

## LETTER FROM THE CHAIRMAN

*Hi Everyone,*

Hope everyone is feeling good, I cannot believe the long nights are back with us already it seems like a very quick year, and it only felt like yesterday that we were getting the patio furniture out ready for the summer season. I did get away in September for a short break to Portugal with my better half Frances and it was lovely just to chill beside the pool for a few day and have a glass of wine. I had no problems going through Dublin or Faro Airports with my Ostomy Supplies, I was flying Aer Lingus and they give you an extra allowance for all your Medical Supplies once you are checking your bags in. just carry what you need for the flight in your shoulder bag,

### WHAT A GREAT DAY WORLD OSTOMY DAY

I would just like to thank Mark for all his hard work putting the Conference together in DCU for World Ostomy Day on the 2nd October. I know a lot of people were still a bit nervous about meeting up in groups, but I think with all the planning and support we received from DCU made the day a great success, Thank you to Kevin Reynolds from the Dublin group, Tony Connolly from my own group the Drogheda Northeast group and Frank Norris from the Wexford group for all their help during the conference day. Thank you to all the Ostomy Companies who attended on the day and staged an exhibition of Ostomy products. It was great to see dedicated people helping to improve the lives of Ostomates either by just having

a chat with them on the day or by recommending them a new product that can help them lead a better and more fulfilled life.

It was great to see the launch of our new Booklets and Travel Cert on World Ostomy Day, if anyone has not received them and would like a copy, please contact our Secretary Mark and he can post them out to you,

I do think that we sometime become balsa about our stoma's and forget about how difficult it was for the people before us and how much they had to fight to get all the appliances that are now available on the Irish market and we must keep up the good work so people in 20 years' time have a better selection and a better quality of life than what's available now.

I am looking forward to the festive season this year and meeting up with family and friends over the period, I will be missing a few people from my own family this year which can also be a sad time, my own group Drogheda and Northeast Area will be meeting up in early December for a brunch and I am looking forward to meeting everyone again.

Just remember if you can help one person with the knowledge you have from your journey, why not help

STAY SAFE  
PAUL



# CHRISTMAS DUBLIN OSTOMY ONLINE MEET UP



Meeting ID 7391633220

Password 1606

## 8th December 7pm

Line Up

7pm -720pm Laughter Yoga with  
Cathy

720-740 Vanilla Blush

740-8pm Coloplast Nurse on  
stoma Care in Winter

& difficulties of rich foods over  
the Christmas Season

8pm-820 Guest Speaker Keith  
McCracken (Provisonally)

820-840 Anne From Dotera oils  
on alternative Theraphies

Finish Up

Next Meeting Will be advised  
for Inperson



Caraldine Nolan  
0851191803 Dublin Ostomy  
Association Co-ordinator

## SECRETARIES REPORT

Hope you all had an enjoyable summer and even though many Covid restrictions are still in place we are hopefully soon going to be able to hold Local Ostomy Support Group Meetings again early in 2022. Covid has changed many things in our lives and how we now do things. Despite 90% of the population having been vaccinated twice and the booster campaign is under way, we are still seeing large numbers of new cases of people infected with Covid. Hopefully we have reached the peak of the current wave of infections and by early December hopefully numbers of people infected with covid and in hospital will reduce considerably. We are all looking forward to being able to celebrate Christmas this year after last year's lockdown.

Some of the Local Ostomy Support groups have managed to hold meetings where it was possible to have social distancing but many members are still nervous to attend. Some groups have successfully organised Zoom Meetings, and several groups have active WhatsApp groups for members communication. Covid has for many of our members opened new means of communication, but we still have many members who do not have smart phones or communicate by email. We are now in a new era of digitalised communications, and we are hoping with the support of one of our corporate sponsors to be able to upgrade and make communication more digitalised

and easily accessible during 2022 with a redesigning of the OAI website. Over the past two years many of our members have told us they are happy to access Ostomy Ireland News in PDF format from the website. There is no problem receiving a hard copy of the journal even if we have your email ID and we send you a newsletter by email. We will continue to send newsletters by email to our members.

World Ostomy Day on 2 October 2021 was celebrated in DCU, St. Patricks Campus and our one-day Conference was a great success despite the restrictions and limitation imposed on numbers being able to attend. The venue was easily accessible by Public Transport and from the M50 approaching Drumcondra from the northside of the city. Facilities were excellent and spacious for the companies to exhibit their range of Ostomy Products and Auditorium for the Conference. The date of the next Public Meeting is tentatively scheduled for Saturday 5th or 12th March depending on Covid restrictions again in DCU, St. Patricks Campus, Drumcondra, Dublin 9. It is proposed that an AGM would be held in the morning for paid up members. Exhibition by Ostomy Companies would be from 12noon to 2pm and the afternoon meeting open to all Ostomates, (Membership of OAI not required to attend the afternoon meeting ), Family and Friends are also welcome to attend the afternoon session and exhibition by Ostomy Companies



from 12 Noon. From 2pm to 4pm there will be a presentation by a panel of speakers on topics of interest to Ostomates. Thanks to everyone for renewing their membership for 2021. Our Database of members is now updated and is GDPR compliant.

Enclosed in this issue is a membership renewal form for 2022. It will also be online on the Website from mid December 2021. If you are renewing your membership by EFT payment through the Bank or by PayPal, please complete the form and post it to the Treasurer, OAI, 6 Marian Place, Tullamore, Co. Offaly, R35 KD78. It is required for GDPR compliance and confirms your contact details.

**PLEASE DO NOT RENEW MEMBERSHIP FOR 2022 BEFORE 1 January 2022.**

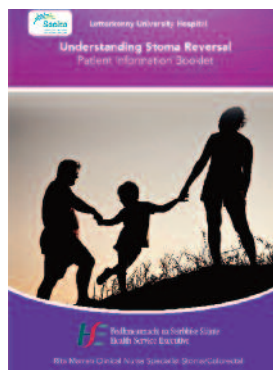
**Thanks.**

If you did not complete the Survey Questionnaire sent out in September and you still have it, please complete, and return ASAP. It is also available online now on the website and can be completed and submitted online. It will be analysed in early February and results published in the Spring issue of Ostomy Ireland News. We hope to meet with Minister Anne Rabbitte, Minister of State at the Department of Health with responsibility for Disability in March 2022. We need as many ostomates as possible to complete the Survey/Questionnaire, so we have as much up to date information on the lives of Ostomates as possible when discussing issues of concern

to you, our members with the Minister. The entitlement of Ostomates to have a MEDICAL CARD due to their Lifelong medical condition needs to be pursued. Despite the limitations of COVID in 2020 there were 2123 Ostomy Surgeries performed last year– 893 were Colostomy, 1087 were Ileostomy and 143 were Urostomy. No figures are given in the Stats for the number of Internal Pouch Surgeries performed and very limited information on the number of Ostomates who had Reversal Surgery.

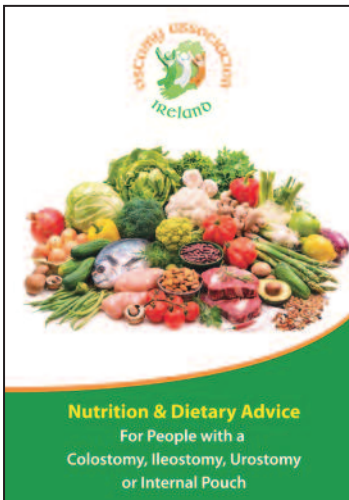
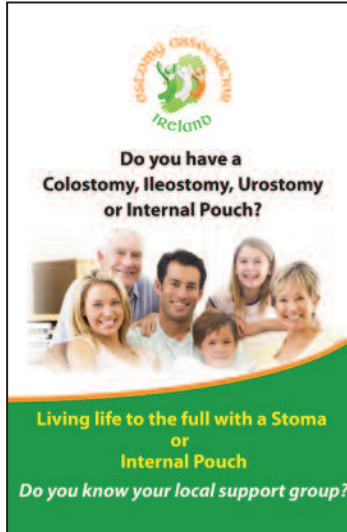
I hope everyone can celebrate with family and friends this Christmas in a safe environment and look forward to hopefully a New Year which despite the concerns we still have about COVID, we will be able to meet up again in our Local Ostomy Support Groups safely once more and as Ostomates celebrate Life to the Full with a STOMA.

*Take Care and Stay Safe*  
**Mark**



*If you would like to receive a copy of this booklet on reversal surgery please contact the secretary.*





*If you would like to receive a copy of  
any of the above information booklets  
please contact the secretary.*



# Stoma Solutions



## Odour

**LiftPlus 360 Citrus:** a fresh citrus scent for added discretion

**AbsorbaGel:** solidifying agent to minimise odour\*

**DeoGel:** enzyme action helps to reduce pouch odour\*



## Skin Issues

*Check the fit is snug around the stoma to help prevent skin issues<sup>1</sup>*

**Lift Plus Wipes** and **LiftPlus 360:** help to reduce the pain associated with the removal of stoma pouch adhesives

**Lift Plus:** can be used to help remove any sticky residues left on the skin around a stoma

**Skinsafe:** an effective barrier film that helps protect the skin and prevents skin stripping



## Leakage & Noise

**AbsorbaGel:** fast acting discharge solidifying agent, which solidifies stoma output into a gel and reduces pouch related noise and leaks\*

**Skinsafe:** a highly effective barrier to help protect the peristomal skin



## Pancaking

**DeoGel:** lubricates the pouch walls and helps prevent static problems such as pancaking, with the nozzle allowing for simple application to the inside of the pouch



## Order information

**LiftPlus 360 (50ml spray):** order code 5506

**LiftPlus 360 Citrus (50ml spray):** order code 5507

**LiftPlus sachets (30 per pack):** order code 5502

**LiftPlus spray (50ml):** order code 5503

**Skinsafe (50 wipes per pack):** order code 6600

**AbsorbaGel (150 sachets per pack):** order code 9900

**DeoGel bottle (200gsm):** order code 2010

**If problems persist, consult your Stoma Care Nurse or GP**

For further information or samples, please contact: Sheila Sweeney RGN/ RSCN  
SCN (Stoma Care Nurse) sheila@opus-healthcare.ie 0667181636

\* Not intended for urostomy patients

Reference: 1. Stoma Complications <https://www.bladderandbowel.org/bowel/stoma/stoma-complications/>  
Last accessed July 2020. Code: JB-000371. Date of Preparation: July 2020

 **ALLIANCE**

## *"Ostomates' Rights Are Human Rights - Anytime & Anywhere!"*



**Speech by Jon Thorkelsson  
President Of The European Ostomy Association  
At the World Ostomy Day Conference - 2nd October 2021  
of the Ostomy Association of Ireland.  
Dublin City University, St. Patrick's Campus, Dublin 9.**

Mr. Chairman, members of OAI and other distinguished guests.

It is a great honour for me to be asked to address you on this occasion and I thank you for that. Most of us here are ostomates and one great thing in the existence of ostomy organisations is the World Ostomy Day or WOD which is celebrated on the first Saturday of October every third year. That has been done since 1993 when WOD was initiated by Gerhard Englert who at the time was president of IOA. So today is the big day. We in the EOA-EC were made responsible to choose an appropriate motto for WOD this year and our final decision was, Ostomates rights are human rights – anytime and anywhere“. But why this motto – isn't everything alright in the world of ostomates, do we really need to fight for basic human rights ? And YES, sadly we do ! People in many countries of Africa and Asia don't have any appliances at all, they get operated and then have to rely on foreign aid to get appliances. And there are more places where appliances are not basic human rights, we can point to some places in America and also here in Europe, people have trouble getting appliances. Even in Scandinavia people are not treated completely right and those countries are supposed set the example on good treatment for patients of all kinds worldwide. In many place in Denmark and Sweden you only get one type of appliances, whether that type suits you or not. COPA, the Danish Organisation puts out newsletter every two months and in the July-August version this year the Danish chairman writes a serious complaint on this. This shows very clearly that ostomates need to stick together and help each other. The World Ostomy Day is a perfect tool for that.

But there have been many mottos in the past; I particularly like 2012's Lets be heard and 2018's Speaking out changes lives. I'm not a very open and outspoken person about my feelings and health but when I became an ostomate in 1995 I decided to be open about this to anyone who wanted to know something about my life as an ostomate and I have tried to run both the Icelandic Ostomy organization and EOA in context with those two mottos. Even before I heard them. But there have been others like the one from 2006 Living life to the full, and what is stopping us to do exactly that other than our own mind ? NOTHING, we are perfectly capable as we are.

But an organisation like yours is nothing without the people who put in countless hours to make it work. So I take off my hat to celebrate all of you who have worked day and night for the benefit of your organization. New ostomates need to be taken care of, new information and appliances need to be introduced to ostomates, health workers sometimes need assistance, politicians need to be pressured a little bit to make the right decisions, the number of jobs that need to be done are beyond imagination so please keep up the good work. Only in that way the world will be fit to take decent care of ostomates in the future.

Your organisation is a fairly new one and has recently applied to be accepted as a member of the European Ostomy Organisation. I was hoping that this could be accepted at our conference in Italy later this month. Sadly we had to postpone the conference one more time so it will be held in April next year. And there is no doubt in my mind that on this occasion you will have completed all the preparation work to fulfill all the requirements to become members. I look forward to seeing your representatives in Garda and to witness the acceptance of your membership. The more we are in numbers the stronger we get.

Thank you.



## Charter of Ostomates' Rights

The Charter of Ostomates' Rights presents the special needs of Ostomates and the care they require. They have to receive the information and care which will enable them to live a self-determined and independent life and to participate in all decision-making processes. It is the declared objective of the International Ostomy Association that this Charter shall be realised in all Countries of the World.

### ***The Ostomate shall:***

1. Receive preoperative counselling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.
2. Have a well-constructed stoma placed at an appropriate site, and with full and proper consideration to the comfort of the patient.
3. Receive experienced and professional medical support and stoma nursing care in the preoperative and postoperative period both in hospital and in their community.
4. Receive support and information for the benefit of the family, personal caregivers and friends to increase their understanding of the conditions and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.
5. Receive full and impartial information about all relevant supplies and products available in their Country.
6. Have unrestricted access to a variety of affordable ostomy products.
7. Be given information about their National Ostomy Association and the services and support which can be provided.
8. Be protected against all forms of discrimination.
9. Receive assurance that personal information regarding their ostomy surgery will be treated with discretion to maintain privacy, and that no information about their medical condition will be disclosed by anyone possessing this information, to an entity that engages in the manufacture, sales or distribution of ostomy products, nor shall it be disclosed to any person that will benefit, directly or indirectly, because of their relation to the commercial ostomy market without the expressed consent of the ostomate.







**Speech by Anne Rabbitte, TD, Minister of State  
with Responsibility for Disability.  
At the World Ostomy Day Conference - 2nd October 2021  
of the Ostomy Association of Ireland.  
Dublin City University, St. Patrick's Campus, Dublin 9.**

Good afternoon, I'm delighted to have the opportunity, on behalf of the Minister for Health, Mr. Stephen Donnelly, to address you all today. I would also like to thank the Ostomy Association of Ireland for their kind invitation to launch World Ostomy Day. There are approximately 2,000 ostomy surgeries performed in Ireland on an annual basis. Given the number of people and their families affected by this, I wish to acknowledge the commitment shown by the Association to working in partnership with medical professionals, ostomy companies and stoma care nurses to enable ostomates living in Ireland to enjoy an improved quality of life.

I recognise that the Association has faced a challenging time since its inception on 1 January 2019, and especially during 2020 as it was unable to hold any public meetings due to the Covid-19 pandemic. I acknowledge that local support groups were also unable to hold in-person meetings.

I am pleased to note that some organised WhatsApp groups and Zoom meetings for their members. This is a wonderful illustration of their determination to support each other. A key objective of health care reform is the exploration of how to contribute most successfully to the health and wellbeing of patients. Sláintecare, the healthcare reform roadmap, aims to ensure that the right care is given at the right place and the right time. It also seeks to ensure that as much health care as possible is delivered in a community setting.

In that regard, the establishment of the **Ostomy Visitor Training Programme** is a prime example of community-led healthcare at its best. I believe it will play a key role in ensuring that ostomates, and their families, are fully supported during the post-surgery rehabilitation phase. I wish to thank the Association for developing this programme. I note that several information booklets have been published and these endeavour to provide practical advice and information for all those affected. I am sure that these booklets will provide a valuable reference point for all ostomates and their families.

Finally, I would like to recognise that the Association has plans to grow the number of support groups that operate locally and to increase its partnership with all those who work with ostomates. I wish you success in these plans. I wish to thank you for the opportunity to speak with you this afternoon and hope you will enjoy the rest of the conference.

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## ConvaTec -

### Team of Dedicated Stoma Care Nurses

The ConvaTec Team of Stoma Care Nurses led by Caroline Cord – ConvaTec Ostomy Services Lead Ireland together with her colleagues Darina Jennings and Paula Kennedy provide a most valuable service of stoma care in the community. They provide advice, support and guidance for Ostomates and also for their Families and Carers.

### Want help, support or just someone to talk to?

We are here for you. You can get in contact by phone on 1800 721721 or email on [stoma.webcare@convatec.com](mailto:stoma.webcare@convatec.com) If you would like more information about any of the services in this article, just visit on of the websites below:  
[www.convatec.ie](http://www.convatec.ie)  
[meplus.convatec.co.uk](http://meplus.convatec.co.uk)

The contact details for the ConvaTec Team of Stoma Care Nurses and the geographic areas they provide a service in Ireland and their contact details are:



**Caroline Cord** RGN/SCN

*Ostomy Services Lead Ireland*  
 Ostomy Division. Republic of Ireland  
 Tel **086 245 3849**  
 email [caroline.cord@convatec.com](mailto:caroline.cord@convatec.com)

**Areas covered**  
 Carlow, Cork, Kilkenny, South Tipperary, Waterford and Wexford.



**Darina Jennings** RGN/SCN

Senior Territory Manager  
 Ostomy Division. Republic of Ireland  
 Tel - **086 853 8421**  
 email [darina.jennings@convatec.com](mailto:darina.jennings@convatec.com)

**Areas covered**  
 Galway, Mayo, Roscommon, Leitrim, Sligo, Donegal, Clare, Limerick, Kerry, North Tipperary, Longford, Westmeath.



**Paula Kennedy** RGN/SCN

Senior Territory Manager  
 Ostomy Division. Republic of Ireland  
 Tel **086 854 3642**  
 email [paula.kennedy@convatec.com](mailto:paula.kennedy@convatec.com)

**Areas covered**  
 Dublin, Louth, Meath, Cavan, Monaghan, Offaly, Laois, Wicklow, Kildare.



*"Ostomates Rights are Human Rights  
- Anytime & Anywhere!"*

**World Ostomy Day  
2 OCTOBER 2021**

This year was the 10th occasion that World Ostomy Day was celebrated around the world by Ostomates. The theme this year for World Ostomy Day was

*'Ostomates' Rights Are Human Rights – Anytime & Anywhere!'*

Despite the restrictions in being able to find a venue the Ostomy Association of Ireland were delighted that Dublin City University were willing to allow us to hold a one-day Conference in the St. Patrick's Campus in Drumcondra, Dublin 9. Numbers were restricted to 100 people including Ostomy Company representatives. Covid certificates were required, Face Masks, Hand Sanitising and Social Distancing. The spacious Auditorium which can hold 800 people was a safe space for the Conference and the spacious foyer beside the Auditorium allowed the

Ostomy Companies sufficient space to distance their stands from each other and allowed Ostomates to be able to freely move around and visit the stands to ask for advice and obtain samples of products.

*Paul Hughes,  
Chairman OAI*



The morning session of the conference was opened by Paul Hughes, Chairman OAI, who welcomed everybody and introduced Madeleine Grant,

*Madeline Grant  
Co-Ordinator  
OAI -  
Ostomy Visitor  
Programme*



who is an Ostomate, Qualified Stoma Care Nurse, RGN, has an MSc in Bereavement Studies and is an Accredited Play Creative Art Therapist, and she has a Diploma in Integrated Counselling & Psychotherapy. Madeleine is also a member of OAI. Madeleine was approached to be the Coordinator of the Proposed **OAI OSTOMY VISITOR PROGRAMME.**



Madeleine gave a presentation on the proposed Prospectus which has been drafted by the OAI after looking at numerous Ostomy Visitor Programmes which have been designed by other Ostomy Associations throughout the world. The First Ostomy Visitor Programme was launched on World Ostomy Day back in 2006 by the International Ostomy Association - IOA. The Visitor Programme which has been designed by the Canada Ostomy Society in 2019 is the template the OAI has used in designing an Ostomy Visitor Programme to be used here in Ireland by OAI members who wish to become qualified as OAI OSTOMY VISITORS.

Madeleine outlined the content of the Prospectus and how the Visitor Programme would work. It is proposed to establish 5 Panels of qualified OAI Ostomy Visitors who would have successfully completed a OAI OSTOMY VISITOR TRAINING WORKSHOP. All OAI Ostomy Visitors will be required to have Garda Clearance before they can visit another Ostomate under the Visitor Programme. GDPR guidelines are

an integral part of the Visitor Programme. The 5 Panels for Ostomy Visitors would be – DUBLIN, LEINSTER, MUNSTER, CONNAUGHT, and ULSTER. OAI have established a working Group to examine the proposed Visitor Programme and the Proposed Prospectus which outlines the Mission Statement, Goals and Objectives of the Training Programme. The working Group include HSE Stoma Care Nurses who are members of the ISCCNA, Ostomy Company Stoma Care Nurses, OAI Ostomates many of whom completed the Visitor Programme organised by the Ileostomy and Internal Pouch Association UK here in Ireland.

*Cepta Burke*



Cepta Burke who was for 24 years the secretary of IA Ireland, gave a presentation on her reflections about the value and need for a National Visitor Programme. She spoke about her involvement in organising Visitor Training Programmes in Ireland which were also attended by IA members



from Northern Ireland. Despite many members training as Ostomy Visitors many Ostomates who qualified were never approached to speak with another Ostomate. Cepta spoke about the many times she had the opportunity to speak with another Ostomate and to help them come to terms with having a stoma and give them the encouragement to be able to live life to the full. As an Ostomate you can share with others how you have coped with a stoma and are able to give hope to others when they see how you are able to live your life and can enjoy yourself being able to play a game of Golf and live life to the full.

As an Ostomy Visitor you do not give medical advice that is for the medical professionals who provide us with Ostomy care. As an Ostomy Visitor there is no substitute for the visual proof another ostomate receives when they meet or come in contact with another well-adjusted Ostomate who is cheerful, attractive, and living with an Ostomy. Ostomy Visitors come in various shapes and sizes, ages, and sex.

They may be models, businesspeople, athletes, doctors,

nurses, homemakers, young and old alike, but they all have the common bond of having undergone Ostomy surgery and are now living productive and happy lives. Cepta said this was how the success of the OAI OSTOMY VISITOR PROGRAMME should be perceived.

*Anthony Connolly*



Anthony Connolly who is an Ostomate and the Coordinator of the Drogheda & North East Ostomy Support Group spoke about his experience being in hospital shortly after his surgery and being terrified and wondering how he was going to be able to have a life again. He was asked would he like to speak with another Ostomate, and he said he would. He told the delegates how he waited for the day this Ostomy Visitor would arrive to talk with him. He wondered what he would look like. Would his pouch be visible? Would he be wearing normal clothes? The day came and the ostomy visitor came to see him. The first thing he noticed was he looked





totally normal. You could not see any pouch. He asked him many questions all of which he answered for him without any hesitation. Then after maybe a half hour of talking with him, his Ostomy Visitor left, and he felt totally reassured and comfortable when leaving hospital. He says he did not ask his visitor his name and until this day still does not know who he was. Anthony said there are so many Ostomates who would love to have had the opportunity to speak with another Ostomate either before or after surgery. Having Local Ostomy Support Groups where Ostomates can come together and socialise in a pleasant environment is wonderful.

*Caraldine Nolan  
Co-Ordinator  
Dublin support  
group*



Caraldine Nolan, the new co-ordinator for the dublin group, spoke about the challenges of establishing a support group in the Dublin area. Caraldine spoke about the dedication and effort in establishing the Dublin group by Melissa Lyons, who due to work and family commitments, was no longer able to continue as the

co-ordinator. Caraldine spoke of the geographic challenges in finding a suitable venue for local meetings and that the Dublin group had now become such a large group, maybe two venues for meetings, one north side and one south side need to be looked at. Hopefully when Covid restrictions ease in the new year, a public meeting for the Dublin group can be organised, so members can decide on what they would like. Caraldine said she had a successful zoom meeting recently with the Dublin group, and that this may become an important means for communication in the future for members.

Mary McLoughlin Coordinator spoke about the Sligo Ostomy Support group which this year is celebrating 21yrs in existence. Mary spoke about how the group started in a small way initially with the support of Susan Moore, the HSE Stoma Care Nurse in Sligo University Hospital. Susan still provides support to the group. Mary explained they meet in the Sligo Cancer Support Centre on Wine Street in Sligo. They organise many functions – Quiz nights, Annual Dinner Dance, and



numerous outings. They have around 60 members. This year despite COVID restrictions she said they had a very successful outing where they visited Knock Shrine on their way to the Connemara Coast Hotel near Spiddal, Co. Galway, where they spent the night and had a fabulous meal followed by a night of great entertainment provided by the group themselves. Next morning, they took the ferry to Inis Mor Aran island. It was a beautiful day and many of the group visited Dun Aonghasa, a spectacular fort on the cliffs at Inis Mor. The group then returned to Sligo and enjoyed a lovely meal on their way back to Sligo.

Mary also mentioned that through many of their fundraising activities they also share what money they raise with the Sligo Cancer Centre. Mary said she would be happy to visit any of the new Ostomy Support Groups recently established or new ones which it is hoped will be launched next year once Covid restrictions allow us to be able to meet again and talk to them about the activities of the

Sligo Ostomy Support Group. The presentations were followed by a short discussion and questions and answer session.

*Glen Doherty*



The next presentation was by Glen Doherty, Consultant Gastroenterologist. St. Vincent's Hospital, Dublin 4 and the UCD, School of Medicine. Glen gave a presentation on a research project he is undertaking, and has asked the Ostomy Association of Ireland to become collaborators with the Project which he hopes to launch early next year. The Project is called TOAST – IBD Study (Treatment related Outcomes Associated with Stoma in IBD). The research project is about developing core outcome measures for intervention studies in Ostomates with IBD who have Stomas. Glen explained that most trials involving people with IBD health issues exclude Ostomates. The TOAST – IBD research project will involve Ostomates/ Nurses / Doctors and interviews with Ostomates. There will be a systematic review of



scientific publications. Outcomes will be measured and once a final list is agreed it will be validated to see can we measure them and then Verification will be sought to see do the outcomes change with treatment. There will be a detailed article in the next Issue of Ostomy Ireland News in which Glen will explain the research project and the involvement they are hoping for from Ostomates who are willing to participate in the research project.

The Ostomy Association of Ireland are very happy to be collaborators with this research projects and hope many of our members will get involved.

Mark Sheehy  
Conference  
Organiser  
Secretary OAI



The morning session then concluded with Mark Sheehy, Conference organiser and Secretary of OAI making a presentation with some preliminary results from the recent Survey/Questionnaire after analysing the responses from 150 respondents to the Survey/Questionnaire. The questionnaire is still available now on the

website. If you received the Survey/Questionnaire and have not yet returned it do so, ASAP in the Prepaid Post Envelope. It can be also completed on the website and the responses will be immediately recorded in the Database of results for each question. *Some of the responses analysed were as follows –*

Reason for surgery  
Ulcerative Colitis, Bowel Cancer, Crohn's, and Colorectal Cancer were the 4 main reasons necessary for Ostomy Surgery in 2020.

67% of respondents said their stoma was permanent.

69% of respondents said they had an Ileostomy.

21% had a Colostomy

6% a Urostomy and

4% had an Internal Pouch.

73% of respondents said their Quality of Life had improved.

53% of respondents said they had a visit by a company Stoma Care Nurse to their home.

58% said it was easier to have a visit with a company Stoma Ostomy Care nurse than trying to visit an Ostomy Stoma Care Nurse stoma care in a hospital.



Because of Covid it is now not possible to visit people in Hospital due to visiting restriction.

86% respondents said they had trouble obtaining Ostomy supplies from Pharmacies.

64% Respondents said they were interested attending a meeting in their local Pharmacy on information concerning their Quality of Life with a Stoma.

65% of respondents said they did not believe their GP was knowledgeable concerning Ostomy surgery.

87% of respondents said they would have liked to have spoken with another Ostomate before and after their surgery.

58% of respondents said they were interested in the OAI

#### OSTOMY VISITOR PROGRAMME.

62% respondents said they had never been told or advised about a National Ostomy Association or about Local Ostomy Support Groups by any medical professional.

92% of respondents said they had found it very helpful meeting with other Ostomates.

97% Ostomates responded that all Ostomates should be entitled to a

Medical Card because having a Stoma or Internal Pouch was a Life Long Medical Condition.

53% of respondents said they had a medical Card.

89% of respondents would like to see signage on toilets for the disabled in public places, Restaurants, Hotels etc stating that not all Disabilities are Visible. And were also accessible to Ostomates.

76% of Respondents said they had private Health Insurance.

71% of respondents said they felt they were IT - Information Technology knowledgeable.

38% respondents said they had a Smart Phone, 28% a Laptop, 22% a Tablet, 9% Desktop and 3% none of these.

When asked how members communicated out of 150 respondents 136 said they used WhatsApp and 131 said they also used Emails, 69 also used Facebook and 68 also used Zoom, 24 also used Instagram and 14 also used Twitter.

The three most preferred ways of communicating indicated by respondents was



33% by Post, 33% by Email.  
21% by WhatsApp Messages,  
13% by Mobile / Landline.  
66% of respondents said they  
were happy to receive Newsletter  
by Email and access the Journal in  
PDF format from the Website.

18% respondents said they were  
very healthy, 65% said they were  
healthy, 14% said they were not  
well and 2% said they were very  
unwell.

54% of respondents felt they were  
Fit.

58% respondents said they would  
have liked to have spoken with a  
dietician before leaving hospital.  
85% they would have liked to have  
had a discussion with a Dietitian  
before leaving hospital.

87% respondents said they were  
presently on a Diet.

Respondents declared they also  
had other medical conditions  
which were as follows –

25% Heart Problems,  
17% Diabetes, 16% Asthma,  
8% Blood Pressure and  
35% said they had other Health  
Problem conditions,

A Full report of the results of the  
2021 Quality of Life Survey/  
Questionnaire will be published in  
the next Issue of Ostomy Ireland

News. If you have not already  
completed the Survey/  
Questionnaire please do so before  
31 January 2022. The more  
information we have when we will  
meet with Minister Anne Rabbitte  
, TD, Minister for Disability in the  
Department of Health to discuss  
Ostomy Care in Ireland and how  
having a Stoma affects the lives of  
Ostomates.

The afternoon session of the  
conference was opened by Paul  
Hughes, Chairman OAI.

The President of the European  
Ostomy Association EOA  
Jon Thorkelsson addressed the  
delegates by Video. Text of his  
speech is printed separately in  
the journal.

Anne Rabbitte, TD., Minister of  
State at the Department of Health  
with responsibility for Disability  
also made a video presentation  
address to the delegates. Text of  
her speech is printed separately  
in the Journal.

These speeches were followed  
with the presentation and launch of  
the three booklets OAI  
produced this year with the  
collaboration of  
two of our Corporate Social  
Partner Sponsors.



The first booklet launched was – Living Life to the Full with a Stoma or Internal Pouch. Every year more than 2000 people in Ireland receive Ostomy Surgery in Ireland. It is hoped that every new Ostomate will receive a copy of this booklet before they are discharged from Hospital.

The second booklet was Nutrition and Dietary Advice for Ostomates which was produced in collaboration with Coloplast and Marie Sheahan the senior HSE Dietitian in gastrointestinal surgery and critical care at Cork University Hospital.

The third booklet was Going on Vacation – Holiday Advice for Ostomates which was produced in collaboration with ConvaTec. A Travel Certificate in 16 languages was also launched together with the booklet.

After the launch of the booklets there were presentations of Certificates of Appreciation for three people who had made major contributions to improving the quality of Life for Ostomates over the past 50 years.

The First Presentation was made

to Mr Tom Eakin of T. G. Eakin Ltd., for his pioneering research work in developing Ostomy products for Ostomates. The Eakin Seal together with a wide range of appliances and other Ostomy products are exported all over the World and help to make the lives of Ostomates easier. Mr Eakin made a pre-recorded Video acceptance speech.

*Mark Sheehy &  
Gerry Nally*



The Second presentation was a Posthumous Award to Liam Murray, Murrays Pharmacy on Talbot Street, Dublin 1, for his dedication and support to Dr Paddy Leahy in the early days of Ostomy Care in Ireland back in the 1970's. The award was accepted on behalf of the Murray Family by Gerry Nally who was secretary of IA Ireland back in the 1990's. Gerry then made an acceptance speech on behalf of the Murray Family and spoke about Liam Murray and Dr Paddy Leahy in those days of Ostomy Care in Ireland when





the life of an Ostomate was very difficult and different to how it is today.

*Mark Sheehy &  
Cepta Burke*



The Third presentation was to Marianne Doran, HSE Stoma Care Nurse who retired from Beaumont Hospital last year. Marianne was also a past Chairperson of the ISCCNA. Marianne was one of the first nurses who specialised in Ostomy Care, 50 years ago there was not the range of Ostomy products which are available for Ostomates today to be able to Live Life to the Full. Ostomy care back in the 1940's and earlier was very primitive and basic and one can easily understand why so many Ostomates in those circumstances lived lives like Hermits hidden away, with little or no contact with other people – Family members, Neighbours and Friends.

Thankfully today we live in a very different world. Marianne helped so many people during her time as a Stoma Care Nurse at Beaumont Hospital and contributed greatly to the lives of so many Ostomates. Cepta Burke accepted the Certificate of Appreciation for

Marianne and in her acceptance, speech spoke about how much Marianne had contributed to improving the standard of Ostomy Care in Ireland. Marianne was also Cepta's Stoma Care Nurse after her Ostomy Surgery.

Mark Sheehy thanked everyone for coming especially during the difficult times in which we are living due to the Covid Pandemic. Mark thanked DCU and especially Brian Kavanagh the Events Manager and Coordinator for holding Conferences in DCU. The venue and the facilities were excellent and both Delegates and representatives from Ostomy Companies expressed their delight with DCU's St. Patricks Campus as a venue for future meetings of the OAI.



**"Ostomates Rights are Human Rights  
"Anytime & Anywhere!"**



Jamie Alcock & Nicola Dames  
*Vanilla Blush*



Madeline Grant & Frank Norris



Akshay Bhujbal, Kevin Reynolds, Paul Hughes



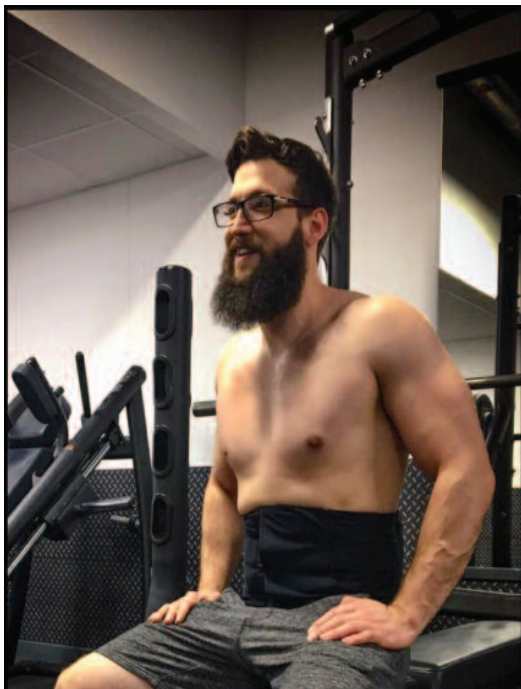
Caraldine Nolan & Sandra Farmer



Sandra Farmer & Rory McNichol

## **World Ostomy Day Conference at DCU**

St. Patricks Campus,  
Drumcondra, Dublin 9  
2nd October 2021



**Our Support Belt  
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**For further information:  
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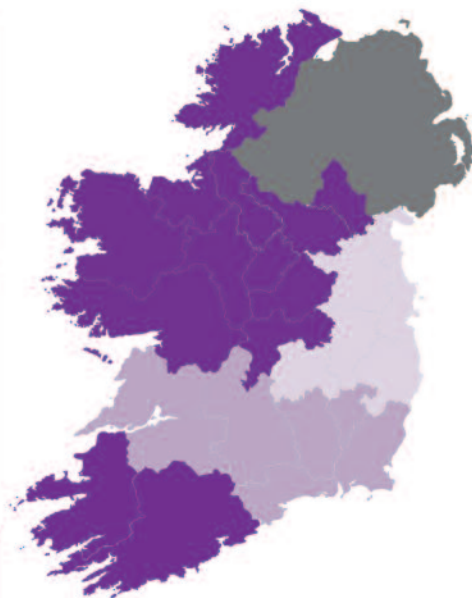
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## MY LIFE, MY STOMA CARALDINE NOLAN



Hi My name is Caraldine Nolan and I am the new Co-ordinator for the Dublin Ostomy Association after Melissa stepped down due to family commitments. The Dublin Ostomy Support Group needed a new coordinator and I put my name forward as I felt I would like to help the group in organising meetings, get together's and to be able to help other Ostomates given that I had such a positive experience with my ileostomy.

I have suffered with my bowel all my life really; I had my 1st operation when I was 8 and had the same operation done twice more unsuccessfully. I have a medical condition called atonic bowel. I had a very bad time after an operation to peel a large cyst off my ovary that had stuck to my bowel and left me basically with a dormant bowel. I tried a lot of methods and medications but when clean prep was stopping to work, I knew I was in a bother. After the operation I spent 2 years in and out of hospital in persistent pain and vomiting. On May 20th 2018, I had to have an emergency Ileostomy. Although I was on the list to have elective surgery for a bag, I ended up having mine done as an emergency under Dr Prof Neary.

Since having my Ileostomy bag my main issues is low blood pressure. I really have never looked back since having my surgery. I was losing weight just before my operation and continued



to do so after it. However, I went on to become a Weight Watchers Coach, a job I absolutely love. Before my bag I would not have been able to become a Weight Watchers Coach as I was quite sick. Now I am able to hold in person and virtual meetings. Although not everyone will know I have an ileostomy bag it does not stop me in my everyday life.

I am not the only person in my family to have a bag. My Son Declan, who is 10 yrs old, has the same condition as myself and now has a bag. Declan having a bag at 10yrs of age ,20 years earlier than myself, which to me screams out the condition worsens through generations in my family. It was a tough decision to make as a mother to agree to give Declan an Ileostomy. As a mother you always want what is best and a miracle cure. But just like my story as all medical efforts were exhausted, I cried when I agreed for it to happen. Why I am not sure as I did know the life changing experience it was for me. Declan had his

ostomy surgery done in December 2020 and this too has been a life changing experience for him.

My reason for joining the Ostomy Association was to show Declan and other Ostomates that there is support available and that having an Ileostomy, Colostomy, Urostomy or Internal Pouch is not the end of the world, in fact in many cases it is only the beginning to be able to have a quality of life again and to be able to live Life to the Full. I have probably taken more care of myself Physically & Emotionally since getting the bag. I do not let too much phase me to be honest and I would like to show Declan and others that life, can be successful with this invisible disability.

For me once I began to feel well again, I had other things to worry about like finding myself again outside of the hospital environment. I am no fashion guru, but I do like to feel I am dressed up so when I first got the bag I was





completely overwhelmed when I started looking at what clothing I could wear. I set up a page for to show ladies some clothes for Ostomates that are in fashion. It is called @fashionostomy on Instagram where I show clothes, and products to help us along the way.

Although I am a member of the Ostomy Association of Ireland, it is a little different for me as an Ostomate and also having a son Declan who also is an Ostomate.

I felt I knew no one who was also a parent of a child with a bag. I have since set up a group in which there are 12 Mammys with children with stomas around Ireland helping and supporting each other. This is very important to me as not all children will have a Mammy with an ostomy like Declan. While I now enjoy working, Declan now enjoys being able to be part of different groups such as coding and robotics and he absolutely loves swimming. Jamie Alcock from Vanilla Blush got him some swimming trunks

and now he is like a fish in water. This is the first time in 10 years we are not on an admission list to be admitted to the hospital. That is a very nice feeling.

For my family having an ileostomy bag in both cases has given us life, it has taken us from a comfort zone of a hospital setting to find out what we really love to do. It has given us independence and we no longer look at the stoma bag as a disability , but more as an ability to be able to do so many things we could not have dreamt of doing before now.

***The world will be forever  
our Oyster.***

*Take Care and Thanks  
Caraldine*





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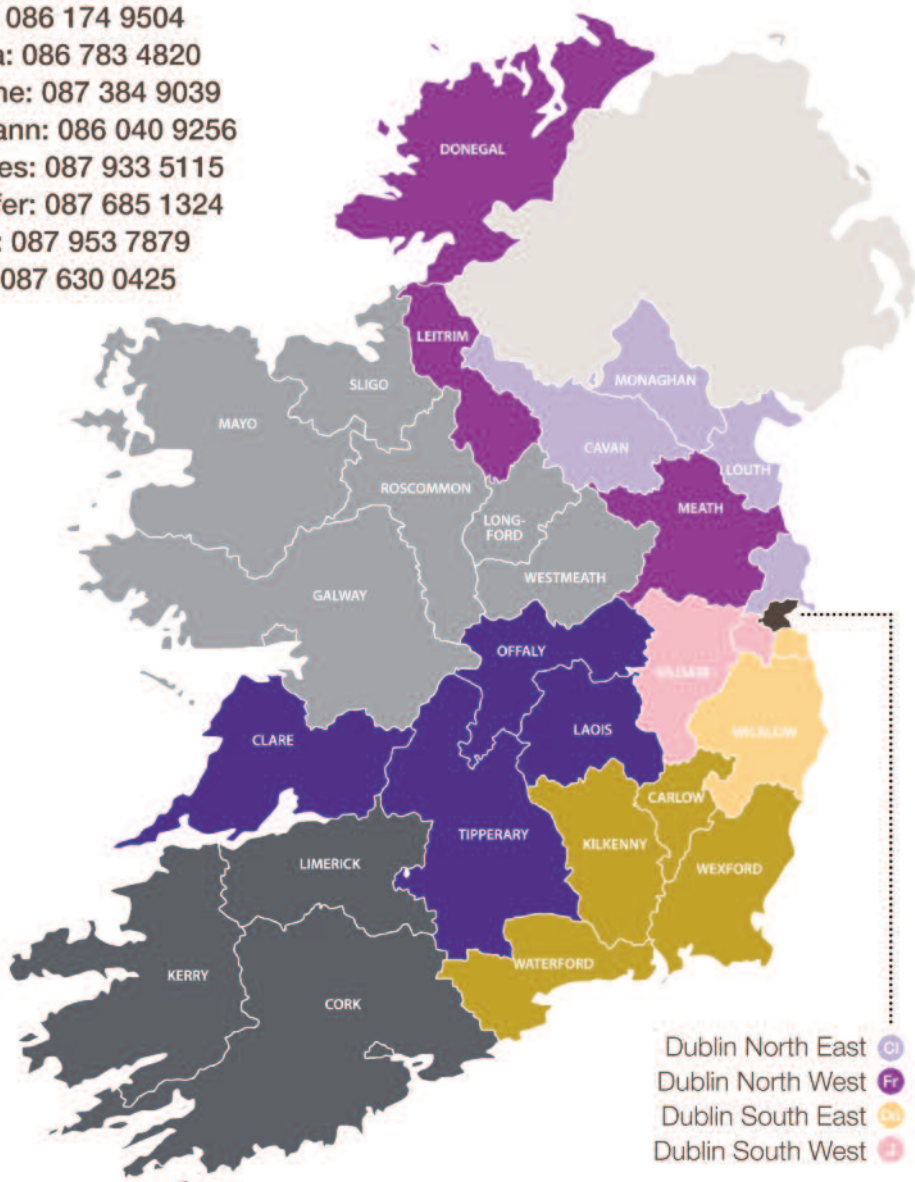
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# Stoma Care Nursing Service

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## MY LIFE, MY STOMA CLAIRE STEWART



My name is Claire Stewart, and I am 36 years old. I live in Mountmellick, Co. Laois. My story begins in 1999 when I was 14 years old, and I was diagnosed with Crohns Disease. It took about 18 months to be diagnosed. I was suffering with symptoms of abdominal pain, acid reflux and vomiting after every meal and losing weight. My GP initially questioned if I had an eating disorder, as I was a young teenage girl. This was really upsetting to me at the time as I did not want to be getting sick.

I was referred to Crumlin Children's hospital and was seen by a gastroenterologist. After multiple tests and scans and x-rays I was put on a long-term course of steroids as it was suspected I had IBD. Being on the steroids long term resulted in masking my pain. I had developed a duodenum ulcer which perforated. (Burst a hole in my stomach). As my pain was masked, I did not know anything until the day it burst. I will never forget the pain of that very long day. When I was brought to Crumlin, they quickly diagnosed what had happened and performed emergency surgery to repair my stomach. After this surgery I developed infections and spent 3 months in Crumlin recovering.

The next few years of my teens were managed by a multitude of medications to keep symptoms of my Crohns under control. When I turned 18 my care was transferred to Tullamore regional hospital where I still attend the same gastroenterologist. Over the years my Crohns has flared up occasionally but was



monitored with routine endoscopes and colonoscopies and MRI scans.

I have been on pretty much every medication available for my Crohns flare ups. My symptoms at this point had developed into mucus and bloody diarrhoea and urgency in needing the toilet. I had lost weight and was put on weight supplement drinks to try help me gain weight.

2018 began my longest flare up that I could not get under control or get much relief. My urgency worsened and I was admitted to hospital after a colonoscopy in 2019 which showed a stricture (narrowing) of the large bowel close to the rectum. This was the first time the possibility of surgery and a stoma were discussed with me. I was devastated and hated the thoughts of having a 'bag'. The surgeon was willing to let me try a biologic medication infliximab to try buy me some time, before possibly needing the surgery. I spent the next 6 months on this treatment but got no relief from the symptoms and developed infection after infection and because of having to take lots of antibiotics, my immune system was so low,

and I picked up everything. Eventually in January 2020 I was admitted to hospital for emergency surgery. The plan was partial resection of my large bowel giving me an ileostomy. I felt so happy that my 2-year flare could be coming to an end, and I could start living again instead of surviving. I met with the stoma nurse, and she marked out where to place my ileostomy. She explained all about ileostomies and about emptying the bag. I felt prepared. The following day I had the surgery and woke up smiling. I had no Crohns pain, I could not believe it. I also discovered I had a colostomy not an ileostomy as planned. This was a decision by the surgeon to try and leave as much bowel as he could for a possible reversal in the future.

I have named my stoma Winnie, *(as in Winnie the Pooh!)* I picked his name after first meeting with my surgeon in 2019. *(I love Disney).*

When I got home and was recovering, I researched to see if there were any support groups for people with stomas. While the stoma nurses and family





and friends support were great, I wanted to meet other ostomates with a stoma. This is when I found the Ostomy Association of Ireland and the Tullamore group had a meeting the following week. So, 5 weeks after I had my stoma surgery, I went along to meet everyone at the Tullamore group, who meet bi-monthly on the second Wednesday in the Dochas Cancer Day Centre from 6.30 – 8.30pm. I am looking forward to returning to in person meetings once Covid restrictions allow Local Ostomy Support groups to be able to meet up again.

My recovery was going well, and I had adjusted to changing my bag. Then with covid and lockdowns my follow up care became phone calls and emails. This was quite helpful in that I could send pictures to my consultant of my stoma if I felt there were any issues. After 4 months of having my colostomy, I started to develop skin irritation. Between my GP, stoma nurse and consultant I was prescribed pastes and topical steroids and barrier creams. I was having lots of leaks and this further irritated skin

around my stoma.

Eventually I ended up going back into hospital as after assessment I had developed a large abscess around my stoma site. This was repeatedly drained. It was believed my Crohns had developed on my skin coming from my stoma.

I had a scope done through my stoma and it was recommended to try a further biological treatment – vedolizumab, to try and get Crohns under control enough so they could operate again. The plan was to remove the remainder of my large bowel. I met with pre op team and stoma nurse beforehand and my surgery was scheduled for 2nd March 2021.

My second surgery was a total colectomy and I discovered they had also removed my appendix at the same time! I felt sore when I woke from surgery, but only where my old stoma was. I had a new ileostomy, Winnie 2.0 new and improved. I was left with an open wound that needed to be packed and dressings changed every day. I developed an infection in this after 3 weeks as it was healing too quickly leaving a pocket of puss.



A course of antibiotics cleared this up and it was fully healed to skin level in 3 months. I am still on vedolizumab infusions for my Crohns every 5 weeks and managing my stoma well with no issues.



I am starting to have a Quality of Life again to be able to Live Life to the Full again.

I attended my first ostomy event on 2nd October 2021 on World Ostomy Day in DCU. I met some lovely ostomates and really enjoyed the day. It was also great to see most of the Ostomy companies exhibiting their ostomy products and their stoma nurses were there to give advice and be of support to ostomates attending the conference.

*Thanks for reading my story,  
take care.*

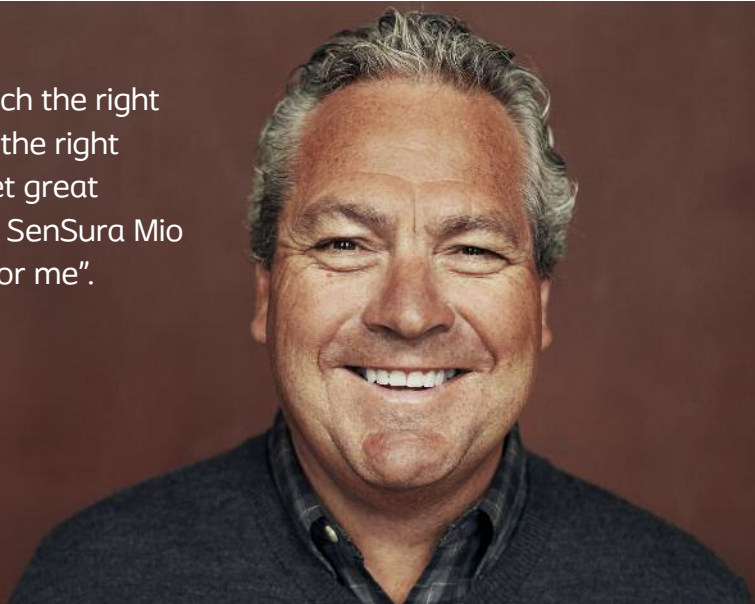
*Claire Stewart*

I love Winnie my ileostomy for giving me my life and independence back. Since having my stoma surgery I have started kayaking, this is something I never would have dreamed of doing before for fear of needing the toilet urgently while out in the water. Winnie really has helped me to be more confident and try new things.



"When you match the right body type with the right product, you get great results, and the SenSura Mio has done that for me".

Mike



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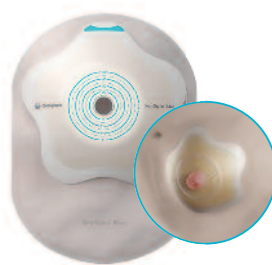
SenSura Mio is the worlds leading ostomy product - from the elastic adhesive on SenSura Mio, our three unique levels of convexity, through to the fit zones on SenSura Mio Concave - these are all examples of BodyFit Technology and demonstrate that when we innovate – we have you and your needs at the heart of every decision we make.



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# Christmas with a Stoma

*Hints & tips to make the most out of the holiday season*

## Can you drink alcohol with a stoma?



It is possible to drink alcohol with a stoma, but as always be responsible. People with a stoma can get dehydrated easier, and drinking alcohol can make you dehydrated, so make sure to drink enough water, especially if you're off dancing the night away!

## Eating out at restaurants with a stoma



If you are going out for a meal with friends, a lot of restaurants will have their menu online, so search for the restaurant's website to check ahead for suitable menu choices. Most places will cater for different dietary requirements so don't be afraid to ask for your food to be prepared in a certain way.

### TIP - Where to go?

A good idea is to start with a restaurant you know well and keep it simple when ordering. There is no need to be too cautious, just be practical. Order what you want but be aware of how certain foods make you react. Also, don't be afraid to ask the waiter what ingredients are used for the meals.

If possible, you may want to order a type of food that you have already tried at home first so you know how you will be likely to react. As you slowly eat more and different foods, you will feel more confident when eating out as well. Even if you are used to having a drink at home, it could be best to 'start small'. For example, drink a small beer rather than a large one. This

will help your body build up your tolerance to alcohol again and help reduce – or completely avoid – any reactions.

**TIP** - Marshmallows can help thicken your output, which may be helpful if your output is particularly loose.

**TIP** - Avoid anything with dried fruits like raisins/sultanas, currants/peel as they can cause blockage of the stoma. (All the nice Christmas treats unfortunately!)

**TIP** – Christmas time brings the temptation of those richer foods which we can often be guilty of overindulging in. To avoid episodes of pancaking or ballooning, try to take your time chewing and ask for smaller portions

## Minding your mental health at Christmas

Christmas time can be a difficult period for many people. Different years bring with them different challenges, and if this year has been a difficult one for you, make sure you mind your mental health this festive season.

HSE Health & Wellbeing has launched a free, online mental health and wellbeing programme called *Minding Your Wellbeing*. This evidenced based programme, focusing on the promotion of mental wellbeing, has been adapted from a face-to-face programme into a series of online videos for everyone at this time.

What does the programme consist of?

Consisting of 5 video sessions (20 min) which can be accessed via [www.hse.ie](http://www.hse.ie)

The content focuses on:

### 1. Practicing Self-Care

Explores the importance of individual 'self-care' and encourages participants to build their own 'self-care toolkit' which includes healthy habits for their mental health and wellbeing

### 2. Understanding Our Thoughts

## *Hints and Tips to make the most out of the holiday season.*

Invites participants to reflect on their own thinking and consider how thinking patterns can impact wellbeing

### **3. Exploring Emotions**

Encourages participants to notice their emotions and increase their positive emotions to improve their wellbeing

### **4. Building Positive Relationships**

Discusses ways in which participants can nurture, value and foster positive relationships which are so important for mental wellbeing

### **5. Improving Our Resilience**

Invites participants to improve their resilience, learn about the building blocks of resilience including the importance of focussing on strengths

This provides a unique opportunity for everyone to learn and practice key elements of mental wellbeing such as mindfulness, gratitude, self-care and resilience.

Please do not hesitate to contact our nursing team on the details overleaf or on [nurseteam@coloplast.com](mailto:nurseteam@coloplast.com) should you have any queries or questions on keeping well over Christmas.







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## LOLE BOLLARD FUNDRAISING EVENT



In Memory of my Aunt Dolores Bollard who everyone called Lole a Fundraising appeal was organised in her Memory in the hope of obtaining an AED machine to be installed in a public place in Rush north county Dublin. Lole's maiden name was Weldon and she was the youngest of 9 children. 7 years ago she became unwell and was rushed to hospital with a blockage in her bowel which led to sepsis and major surgery. This resulted in her having ostomy surgery and having an ileostomy procedure which saved her life. Last year she decided to go for a reversal and after numerous cancellations she was called for reversal surgery. After her surgery she seemed to be recovering well but shortly afterwards she became quite

unwell. Her family was called for and she passed away 4 days later. Lole was only 55. She was a mother of 4 children, her son John Daniel unfortunately was born stillborn. She had twin boys Jamie and Brian and a daughter Clara. She was full of life and fun and always cared for everyone including her mother until her death in 2018. She was active in fundraising for St John's Ambulance and Rush Community First Responders as her children are involved with these groups. Her son Jamie is a Superintendent for Swords Division of St John's Ambulance and is also a Paramedic for the National Ambulance Service.



My name is Fiona Crosby and together with some family members we decided to organise a fundraising event in her memory. Due to Covid restrictions it was decided to organise outdoor activities a 5k walk and a Sea swim.



The swim in particular was an outstanding success where together on a beautiful summers evening with family members and members of the local community the great swim took place.

*Plaque  
donated by  
Pierce Memorials  
Swords*



We had originally hoped to raise €1000 to enable us to buy a new AED machine and place it outside her family home. However, within a day we had already passed this target with nearly €2000 euro being donated. We continued fundraising and a total of €4264 euro was the amount raised in the end. The Community of Rush really came together. Because the fundraising events were more successful than we had dreamed my cousins and myself decided to purchase two AED machines. One was a top of the range AED Machine, which has been placed outside her family home and the other AED machine was donated to the Rush Community First Responders.



*Lole's husband Des and children, Jamie, Brian & Clara, and members of the Weldon & Bollard families.*

There was still money left over after purchasing the two AED machines and it was decided by the families to divide it between charities that were close to Lole, the St John's Ambulance, Hampton Clinic Balbriggan, and the Ostomy Association of Ireland.

Lole's sister Tina was in hospital having surgery on her Bowel resulting in an Ileostomy at the same time as Lole's untimely death. This really resonated with us all and is why we chose the Ostomy Association of Ireland to also be a beneficiary and the sum of €420 euro was donated.

The Bollard, Crosby and Weldon families wish to thank the Ostomy Association of Ireland for the work they do in supporting Ostomates and their families in Ireland to be able to live Life to the Full.







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