

Report: Returning to my “new” normal presented by YOU Inc. 25th February 2017

Special thanks to Catherine Granger, Senior Physiotherapist in Research and Education at the Royal Melbourne Hospital. Her report is attached including a special handout for members.



Following lunch and an opportunity to check out the Trade Displays Anne Epifanio, an inaugural member of YOU Inc. chaired a small panel discussion; this was the *highlight* of the days' proceedings.

Ros: Diagnosed with Ulcerative Colitis in the early 90's, felt she had it 'easy' because she was only sick for 2 years prior to surgery and formation of a J Pouch, then in the last 2 years diagnosed with Crohns Disease which presented new challenges even though it has been controlled with medication. Ros feels she has coped well but general fatigue seems to be her enemy at present, is it Mental or physical fatigue? Dehydration is always an enemy to be avoided.

Susan: Had stoma surgery in 1988 for Ulcerative Colitis, having her stoma resited in the 90's. Joining YOU as a young person offered a rare opportunity for her to identify and connect with other people. Susan has coped with her ileostomy but despite a supportive husband and a much loved son she has suffered many personal tragedies and was finding life very difficult until she found Meditation. Susan has written a wonderful article titled 'My Spiritual Journey' which will be included on the YOU webpage. Susan feels the toughest part was getting someone to LISTEN & to be able to acknowledge her feelings and that is how meditation has helped.

Andrew: Was diagnosed with Ulcerative Colitis when 19, four years later he had surgery for a J Pouch. This was the first of 50 surgeries in just a few short years, at present he has a loop ileostomy in the hope that his recurrent abscesses close to the pouch will heal so he can have the pouch reconnected. Having a stoma with all these complications has been super challenging, he feels he has been in a "tunnel" in and out of hospital constantly. Initially he struggled with the physical adjustments of having a stoma which was made worse by being unable to work. Everyone present was very grateful to Andrew for "opening up" about his mental struggles, he felt isolated socially and was in the depths of despair. Socially his friends would exchange experiences around the usual happenings in a young person's life, Andrew could not really relate or join in as his life revolved around medical appointments, illness and not working. Andrew talked about the lack of EMPATHY amongst medical professionals, one counselor suggested he went home & did puzzles!! Andrew is now on the upward climb of the 'Grief Curve', but he is adjusting, feels better & more NORMAL.

Following this insightful discussion everyone chatted about their own coping skills, both mentally & physically. One of the attendees was having stoma surgery in a few weeks, she was so grateful for the helpful advice and now felt 'not alone'. Two stomal therapy nurses were also present, I am sure they learnt a lot about assisting their clients, a saying we have always had at YOU Inc. "Anyone can fit a bag but help is needed to cope mentally"

Thank you Anne for your skills as presenter, enabling the panel members to feel comfortable opening up' about these personal issues. YOU Talk continues to help so our heartfelt thanks to Ros, Susan & Andrew.

Special thanks to the committee of YOU Inc. Helen, Anne, Carol & yours truly Lilian