

# YOU Inc. Education Day 24th February 2024 at Nurses Memorial Centre

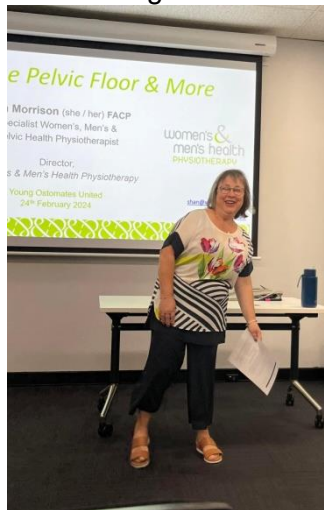
Saturday morning hit and all hands arrived on deck to help set up the room. Everyone rolled up their sleeves to get the tables and chairs out and placed and the food organised.

It was very unfortunate that Lisa was unable to attend as she was ill in hospital. Lilian was also unwell and both ladies were very much missed.

Josie brought a fantastic array of raffle prizes which were presented in a very impressive way. Most people bought a raffle ticket or two which was great considering the effort that Josie went into organising the prizes. Most people brought some food, which Helen (Bonnie's mum) and Katie set about heating up in the kitchen and placing food on plates.

The trade companies arrived and set up their displays. Coloplast, Dansac, Hollister and Omnigon with apologies from FES and Convatec.

Bonnie, Treasurer arranged for a mini eftpos machine which came in handy for cashless people. She also arranged for the event to be successfully streamed on Facebook



Jane Panaccio stood in as MC at short notice for Lilian, YOU is very grateful for her knowledge & expertise.

Josie, Michelle and Bonnie talked about their Ostomy journey necessitating the formation of stomas. This was followed by Lisa's journey, presented by Jane in her absence.

## Michelle

*"My Ostomy journey started approx. 4 years ago; it started with me being on some pretty heavy doses of prescribed medication for an unrelated condition with one of the side effects being chronic constipation. The turning point came when I collapsed one night, taken to hospital, various tests found my bowel was completely blocked being irreparable damaged. An emergency colectomy was performed with an unsited ileostomy. Waking up in ICU it was a shock to hear that I had a stoma, what was that? 6 months post surgery I developed allergies*

*to the pouch/bag I was using but with the help of Stoma District Nurse the use of Manuka Honey with a different pouch my skin has healed and no further issues with leakage. Unfortunately I developed adhesions & since the formation of my ileostomy I have had a minimum of 7 blockages with numerous hospital admissions. Trying to stay positive I have reduced the intake of fibre in my diet which has helped fingers crossed. Recently I had my first holiday flying on a plane, I was particularly scared about leakages in-flight and airport security, I did a few practice runs each time I was stopped by security requesting me to lift my shirt. I requested a private room, a swab was taken from my bag, tested then I was given the OK to proceed. Just to be sure I had a light meal the night before and minimum fluids to reduce number of bathroom visits after four years I am now successfully managing my ileostomy, appreciated the support of my family and close friends. **I refuse to let my stoma rule my life and I am back doing the things I love like walking, personal training and swimming"***

## Josie

*"Hey I'm Josie; I'm 24 and have lived with multiple chronic illnesses my whole life. Growing up in and out of the Royal Children's Hospital my whole life I was suffering with chronic constipation with little to no answers. I've currently got a Mitrofanoff. Ileostomy and a jejunostomy tube. I've got Ehlers Danlos Syndrome and co-morbidities and was born with anorectal malformation."*

## Bonnie

*"My name is Bonnie and I was diagnosed with Ulcerative Colitis when I was 20. I suffered through my 20's but the disease eventually progressed to a point where surgery was my only option. In 2019 I had my colon removed and an ileostomy formed – and my Stomie buddy came into my life. Since then I have had many health wins and personal wins, including getting married and having a baby. I have recently had a JPouch formed and my rectum removed, so my health story is still unfolding."*

## Lisa

*“Diagnosed 2021 with Crohns disease after 8 years of being symptomatic & fighting doctors and hospitals for a diagnosis and always being told it was IBS. In 2012 I was hospitalised with sepsis from perianal abscesses & fistulas. I quickly began a biologic medication (infixamab) which I had a severe allergic reaction to, I was then sent to another hospital for second opinion where I was started on Humira, where I had a similar reaction, then I began to lose my hair and my skin condition worsened. I was diagnosed with Alopecia & lost all my hair.*

*My gastro worked with my dermatologist and rheumatologist trialling a third biologic. This one gave me some relief with my skin and after a year my hair began to grow back.*

*My Crohns and fistula were not settling and the disease was worsening in my rectum. It was decided after a large number of hospital admissions & surgery that I would get a loop ileostomy. This was May 2023. My ileostomy has improved my symptoms significantly and I have been able to get some quality of life back”*

After their talks concluded there were questions from the audience.

Then there was a short break for morning tea and an opportunity to talk to trade company representatives about their products. We also had a chance to talk to other ostomates about day to day management of their stomas among other things. It was great to be able to connect with other people experiencing similar challenges and situations.

After morning tea we had a wonderful presentation from pelvic floor specialist physiotherapist Shan Morrison. She provided much information on the wide role all the different parts of the body plays in maintaining a healthy, well functioning body both prior and post surgery.

## Shan's Presentation

This is just a brief summary highlighting one aspect of Shan's presentation



***Breathing** is something we do all 24hours a day but we need to know how to breathe effectively, being aware of your breathing will assist your pelvic floor and your general health. Think of breathing as the remote control of our automatic nervous system e.g. when you breathe slowly and deeply into your belly you feel calm and relaxed compared to shallow faster breathing following exercise which can heighten tension, pain, muscle tension and anxiety.*

***Breathing and the Bowel:** calm deep breathing stimulates your parasympathetic nervous system, as your lungs expand when you inhale the diaphragm should descend about 10cms which almost has a massage effect on your bowel assisting with emptying, then breathing out completely helps relax the back passage.*

*For more on breathing see this blog on Shan's website*

<https://www.wmhp.com.au/blogs/breathe-your-pelvic-health>

**Shan's contact details:** [www.wmhp.com.au](http://www.wmhp.com.au) Email: [physio@wmph.com.au](mailto:physio@wmph.com.au)

During Shan's presentation I noticed the trade reps shutting up shop and packing away their displays, which was a little disappointing but I suspect it was because the number of attendees was a little low.

After Shan's presentation concluded we had our light lunch and a chat with others.

The raffle was drawn which I believe was a great success and a delight to the lucky winners.

I feel it was a successful event although the number of attendees was a little disappointing. I'm not sure what others think?

A huge thank you to everyone involved including all of the YOU committee and, Helen (Bonnie's mum) Luna (for being so cute!) Katie, Carol, Kath and anyone else.

And, a huge thank you to Helen and Bonnie for arranging the all important last minute insurance at such short notice.

**Compiled by Michelle and Lilian Leonard**