

YOU Inc. Committee Meeting with Victorian Stoma Nurses via Zoom 25/05/23

Attendees: YOU – Lilian, Helen, Anne Paton, Julie S (Pres of Mitrofanoff Group), Anne Epifanio **Apologies:** Bonnie, Aimee & Josie

STN's - Rebecca Howson (Cabrini- Pres. of Vic Branch AASTN), Joan, Freya (both from the Colostomy Association), Carmen (RCH), Felicity (Peter Mac - Sec. of Vic Branch AASTN) Andrea (OAM& Coloplast free clinics)

Lilian with Rebecca chaired the Meeting

Anne Epifanio mentioned the aim was collaboration between the two groups which was agreed to by all.

AGENDA

1/ Summary of concerns from parents of children & adults with Mitrofanoff stomas

YOU: Julie spoke about the frustrations with the lack of knowledge re these newer types of stomas not only from stoma nurses but other medicos, even some urostomy consultants have no knowledge. Julie as President of the Mitrofanoff states all 140 members of the group have similar experiences, despite to her knowledge Mitrofanoff was first performed in the 80's. Further concern was as these children transition to adulthood and leaves the paediatric hospitals; there is no knowledge to assist. Anne Paton reiterated with similar experience with her 15yr old son.

Another concern is that these children/young adults require psych support; a funding model incorporating mental health is required.

Confusion regarding funding for supplies? NDIS OR Stoma Appliance Scheme.

STN'S: Rebecca advised that majority of stoma nurses have had very little experience apart from those in the paediatric environment.

Carmen, who is also on the Education Committee of the AASTN said she would bring this up at their next meeting in an effort to make it part of stoma education. Strongly endorsed by all present. Carmen encouraged YOU to check out the Children's Hospital website on Mitrofanoff.

*Soon there will be no funding for Mitrofanoff through the NDIS.

2/ Skin Care and follow up appointments post discharge. [OBJ]

YOU: On the YOU Facebook Page there are constant enquiries for leaking appliances leading to skin problems and psychological trauma. Ostomates on discharge not given sufficient information re follow up care.

STN'S: The Colostomy Association of Victoria provides a Free Stomal Therapy Nurse Clinic twice a week always on a Monday and one other day (often a Thursday). These are conducted by Joan & Freya. No referral required but appointments are necessary, Rebecca will send YOU the specific link to go on the YOU Facebook and Website. <https://www.colovic.org.au/contact-us/>

Victorian Private Hospitals *usually* provide post discharge stoma consultations. Monash Health do not offer post discharge stoma support.

For ostomates travelling around Australia check the AASTN Nationwide website 'Find a Stoma Nurse'? OAM Stoma Nurse Andrea Farrugia no longer conducts stomal therapy face to face clinics only online or phone.

However Coloplast has assisted by providing clinics throughout Melbourne Suburbs for stoma reviews by Andrea, once again Andrea will send YOU the referral link. Andrea emphasized the ostomate does not need to use Coloplast products & will not be pressured to use their products

<https://www.coloplast.com.au/care-services/care-clinics/>

3/Hernia Education, particularly in the early days of stoma formation &? prevention of parastomal hernias.

YOU: This is an ongoing issue with ostomates, particularly demoralizing with younger ostomates, do they require a support garment post op, many new parents question picking up toddler/ baby, also with their type of employment?

STNS: Felicity discussed these issues, very difficult to prevent despite good siting there are predisposing criteria unfortunately no matter what type of prevention they can still occur. Abdominal Support garments should not be fitted until the ostomate is 6 weeks post op & it is imperative they are measured by a stomal therapy nurse. * **Omnigon has reported from 30th June 2023 boxer shorts and support briefs will be taken off the Stoma Appliance Scheme. This needs to be confirmed**

4/Diet: It is a concern that post stoma surgery when they get home eat anything and then have blockages

YOU: Question does the new ostomate see a dietician prior to discharge, so many claim they can eat anything post op and develop blockages, YOU encourages them to have a bland diet for a few weeks post op, gradually adding new foods. Remembering that majority of the ostomates in YOU have ileostomies. What do the surgeons tell their patients? Do they need educating?

STNS: Rebecca answered on behalf of the other nurses, all ostomates with an ileostomy are seen by a dietitian and are given a dietary education including printed information sheet prior to discharge, questions that at the time of discharge the patient is so overwhelmed with information that they have no memory recall, please encourage members to read all the paperwork. There is AASTN Dietary Pamphlet available on the AASTN website. <https://stomatherapy.au>

5/ Wastage of Products

YOU: Because of early discharge patients are fitted with a permanent appliance too early, stoma shrinks in the next few weeks resulting in new sizing ordered resulting in wastage of supplies, can the stoma nurses fit new patients in a cut to fit and educated to get a review in 4 weeks. Prevents wastage and protects peristomal skin. YOU sends excess appliances to Uganda, with the assistance of the AASTN, there is strict criteria with only drainable or urostomy pouches eligible. [OB]

STNS: Rebecca—due to lack of follow up will not adequately explain ongoing ordering to ensure new ostomates have sufficient supplies but try to tell patients that is your maximum order not monthly order. There is a Stoma Appliance Scheme Criteria; ostomates in rural areas tend to over order which is understandable. Freya & Joan who work in the Colostomy Association send excess appliances to PNG & other 3rd world countries.

YOU Inc. is very grateful to Rebecca and her team meeting with some members of the YOU Committee, our main aim is to be a support group to our members by liaising with the stoma nurses we can openly discuss some of our challenges, thank you and we look forward to further discussions but an invite is available to join YOU at any of our functions.

AASTN Victorian Branch is celebrating Stomal Therapy Week in June, YOU is providing large flyers, Practical Hints booklets & 'Did you know' leaflets.

Minutes compiled by Lilian Leonard OAM, Committee of Young Ostomates United Inc.