# OSTOMY IRELAND NEWS

Quarterly Journal of OAI



# Ostomy Association of Ireland

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### LETTER FROM THE CHAIRMAN

Hi Everyone

I want to wish you all a belated Happy New Year and I hope everybody had a good 2019 and wish you all a very good 2020 despite concerns some you may have because of Coronavirus.

2019 was a historic and challenging year for the Ostomy Association of Ireland. We took the leap and established our own all Ireland association for Ostomates.

We saw 6 new support groups up and running during the year and I would hope we can further strengthen our support groups during 2020 and possibly get a few more support groups established that we had hoped would have been established during 2019.

WE also launched our own Ostomy Ireland News and printed 3 Issues during the year. I would like to thank those of you who sent in your stories for My Life My Stoma for members to read. Many members are encouraged when they read the challenges you have faced.

I would like to acknowledge the Corporate sponsorship which we received from some of the Ostomy companies it was very reassuring for us to have that support in our first year as we took a new approach as we endeavoured to strengthen the Association and support all ostomates. The costs involved were quite considerable.

I am conscious that there may have been more we could have done during the year and accept that getting everything right is not always achievable especially in our first year. We need us all working together to grow the association. There are over 2500 people who have stoma surgery each year statistics have shown us for the past 3 years.

The support of Stoma Care Nurses who have attended our support groups around the country is greatly appreciated and we look forward to strengthening our working relationship with the Ostomy companies and all Stoma Care Nurses HSE and Companies so together we can improve the quality of life of people with a stoma or internal pouch. Travelling around the country during the year and attending many local group meetings was most encouraging. I would ask members to renew their subscriptions for 2020 and thank those of you who also generously include a donation when renewing your annual membership. Regrettably our secretary Mark was not in good health from October and is awaiting surgery soon he hopes and as a result we did not print a winter issue of Ostomy Ireland news. We have decided considering the cost involved we will print 3 issues in 2020 - Spring, Summer and Winter. Our Spring meeting which was to be held in the Ashling Hotel, Parkgate Street, Dublin 8 on Saturday 21 March 2020. Format as usual Companies in attendance from 12 Noon to 2pm followed by AGM meeting at 2.30pm. I looked forward to a big attendance and meeting many of you again. Regrettably the metting had to be cancelled due to Covid 19 and will be rescheduled as soon as its safe following HSE guidelines.

Best wishes for 2020 Paul

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### SECRETARIES REPORT

2019 was a year of celebration as the Ostomy Association of Ireland was established representing all Ostomates living in Ireland, members who had a Colostomy, Ileostomy, Urostomy and Internal Pouch. It was made possible through the support we received from our members and the generous support we received from the Ostomy companies who became Corporate sponsors.

We successfully launched and printed 3 issues of our own Irish Journal – Ostomy Ireland News. It was encouraging to receive articles from our members for inclusion in the section My Life My Stoma. I hope that more of you will consider writing your own stories and sending them to me to be printed in future issues of Ostomy Ireland News.

One of the other successes we achieved during 2019 was the printing of the Medical Travel Card. This card was the result of the efforts of our PRO Kevin Reynolds who liaised with Jean Piggott the Access Officer at Dublin Airport and who kindly sponsored and printed the laminated cards for issuing to our members. If you have not received one of these cards please let us know.

Due to my ongoing difficulties with my health it has been a challenging time for me since June 2019. My reversal surgery which I had at the end of November 2018 has unfortunately not been a success and I am presently waiting to have surgery again and this time I will have a Colostomy pouch. I was very much restricted in how much time and work I was able to give to the association and I was grateful for the support and assistance Melissa Lyons the

assistant secretary was able to undertake. I hope to be called for surgery soon once the Covid 19 emergency is over and be back to my full capacity to work.

Due to not printing a winter edition of our iournal members were not issued with renewal notices for their annual subscription. Members are requested to please renew their membership subscription now and complete the membership form when renewing your subscription. It is most important that the membership form is accurate and legible so that information of Name.Address.Eircode.Contact details and email if you have one can be clearly read. Many of you also make a donation when renewing your membership and this is very much appreciated and is a great help towards the costs of administration of the association.

Please send completed membership forms along with Cheque or Postal Order to The Treasurer, Ostomy Association of Ireland, 6 Marian Place, Tullamore, Co. Offaly, R35 KD78.

Some of you have already renewed your membership for which we are grateful and please disregard this notification for renewal of Membership subscription.

Membership subscriptions should be received by 30 April 2020. If you wish to pay your membership by EFT online, our bank details are as follows:



### **Account Name**

Ostomy Association of Ireland **Branch**Bank of Ireland, Tullamore **Sort Code**90-19-19

Account Number 26207296

IBAN Code

IE42 BOFI90190926207296

**BIC Code**BOFIIE2D

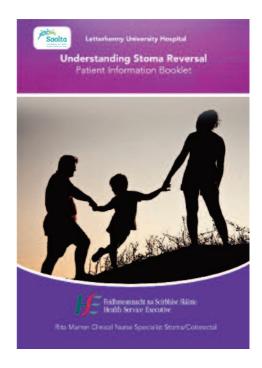
It is most important when renewing your membership by EFT that your name is clearly identified with the payment and you either send a copy of the completed membership form by post or by email. Our Spring Public meeting was to be held on the 21st and two more proposed meetings during the year are on hold until we get advice from the HSE that it is ok to reschedule our meetings.

I wish to thank you all for your encouragement and support during the past year and look forward to us being able to strengthen the association during 2020 by increasing our membership and the establishment of more support groups throughout the country.

Take Care Mark

# Membership Renewal can also be completed by logging on to:

https://forms.ge/c3ghYRNvsedhXaVS7



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



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Which Surgery you had:
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Date of Operation:
Reason for Surgery:
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# EXPLORING GRIEF AND LOSS FOLLOWING STOMA SURGERY THROUGH THE CREATIVE ARTS



Play&Creative Arts Therapy



Madeline Grant

I am a stoma nurse and a Play/Creative arts therapist. I also have a stoma myself. Through my work and personal experience I realise that grief and loss often follow in the wake of illness and surgery. I developed creative arts workshops with another therapist to provide a safe space for people who have stomas to explore their emotions around illness/surgery and life with a stoma.

The majority of people adapt both emotionally and physically to life with a stoma but a significant number of people struggle and may even become socially isolated.

People with a stoma often feel ashamed. We do not want to empty our bag in any public place or in a friend's home for fear of the smell, so we may avoid meals out, travel etc.

It is very easy to become isolated. We can become trapped in our own story, our own thoughts. Loneliness is not always the physical absence of people around us it is the sense that we are not sharing anything that matters with anyone else. The workshops bring people together and it is not just the sense of being heard that is important but also the sense that we can help others by relaying our experience.

### **GRIEF**

Grief is a topic that has come up in many forms during the workshops. We feel guilty about feeling sad when it is expected that we should be feeling grateful - because a person is often thought to be 'cured' following surgery, permission is often not deemed to be given to grieve post operatively. Grief for the 'what if's '.

Those around us see surgery as the solution to a problem, it is, but some feelings of loss/anxiety may need

to be expressed and acknowledged. People may empathise with us immediately post op but 6 months, 12 months down the line they might lose interest and yet this is the time the reality of what is lost can often set in.

However, it can be hard to openly acknowledge what has happened as a stoma is not something people necessarily want to talk about or hear about either!! Stoma bag leaks and smells are not easy things to discuss. More often than not we would prefer others not to be aware of our stoma.



Sample of Items Made at Workshops

The fact that we may feel less 'sexy'/ sexual is also something people have difficulty talking about. Therefore finding the words and finding the right situation to talk can be difficult.

Research shows that the loss suffered due to body image change or post op complications can leave us with high levels of distress, anxiety and depression - even more so than those who have suffered an actual bereavement. Dr Ken Doka called this grief disenfranchised grief – a loss that occurs which we have difficulty talking about and therefore may not receive the support that we need. One of the ways we can prevent grief from becoming disenfranchised is by exploring the grief we feel and by expressing our emotions around it. The workshops are offering people a safe space to delve into their emotions around illness, the trauma of surgery and living with a stoma. Sharing in a group of people who have been through something similar - you realise you are not alone.

The creative arts aids with expression and focuses people on their emotions rather than just the practical issues of living with a stoma. Being with people whose life circumstances mirrors our own and who have the same anxieties and emotional issues and seeing how they deal with these issues can give us new solutions to our problems.

### **EMBODIMENT**

Peter Levine (a renowned expert on Post Traumatic Stress Disorder) describes how our thoughts are guided by our senses and emotions. All of our experiences (stresses, injuries and traumas) shape our bodies. He also discusses how our physical life and feeling life depend on embodiment.



Sample of Items Made at Workshops

Embodiment is how we are and the way we are in the world and how we perceive the world to be. So it is how we live. He emphasises the importance of making direct personal contact with the body's innate capacity to feel, to heal, to know. We need to get to know our bodies. The creative arts therapies can help us to do this.

The creative arts aids with expression and focuses us on our emotions rather than just the practical issues of life with a stoma. The workshops involve the creation of something in the presence of another. This emotional holding and containment is fundamental to the process. We all want to engage fully in our lives. Sometimes people just need a leg up and that is what these creative workshops are offering.

### For more information please contact:

wicklowcreativeartstherapy@gmail.com

Ph: 087 298 1642

Madeleine Grant RGN, Accredited Play/Creative Arts Therapist, MSc Bereavement Studies





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### MY LIFE MY STOMA



Seamus Kiely & His Wife Maureen

My name is Seamus Kiely from New Ross, Co.Wexford. I am 75 years old. Like many Irish people in the 1950's and 1960's I took the boat and emigrated to England in 1961. I went to, London and after 5yrs returned to Ireland in 1966 and started work in the ESB. After working 32yrs in the ESB I retired in April 1999. In 2008 after having a Colonoscopy I received the news that I had Colorectal Cancer. The surgeon requested to meet me along with my wife Maureen after the procedure in his consultancy room. He outlined to us what the Colonoscopy examination had shown.

I had a cancerous tumour low down in my colon close to my anus and following surgery I would have a Colostomy pouch. Because my tumour was so low down in my colon he advised that reversal surgery would not be an option. The surgeon then outlined the procedure for my surgery which involved me having both Chemotherapy and Radiotherapy prior to

my major surgery. The purpose of the Chemotherapy and Radiotherapy was to shrink and kill the tumour which took time.

He told me he would perform my surgery at the end of October. He also explained that after my surgery I would also undergo a period of Chemotherapy. I firmly believe that my mother passed on a positive mental attitude to me and this helped me get through the tough months ahead. The toughest part of all the procedures I found was towards the end of my radiotherapy sessions and also after having my surgery was getting used to having my Colostomy Pouch (Bag). It took time and patience but with the loving support of my caring wife Maureen and family and some wonderful friends I not only made a good recovery, but I also lead a full and active life.

My busy life now in music as an entertainer sees me singing solo and also involved with two choirs, producing shows and giving historical talks in Wexford and Dublin. Most important of all having a Colostomy pouch has not stopped me travelling to many exciting places in the world.

I hope that what I have written will be a help for all Ostomates and especially for those of you who have had cancer and I wish to say how much it helps to be positive and remember that life is still worthwhile if you just smile. Finally my own doctor was a huge help to me and helped me through the duration of my recovery from cancer. We had some laughs as well and he gave me the following monologue.

# Cancer with a sense of Humour

I wish I had the voice of Homer To sing of rectal carcinoma Which kills a lot more chaps in fact Than were bumped off when Troy was sacked.

Yet thanks to modern surgeon skills It can be killed before it kills Upon a scientific basis In 19 out of 20 cases.

I noticed I was passing blood Only a few drops not a flood So passing on my homeward way I asked a doctor now my friend To peer into my hinder end.

To prove or disapprove the rumour That I had a malignant tumour The microscope returned the answer That I had certainly got cancer

So I was wheeled into the theatre Where holes were made to make me better Through this incision I don't doubt The Neoplasm was taken out

Along with colon and lymph nodes Where cancer cells might find abodes A third much smaller hole is meant To function as a ventral vent. So now I am like two-faced Janus The only \*God who sees his anus I swear, without the risk of perjury It was a snappy bit of surgery

My rectum is a serious loss to me But I have a very neat colostomy And hope as soon as I am able To make it keep a fixed timetable

So do not wait for aches and pains To have a surgeon mend your drains If he says cancer! you're a dunce Unless you have it out at once

For if you wait it is sure to swell And may have progeny as well My final word before I'm done Is cancer can be rather fun

Provided one confronts the tumour With a sufficient sense of humour I know that cancer often kills But so do cars and sleeping pills

And it can hurt till one sweats So can bad teeth and unpaid debts A spot of laughter I am sure Often accelerates ones cure

So let us Ostomates do our bit To make surgeons make us fit



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Sheila Sweeney RGN, RSCN T: 066 7181636

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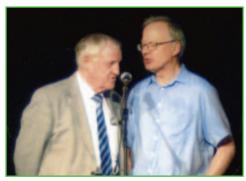






### MY LIFE MY STOMA Brendan Kehoe

# SINGING MY PURPOSE IN LIFE AFTER CANCER



Brendan Kehoe singing

Brendan Kehoe from Wexford tells his story about how singing has given him a new reason to enjoy life. Brendan will soon be 75 yrs and has a stoma since 2014 following being diagnosed with a malignant tumour in his small intestine, Brendan reflects that music was always part of his life growing up as his mother was the local school teacher at Trinity National School and she played several musical instruments.

His father played the fiddle like his father before him. Brendan says music was always his passion; that it is in his genes. When he first heard Blue Grass music, a related genre of American Country Music, he was hooked and travelled to festivals all over the country to hear it. He says although he had

been singing to himself for 50 years he had a deep-seated fear which held him back. Although when he worked with a life insurance company he was well used to speaking to people in public he also experienced anxiety and stress which had been building up over the years. One night the worst happened when he went to a gig where his friend was playing music and he was asked to get up and sing a song.

He had what he now knows was a panic attack, although he did not know what was happening at the time. He felt paralysed with fear and was shaking uncontrollably for days afterwards. He started the song but couldn't continue. Afterwards he vowed he never wanted to put himself in that position again.

Anxiety had become a recurring part of his life and had over time begun to affect his work and daily life. At the age of 60 he took early retirement. In 2014 he began to experience extreme exhaustion. He remembers ironing two shirts one day and had to go back to bed. As luck would have it he met his ex-wife Clare from whom he had amicably separated in 2009. When she saw him she was so concerned at his appearance she insisted he immediately see a doctor.



He had tests done and a malignant tumour was discovered in his small intestine and it was decided he have surgery to remove it. While the surgery was successful, he became violently ill afterwards and had to have surgery again to remove an abscess. During the second surgery he was given an lleostomy pouch which came as a big shock to him.

During his recovery Brendan says he began to realise that he wasn't feeling stressed or anxious, even though he had been through a stressful and worrying experience. Brendan recalls when he was having anxiety people would say to him "wouldn't it be worse if you'd cancer". Brendan says it turned out for him that anxiety was worse than cancer. He says he couldn't eat or sleep at the time.

Brendan got his anxiety under control with the help of medication and a weekly support group which he still attends. Brendan says his experience in hospital changed something in his life after hearing about a young man who was terminally ill who followed his passion to ride motorbikes until he was no longer able to do it. Shortly after hearing about this young man realising his dream Brendan was at a music event at the Forge in Wexford a popular music venue where many people were getting up to sing.

Brendan said to himself 'wouldn't it be great to be able to do that?' he grasped the nettle and sang the Elvis song Are You Lonesome Tonight in front of 40 people. Brendan recalls he was shaking and could barely hold the microphone when he sang the song. Afterwards, people reassured him that while he felt nervous, he sounded fine. This Brendan says gave him courage and he persevered and went along again and again and, each time he sang.

One evening he heard about singer Aideen Ní Riada, who is also a confidence in singing coach, who was doing workshops for people who wanted to sing. This was like a lightbulb going off. It was instant. People had been saying to me since I retired that I should take up gardening or go on a cruise but nothing was clicking. This was the moment I realised that the light went on in the darkness for me.

Brendan went to Aideen's workshop and began to flourish. Singing was now not just something he did in his own head. He started singing regularly. Brendan then decided to fulfil his dream by going into a local recording studio and recorded his own version of Detroit City, a song which won a Grammy for singer Bobby Bare in 1963.

After this Brendan says there was no holding him back. Brendan says his singing classes helped him build up his confidence gradually. Brendan says he began singing also in groups and made many friends and performed in concerts at the Wexford Arts Centre. Brendan recalls he was surprised how calm he felt he couldn't believe it. Singing makes me feel so fulfilled. It's a great feeling. There's a feeling of achievement.

Coming from where I've come from, I've always listened to music and been influenced by music, so to be able to get up and sing is a beautiful thing. Brendan says he now enjoys going to Festivals and mingling and meeting other people. It's given me a whole new lease of life. That stress and anxiety I used feel is gone.

Brendan says that having a Stoma pouch, does not hold him back. Brendan now gets on with things because for so long he was held back by anxiety that it crippled him. Brendan says he is now at the happiest stage in his life, despite his illness and his marriage breaking up, I'm calm and relaxed and I'm in a peaceful place. It's great to be able to say that. My outlook now is to try to live in the moment and there is nothing holding me back anymore. Having a Stoma Pouch has also given me a quality of life which I did not have for many years.

Brendan singing at The Forge in Wexford







# DROGEHDA / NORTH EAST SUPPORT GROUP



The Drogheda / North East support group was started by Paul Hughes our chairman who lives in Bettystown 18 months ago back in 2018. The coordinator of the group is Anthony Connolly contact 089 4418799.

When we started the local support group we held our first meetings in the Westcourt Hotel in Drogheda. We now are able to hold our monthly meeting in the lovely St. Peter's Community Hall in Peter street on the last Wednesday of each month. Initially we were only a small group of Ostomates with 4/5 members at the meetings but now our group regularly has 10/15 members attending the monthly meeting. We were delighted to welcome 4 new members at our recent February meeting. The Drogheda / North East support group covers a large catchment area covering Co. Louth, part of Co, Meath and also part of North Co. Dublin with members living as far south as Balbriggan, as far West as Navan and as far north as Dundalk. The meetings have been a great success giving members an opportunity to chat and enjoy a cup of tea/coffee and to be of support to each other. We endeavour to have a speaker give a presentation at our meeting and we also welcome having one of our Ostomy companies Stoma Care nurses attend

During 2019 we approached our local Tesco store in Drogheda to enquire about being able to make an application for funding from the Tesco Community Fund for our support group. This is something that will be of interest for the co-ordinators of our other support groups. It was a relatively simple process which involved us contacting the Customer Service Desk and obtaining an application form. Besides completing the application form we also had to submit a letter outlining the work of our group and our involvement in the community providing support forostomates living in our catchment area and how we would utilise any funding we received.



All applications which are deemed worthy to be of benefit to the local community become eligible to be included in the next round of Blue Token collections. It can take some time before a group is eventually selected to become a beneficiary of the Tesco Community Fund. When our application for funding was accepted Tesco kindly included us in 3 local stores and donated €800 to support our Drogheda / North East support group. We were most grateful for the support we received from Tesco and when we thanked them on receiving the cheques at the presentation ceremonies we were advised that Tesco would be happy to accept applications from other support groupsof the Ostomy Association of Ireland.

Relant



### **DIRECTORY OF SUPPORT GROUPS**

# CARLOW / KILKENNY OSTOMY GROUP

Coordinator Jamie Alcock Contact 087 6983719 Meet every 2 months at An Gairdin Beo, Carlow (R93 E1HF) Meetings held on a Saturday at 11.30 hrs Next Meeting is on 4th April 2020

### CASTLEBAR STOMA SUPPORT GROUP

Coordinator J.J. McLoughlin Contact 087 2300580 Meet bi-monthly Meetings held at Rock Rose House, Castlebar at 7pm Next meeting is on 19th March, 21 May, 16 July, 17 September and 19 November

### **CORK STOMA SUPPORT GROUP**

Coordinator Rose Flynne
Contact 087 2953404
Meet on first Saturday of the month
Meeting held in Clayton Hotel,
opposite City Hall
Next meeting is on 1st Saturday
of the month 2 – 3.30pm

# DROGHEDA/NORTH EAST SUPPORT GROUP

Coordinator Anthony Connolly Contact 089 4418799 Meet on last Wednesday of each month from 7.00pm - 9.30pm. Meetings are held in St Peters Church Hall Community Centre

### **DUBLIN STOMA SUPPORT GROUP**

Coordinator Melissa Lyons
Contact 086 8099918
Meetings are held on a Saturday
from 2 to 4pm
Meetings are held every 6 weeks in
the Irish Red Cross Building,
Sunshine Industrial Estate,
Crumlin, Dublin 12
Next meeting is on 14 March 2020

### GOREY OSTOMY SUPPORT GROUP

Coordinator Frank Norris 087 6204533 Meetings are held on a Saturday in St. Columbas Old Folks Club, O'Byrne Park, Gorey Next meeting is in April



### **LETTERKENNY SUPPORT GROUP**

Coordinator Rita Marron Contact 074 9188887 Meetings are held Next meeting is on

### LIMERICK STOMA SUPPORT GROUP

Coordinator Miriam Canty Contact 087 7940850 Meetings are held in the Milford Care Centre, Castletroy, Limerick at 7.30pm Next meeting are on 30th March, 25th May, 27th July, 28th September and 30th November

### NEWBRIDGE STOMA SUPPORT GROUP

Coordinator Veronica Lynch Contact 087 7940850 Meetings are held in The Parish Centre, Station Road, Newbridge, Co. Kildare.6.30 – 8.00pm Next meeting is on 30th April

### SLIGO STOMA SUPPORT GROUP

Coordinator Mary McLoughlin
Contact 086 3608798
Meetings are held on the last
Tuesday of each month
Meetings are held in the
Cancer Day Centre on Wine Street
at 7.30pm
Next meeting is on 24 March,
21 April, 19 May, 23 June

# TULLAMORE STOMA SUPPORT GROUP

Coordinator Ann Dold
Contact 086 3074846
Meetings are held in the Dochas
Centre on Offaly street
Meetings are held every two months
on the second Wednesday
Next Meeting is on the 15 April 2020
from 6.30pm - 8.00pm

### WATERFORD STOMA SUPPORT GROUP

Coordinator Keith Drayton
Contact 087 066668
Meetings are held Quaterly on the
first Wednesday of each month
Meetings are held in the Solas
Cancer Day Centre
Next meeting is on the 4th March
2020 at 7.00pm



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# For information on where and when meetings will be held during 2020 Please contact the following Group Co-ordinators.

CARLOW: Co-ordinator Jamie Alcock 087 698 3719

CASTLEBAR: Co-ordinator J.J. McLoughlin 087 2300580

CORK: Co-ordinator Rose Flynne 087 2953404

 $DROGHEDA: Co-ordinators\ Anthony\ Connolly\ 089\ 4418799\ and\ Paul\ Hughes\ 085\ 7182405$ 

DUBLIN : Co-ordinator Melissa Lyons 086 8099918

GOREY: Co-ordinator Frank Norris 087 6204533

LETTERKENNY: Co-ordinator Rita Marron 074 9188887

LIMERICK: Co-ordinator Miriam Canty 087 6741930

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