exciting activities that offer the children and teens the chance to step outside their comfort zones and have new experiences.

Camp Purple Live 2023 will be held from Saturday 21st to Thursday 26th January 2023 at Living Springs, in Christchurch.

One of the key components of the Camp Purple Live program is the Parents Seminar. This two-day seminar for parents and caregivers has been a part of each camp since the first camp in 2015. The seminar focuses on education and dealing with the challenges of being a parent of a child with IBD. There are always interesting talks such as the impact of technology on our children's lives, breathing and meditation, and managing the ups and downs of being diagnosed with IBD as a young person. But, most importantly, the seminar facilitates networking and interaction among the parents who share so much in common.

The Parents Seminar for 2023 will be held on Saturday 21st and Sunday 22nd of January at a hotel near the Christchurch airport.

The tentative date for our "Experience Camp for a day" (tailored for children too young to attend camp or those who are not sure they want to attend the entire six days) is 25th of January 2023.

If you have any further questions or would like to attend Camp Purple Live 2023, our Parent's seminar, or Experience Camp Purple Live for a day, please email [campenquiries@crohnsandcolitis.org.nz](mailto:campenquiries@crohnsandcolitis.org.nz) to request more information.

To find out more about Camp Purple Live, watch the video at [https://www.youtube.com/watch?v=uin88vOE7\\_s](https://www.youtube.com/watch?v=uin88vOE7_s) or head over to our webpage [www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)



# NEW DATES LIVING SPRINGS 2023



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89530	30 mm – can be stretched to 35 mm
89540	40 mm – can be stretched to 45 mm
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# Finding an appliance that works well for you

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Many of the responses to the survey I carried out some years ago indicated that people were continuing to use the appliances they had started out with. But at the same time there were responses showing that they were living with the problems encountered, such as ballooning, leakages etc, or restricting lifestyle, even to the extent of not going out, not travelling, or taking tablets to block themselves up.

In talking to others at some of our coffee mornings and at Conferences, it became apparent that this is a common theme. There is an inclination to continue to use the appliance provided both due to familiarity and to the belief that such problems are inevitable and you just put up with them. Without wishing to overburden our stomal therapists, it is important that you let them know if you are encountering problems. They do need useful feedback on the use of appliances to help them in better determining which are likely to work best in various situations.

It is important that you describe any problems you have clearly; responses such as “didn’t get on with it” aren’t helpful! While for ileostomates a filter that doesn’t leak or block seems to be the Holy Grail, generally for colostomates it should be possible to find filters that work correctly. Similarly, you should be able to find a product that sticks on well but doesn’t give you grief in removing it. There can be significant difference in the behaviour of the different makes and models of appliances.

If you have problems with your sight or hand movement, or have a significant hernia, you will need to look for products that are designed to be more suitable. If you have uneven or irritated skin or other problems, then you may need to try a range of products which are intended to ease the problem and work well with the appliance of your choice.

## Read the Adverts!

The NZ Ostomate magazine regularly carries adverts from the various manufacturers describing their products. This is a great source of information for you on newer or alternative

appliances. Do respond to the adverts if it appears that a particular product may be of benefit to you, they will all supply samples. If a sample performs better for you, you can arrange with your stomal therapist to maybe switch to that if it proves to be better for you than your current bag or others available. It is clear that we’re all different, and what works well for one person may not suit another.

## Tips on 1 piece colostomy bags

As a colostomate wearing a 1 piece closed bag I have over the years tried all the brands available and have worked out what to look for. Perhaps an experienced ileostomate or urostomate could provide similar thoughts for their bags, and 2-piece users could provide hints on what else to look for. Also the different types of drainables, certainly users had strong views on the relative merits of Velcro and clip closures for example. Remember, though, that we are all different so may have different results, the important thing being to try them out and see what works best for you.

I look for an adhesive that stays on well but is simple to remove (with 1 piece there shouldn’t be any residue) with no discomfort and a filter that lets gas out but not fluid or odour, with comfort and ease of wear being important as well. The principal problem for a 1 piece is sweat dissolving the adhesive.

## Results

Some 2 or 3 years ago I found tried a new type of appliance that performed very well for me and lasted for longer periods, easily 24 hours and up to 36 or 48 hours depending on output, without any disasters. This came in a large size, which I found copes happily with those sudden “runs” you might get from time to time without filling up. I can now change the bag when it suits me, usually just once a day, and I am as a result using around 100 for my 3-month supply rather than the 180 I needed previously. This is much handier for me and better on the DHB’s budget, so a win all round! So, don’t be afraid to try new products, they have been improving markedly over the years.

## David Barnes - Colostomy 2001

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## Useful Links

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**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>
Hollister	0800 678 669	<a href="http://www.hollister.co.nz">www.hollister.co.nz</a>
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.toilemap.co.nz">http://www.toilemap.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>

# Federation of New Zealand Ostomy Societies Incorporated

## Federation of New Zealand Ostomy Societies Incorporated

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### Donations

This magazine is provided free by FNZOS to Ostomates in NZ to help keep you informed of the latest appliances available, along with useful hints and information.

If you would like to donate to FNZOS, or to leave a bequest, it would be much appreciated.

A tax rebate can be claimed for donations of over \$5.

FNZOS account: 12 3011 0809378 00.

Please contact the Treasurer if you require a receipt:

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treasurer@ostomy.org.nz      027 561 2704

### 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

AS KNOWN AT 01/07/21

## Federation of New Zealand Ostomy Societies Incorporated

### Member Societies

#### Ashburton

Sec/Tre	Verna Woods	AshOstomy@outlook.com	027 248 7982	Ashburton
Pre	Dennis Blincoe		03 308 3741	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)

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

#### Manawatu

Tre/sec	Val Rodgers	vmrodgers@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/Tre	Mandy Little	nhos@hotmail.co.nz	021 044 4067	Birkenhead
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#### Northland

Sec/Tre	Margaret Walker	rhys.walker2017@outlook.com	021 123 7799	Whangarei
Pre	Terry O'Meara	terryomeara2@gmail.com	09 432 7351	Ruakaka

#### Otago (incl Southland)

Sec	Sandra Clark	serenitysand@gmail.com	027 270 3053	Dunedin
Tre	Robyn Tourell	tourell.r@xtra.co.nz	027 477 4137	Dunedin
Pre	Phil Elliot	1frostyphil@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	Ngaire Whytock	whyplumb9@gmail.com	021 236 7471	Timaru
Tre	Dave Whytock	whyplumb9@gmail.com		Timaru
Sec	Jill Newton	newtj@actrix.gen.nz	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

# Officers of Affiliated Societies

AS KNOWN AT 01/07/22

## Waikato

Sec	Jan O'Leary	janoiam1st@gmail.com	027 727 2098	Hamilton
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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## Wellington (Including Marlborough)

Sec/Tre	David Barnes	wellington.ostomy@gmail.com	027 472 5148	Wellington
Pre	Brent Hamlin			

## West Coast

Sec/Tre	Thelma Efford	thelmaefford@gmail.com	03 768 6414	Greymouth
Pre	Jean Culling		03 768 7036	Greymouth

## Western Bay of Plenty (including Rotorua, Taupo, EBOP)

Sec	Richard McNair	richardmcnair02@gmail.com	027 474 9812	Te Puke
Pre	Dian Cheyne	ostomybop@gmail.com	07 543 0598	Tauranga

## Whanganui

Sec	Trevor Sammons	trevlinsam@hotmail.com	021 958 758	Whanganui
Tre	Frances Wylie	franwylie49@xtra.co.nz	021 041 8602	Whanganui

## 2023 CONFERENCE AND AGM

Millennium Hotel Rotorua  
1270 Hinemaru Street  
PO Box 1044 Rotorua,  
New Zealand 3010

Friday 8th September 2023 – Executive meeting, Conference registration & welcome

Saturday 9th September 2023 – Conference –

Sunday 10th September 2023 – AGM

Theme is "Bag on, Now What?". We are building the conference round ostomates and their stories. The beginning of the ostomy journey to normal every day life. The struggles and the triumphs. The advice from hard earned lessons.

If you have the courage to get up and share your story, please get in touch with Michael Sumner to register your interest.

Michael.sumner@xtra.co.nz

(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*

## Executive Members

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(A Registered Charity)  
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[www.ostomyinternational.org/newzealand.html](http://www.ostomyinternational.org/newzealand.html)  
OstoMATES NZ [www.facebook.com/groups/237390785093/](https://www.facebook.com/groups/237390785093/)

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OSTOMY NEW ZEALAND (INC.) IS A MEMBER OF THE

