

Coping Mentally with a stoma/chronic illness

Presented by YOU Inc. and the Mitrofanoff Community

29th February 2020

Nurses Memorial Centre

In recent years YOU Inc. has hosted an annual educational day for members, 2020 was different for two reasons. Firstly YOU was combining with the Mitrofanoff Support Group and secondly because YOU was live streaming the event to the YOU Inc. private closed Facebook Page as a trial and at the request of members interstate or in rural areas. Thanks to the enthusiasm of one of our newer members Bonnie, guidelines were set up and signed approval of those that would be videoed, which included the keynote speaker and panel members. It was decided not to use YOU TUBE OR ANYTHING from the G THAT COULD BE STORED AND REPLAYED ON SOCIAL MEDIA.

The guest Speaker Bridgette, who is a Registered Psychiatric Nurse who for the past 17 years has held the position of a senior clinician on a Crisis Assessment and Treatment Team, spoke on the topic of Depression. Some of the points that Bridgette discussed were.

Depression, members of the audience participated in identifying some of the many and varied signs and symptoms

Mood swings(irritability), Sleep disturbances, Lack of motivation, feelings of isolation, decrease in energy levels, weight change (decreased or lack of appetite), Loss of hope (feeling worthless and helpless), Apathy (including decrease in self care), Cognitive changes(lack of concentration and short term memory), Feeling of sadness for more than 2 weeks, Poverty of thought leading to poverty of speech, Anhedonia which means lack of pleasure, Anxiety and panic symptoms (worry, feeling the situation is worse than it is i.e. catastrophizing), and occasionally Suicidal thoughts.

Treatments

Mindfulness(being in the present and tolerating the anxiety)

Breathing exercises

Cognitive Behavioral Therapy: learning how to manage your own thoughts

Acceptance

Medications :such as Anti Depressants, Mood stabilizers, Anti Anxiety meds, Anti psychotics

ECT : Electroconvulsive therapy with approval from the Mental Health Tribunal (6 to 9 treatments usually 3 per week) Patients in Private hospitals do not need the approval of the Tribunal.

Special thanks to Brigette, this is just a short summary of her presentation, she has kindly shared her' Talk' on the YOU Inc. Facebook page and the YOU Inc. webpage.

Following lunch and the opportunity to interact with the Trade Displays the afternoon session commenced

PANEL DISCUSSION and YOU TALK

Prior to the meeting members were asked to write a summary on how they have individually coped mentally with their stoma and or chronic disease, this was compiled into a booklet available to members and online. This is a honest wonderful resource and our thanks for sharing your feelings.

Panel Members

Bonnie who was diagnosed with Ulcerative Colitis at the age of 20, she had an ileostomy constructed in 2018 and has recently been diagnosed with Crohns Disease at the age of 33. Bonnie's main mental health issues have been **body image and anxiety**.

Dave has had an ileostomy for Crohns Disease quite a few years ago, Dave felt that education was the key to coping mentally, **learning the 'how and why' followed by personal interaction with other ostomates**.



Amber a beautiful young lady who has had her stoma, colostomy, since she was 8 years old for slow transit and YOU Inc has been privileged to have had her as a member since then. Now she is happily married with an 8month old baby, DJ pictured. Amber was concerned as she got older about fashion what to wear etc. to combat this she was fortunate to be able to have her stoma repositioned below her waist. Amber has always been honest about her stoma to close friends and found they have always been supportive.

Anne and Declan who was born with Bladder Exstrophy resulting in numerous operations resulting in a Mitrofanoff stoma when he was 7 years old. He now catheterizes his stoma 5 times a day. Declan now 12 started secondary school in 2020, goes on school excursions but does not do sleep over's and is very private about his condition. Declan knows he will have his stoma for life and with Anne's help accepts it



Introducing the panel and with them openly discussing their mental health and anxiety issues enabled members of the audience to open up about their concerns, this is what we call YOU TALK. Thank you to everyone sharing your anxieties and challenges, not only the ostomates present but carers of younger people and children who have specific problems and concerns.

The day concluded with parents of children with Mitrofanoff explaining this relatively new urinary procedure which helps preserve kidney function.

Special thanks to Justin who video streamed the guest speaker and panel discussion, Paige who worked endlessly in the kitchen, Ros the YOU Treasurer, Julie and Anne from the Mitrofanoff Group, and last but not least Helen the 'engine room' of YOU Inc.



Compiled by Lilian Leonard OAM

Bonnie, Justin, Tony, Ros & Amber