

# **The Way Forward to Better Serve**

**the**

## **Needs of Ostomates in Ireland**

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## 1. Preamble :

The **Ostomy Association of Ireland** is the national support organisation for people who have a Colostomy, Ileostomy, Urostomy and Internal Pouch. Individuals of all ages can have a stoma as a result of having Cancer, Diverticulitis, Ulcerative Colitis, Crohn's Disease or following having a trauma to the abdomen.

### **The Ostomy Association of Ireland**

Was established as an unincorporated organisation on 1<sup>st</sup> January 2019.

Charitable Status will hopefully be ratified during 2021.

It is now two years since the Ostomy Association of Ireland (OAI) was established.

OAI had previously existed as **IA Ireland** and had served the needs of Ostomates with an Ileostomy or Internal Pouch. **IA Ireland** was a member of IA UK for 54 years. The Ileostomy and Internal Pouch Organisation – IA UK decided to restructure its Association in 2017/2018 and following consultation with the membership of IA Ireland a Questionnaire was sent to all members so that a decision could be taken to either remain as a branch member of IA UK or to become Independent and represent all Ostomates in Ireland.

It has been a challenging time establishing the Ostomy Association of Ireland as the national organisation/association for all Ostomates, people with a Colostomy, Ileostomy, Urostomy or Internal Pouch since its inception on 1 January 2019. The Ostomy Association of Ireland during 2020 was unable to hold any Public Meetings and Exhibition of Ostomy Products by the Ostomy Companies who serve the needs of Ostomates in Ireland due to the COVID PANDEMIC which resulted in lockdowns being imposed by the Irish Government for the protection of Irish Citizens. Local Support Groups were also unable to hold meetings due to the restrictions. However, several of the support groups organised WhatsApp groups and Zoom meetings for the members of their individual support groups.

Consolidating the 12 Support Groups of OAI was the most important activity of the association as there were only 6 groups previously in existence up to 2018 and with the establishment of OAI an additional 6 support groups, doubled the footprint of the association as it endeavoured to have more local support groups established, which were easily accessible for members to attend .It is planned during the period 2021 to 2025 to establish an additional 12 support groups with a good geographic spread to further service the needs of the membership.

The Primary objective of OAI is to develop a **Partnership of Service** together with the Stoma Care Nurses in the HSE and Ostomy Companies to enable Ostomates in Ireland to enjoy an improved **Quality of Life** and to be able to **Live Life to the Full** with a Stoma or Internal Pouch.

## 2. Governance :

The Ostomy Association of Ireland has an Executive Committee which consists of the following Elected Officers :

Chairman

Vice Chairman

Secretary

Assistant Secretary

Treasurer

Public Relations Officer.

These 6 officers represent the management committee responsible for organising the activities planned each year for the development of the association. The coordinators of each support group also have a role in the development of the association by attending Board Meetings and contribute to developing the local services we endeavour to provide for the members of the association.

The Executive Committee is required to meet four times during the year and if required extra meetings may be called.

The Executive Committee is responsible for :

- Creating a clear shared vision for the future of the **Ostomy Association of Ireland**.
- Providing leadership for the association.
- Formulating Policies and Plans for the future to realise the Objectives of the Association.
- Ensure that there is accountability and transparency to Stakeholders.
- Managing the financial resources of the organisation.
- Ensuring that the **Ostomy Association of Ireland** complies with all relevant policies and legal requirements as outlined by the **CRA** ( Charities Regulatory Authority of Ireland ).
- Overseeing the day to day management of **OAI** and assessing any potential risks to the Association.’
- The **Ostomy Association of Ireland** seeks to adopt the Code of Governance for Community and Voluntary Organisations as outlined by the **CRA** – Charities Regulatory Authority of Ireland. It is hoped that during 2021 the association will complete its application to the **CRA** to be approved as a registered Charitable Organisation.

### 3 Vision :

The **Ostomy Association of Ireland** seeks :

To help anyone living in Ireland whose Colon has been or is about to be removed by a surgical procedure such as a Colostomy, Ileostomy, Urostomy or Internal Pouch.

To promote and co-ordinate research in bowel disease and other conditions leading to the removal of the colon, surgical procedures pertaining thereto, and related matters and further to promote the dissemination of knowledge gained by such research.

To keep ostomates who have a stoma or internal pouch operations informed of all matters of interest by the periodic dissemination of information by organising Conferences, Seminars and Courses on topics of interest, and in any other matter which is charitable and which the trustees consider appropriate.

To Liaise with the HSE ( Health Service Executive ) through our membership of the PCRS committee

To advocate for all ostomates who have a stoma to be entitled and deemed eligible to have a medical card as a primary entitlement due to their life long medical circumstance.

To raise awareness with security personnel at airports throughout Ireland about ostomates who have a Stoma and to provide Awareness Training for security personnel .

To raise awareness about ostomates with a Stoma / Internal Pouch who need to access Toilet facilities in Public places, so that Toilets which are accessible to people with a Disability can also be accessed by ostomates with a Stoma or Internal Pouch.

To work closely with other organisations for the benefit of all ostomates who have a Stoma or Internal Pouch, such as the Irish Cancer Society, Marie Keating Foundation and the ISCC (Irish Society for Colitis & Crohn's Disease).

To seek membership of the **EOA** – European Ostomy Association.

To seek membership of the **IOA** – International Ostomy Association.

## 4 Aims :

The **Ostomy Association of Ireland** seeks to :

# Understand - Advise - Support

Ostomates who have had a major surgery involving the diversion of the bowel or bladder necessitating having a Stoma, which changes the bodily function of a person and can disrupt their lifestyle. Ostomates who have had a Stoma for many years say that recovery is often assisted by having contact with Ostomates who have been through a similar experience.

The following Core Activities are provided by the **Ostomy Association of Ireland** for Ostomates with a Colostomy, Ileostomy, Urostomy or Internal Pouch.

- Support Group Meetings
- Public Meetings / Exhibition by Ostomy Companies.
- Publication quarterly of the journal – **Ostomy Ireland News**.
- Website.
- Facebook Page
- Advice Information Booklets
- Visiting
- Social Activities

## 5 Objective :

The **Ostomy Association of Ireland**'s core objective is to help those facing Stoma surgery to be able to return to a normal lifestyle as soon as possible after surgery. Because the members of the Ostomy Association of Ireland have either a Colostomy, Ileostomy, Urostomy or Internal Pouch we can with confidence say :

## **We Understand - We Know - We Care**

The **Ostomy Association of Ireland** seeks to support all ostomates who have a Stoma or Internal Pouch by providing information on stoma care. Through the establishment of Local Support Groups strategically located throughout Ireland, we endeavour to provide a forum for ostomates with a Stoma or Internal Pouch to be able to meet and socialise with other Ostomates.

The **Ostomy Association of Ireland** seeks to work in **Partnership** with Stoma Care Nurses Medical professionals and Ostomy companies to improve the **Quality of Life** of our members.

The **Ostomy Association of Ireland** seeks to establish as a priority during 2021 a working group to develop a '**Visitor Training Programme**' in collaboration with Stoma Care Nurses from the HSE / Ostomy Companies, Ostomates and members of the Medical profession.

It is hoped that this working group can be established in the third quarter of 2021 once the HSE / Nephth give consent for the group to be able to meet. A draft outline of a '**Visitor Training Programme**' is already available and the main task of the working group will be to fine tune the programme and seek to have it recognised by the HSE and endorsed by all Stoma Care Nurses who provide for the medical needs of ostomates. It is proposed that once the '**Visitor Training Programme**' is approved and recognised by the HSE that Ostomates who complete the '**Visitor Training Programme**' successfully can then be registered as available to visit ostomates who are about to undergo stoma surgery prior to having their surgery or after having had stoma surgery. Visits can take place either in a hospital at the request of a Stoma Care Nurse or at the home of an Ostomate following a request by a Stoma Care Nurse or by having a conversation with a new Ostomate over the phone following a request by a Stoma Care Nurse.

Ostomates who successfully complete the '**Visitor Training Programme**' will receive a Certificate of Competency recognised by HSE to confirm that they are competent to become a **Visitor**. It is proposed that there will be a number of Regional Panels established to meet the requests of hospitals. Stoma Care Nurses from both the HSE and Ostomy Companies will be able to contact Ostomates ,

The **Ostomy Association of Ireland** will establish the location of the various proposed Regional Panels following consultation and agreement with the members of the working group. OAI will maintain the register and circulate a list of accredited members to all Stoma Care Nurses in Ireland.

It is hoped that the first '**Visitor Training Programme**' will be able to be organised during March 2022 at a venue to be agreed in Dublin.

Ostomates who wish to undertake the '**Visitor Training Programme**' will be carefully selected as suitable candidates to become a '**Visitor**' and will also be vetted by An Garda Siochana as a suitable person to become a '**Visitor**', and their name will be included on one of the proposed Regional Panels to be established throughout the 32 counties of Ireland.

## 6 Planning for the Future :

Following on the success of increasing the number of support groups in 2018 the **Ostomy Association of Ireland** are seeking to further increase our footprint by establishing more Support Groups throughout Ireland at key locations, so that anybody wanting to attend a Support Group Meeting will not have to travel more 25km to do so.

The Survey / Questionnaire which was sent to over 600 people with a Stoma or Internal Pouch in August 2017 has provided us with valuable information about our membership and what our members would like the **Ostomy Association of Ireland** to achieve and the direction they want the **OAI** to take over the next 3 to 5 years.

The Results of the Survey / Questionnaire were published in Issue No. 1 in our new Journal – **Ostomy Ireland News** which was launched at the Spring Meeting held in Dublin at the Ashling Hotel, Parkgate Street, Dublin 8 on 23rd February 2019.

The Information recorded in the analysis of the responses given in the Survey / Questionnaire provided us with a profile of Ostomates who have a Stoma or Internal Pouch. The information gathered has provided us with valuable statistical information on the members of the **Ostomy Association of Ireland** and has enabled us to understand and seek to meet the needs of our members. The information gained from the Survey / Questionnaire was also valuable for our Ostomy companies, Stoma Care Nurses and Medical Professionals who together support our efforts to improve the quality of life of our members.

The **Ostomy Association of Ireland** will continue to maintain contact with the three main National Organisations in the UK who provide services for people with a Colostomy, Ileostomy, Urostomy and Internal Pouch.

We are also applying to become members of the European Ostomy Association and the International Ostomy Association.

In January 2019 we became members of the WHEEL who are an umbrella organisation providing guidance and support for Charitable and Voluntary Sector Organisations in Ireland.

Through our membership of the WHEEL we were able to obtain Insurance cover for all the activities of the **Ostomy Association of Ireland** and for our Local Support Groups.

We hope to complete the process for Charitable Status and have approval from the CRA ( Charities Regulatory Authority ) before the end of 2021.

## 7 Funding :

The **Ostomy Association of Ireland** is primarily funded through an annual membership subscription paid by its members. Many members in addition to paying an annual subscription also make a donation to support the costs of running the association.

Membership Subscription is presently :

Members aged under 60 on 1 January pay an annual Membership fee of €20

Members aged over 60 on 1 January pay an annual Membership Fee of €15

cover

Ostomy Companies were approached at the beginning of 2019 and invited to financially support the establishment of the Ostomy Association of Ireland through a Social Partnership Sponsorship agreement. Ostomy companies who supported the establishment of the Ostomy Association of Ireland and made a Corporate Sponsorship payment of €2000 euro for the year receive the following benefits :

### **Benefits for Ostomy Companies who become Corporate Social Partners :**

- Corporate Membership of the Ostomy Association of Ireland.
- Attendance at three Public Meetings to be held each year in February, June and October by staging an exhibition of their products for two hours prior to each Public Meeting.
- Promoting their Ostomy Company Website on the **Ostomy Association of Ireland** Website.
- Free colour Full page advert in the **Ostomy Ireland News** journal which is published quarterly – Spring, Summer, Autumn and Winter.
- Receive Three copies of the **Ostomy Ireland News** journal quarterly
- Ostomy companies Stoma Care Nurses are invited to make presentations and promote ostomy products of their company at Local Group Support meetings.
- Submit articles of interest and information on their Ostomy Products for inclusion in **Ostomy Ireland News**.
- Ostomy companies are able to have information included in issues of Ostomy Ireland News showing the territorial areas which their Stoma Care Nurses cover and their contact information.
- Request to submit promotional leaflets which can be inserted with each journal being posted Free of Charge.



## 8 Support Groups :

For information on where and when meetings are held

Please contact the following Group Co-ordinators :

CARLOW / KILKENNY : Co-ordinator Jamie Alcock 087 6204533

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

CORK : Co-ordinator Rose Flynne 087 2953404

DROGHEDA : Co-ordinator Anthony Connolly 089 4418799 & 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

NEWBRIDGE : Co-ordinator Veronica Ruffley 087 7940850

SLIGO : Co-ordinator Mary McLoughlin 086 3608798

TULLAMORE : Co-ordinator Ann Dold 086 3074846 & Mark Sheehy 087 3843412

WATERFORD : Co-ordinator Keith Drayton 087 0666668

It is hoped to establish another 12 support groups during the next three years - 2021 to 2023, so that it is possible for more members to attend a local support group which is not too far away from where they live. It is hoped that once the Vaccination programme is completed and restrictions are lifted and local support group meetings are able to start again, an additional three support groups can be established and will be ready to hold meetings from March 2022.

## 9 Conclusion :

The **Ostomy Association of Ireland** is now recognised as the National Association in Ireland representing Ostomates who have a Stoma or Internal Pouch. Due to the COVID PANDEMIC restrictions which commenced in March 2020 it has not been possible to hold Public meetings or Local Support Group Meetings. Maintaining contact with our members was extremely difficult.

When we conducted the Survey / Questionnaire in 2017 / 2018 with our members prior to the establishment of the **Ostomy Association of Ireland** on 1 January 2019, we were able to ascertain that 40% of our members had limited knowledge or experience with Smart Phones, Tablets, Laptops or Desktop Computers. They did not use WhatsApp, Facebook, Twitter or emails as a means of communicating with Family and Friends.

For the first time in 2019 we communicated with around 60% of our members who had an email ID and we circulated a Newsletter and information on how to access and download the quarterly issue of **Ostomy Ireland News**. Members who did not have an email ID received a copy of the journal in the post instead of receiving it by email. This has proven to be very successful and we hope to be able to increase our contact with members using this method of communication during 2021 and future years.

Each year the Irish Stoma Care and Colorectal Nurses Association ( ISCCN ) undertake a survey involving all hospitals where stoma surgeries are performed and statistics regarding the number of people who became ostomates is recorded. Statistics for the past four years show that approximately 2500 stomas are created each year.

One of the most disturbing facts which was recorded when analysing the results of the Survey / Questionnaire carried out in 2017 / 2018 was that 56% of the respondents said they were never told or advised by any medical professional that there are support organisations for ostomates in Ireland. It is a major challenge for OAI starting this year 2021 to actively promote the existence of OAI and the support groups that exist in Ireland. The continued support by some of the Ostomy Companies who are committed to supporting the association by being Corporate Social Partners is greatly appreciated. It is only through this level of support that the association can reach out to supporting ostomates in Ireland and are able to promote the existence of the association.

This year we have undertaken to publish three information booklets for the benefit of our members and for all new ostomates. The first booklets are :

1. Living life to the full with a Stoma or Internal Pouch – Do you know your local support group?
2. Nutrition & Dietary Advice for people with a Colostomy, Ileostomy, Urostomy and Internal Pouch.
3. Going on Vacation - Travel Advice.

The Ostomy Association of Ireland will continue to pursue a Partnership of Service with the Ostomy Companies, Stoma Care Nurses and Medical Professionals with whom we interact on behalf of our members so that together we can deliver a -

## Partnership

## Living Life to the Full with a Stoma or Internal Pouch

