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Document Description

This policy describes the strategy of EOPD.ie

Implementation and Quality Assurance

Implementation is following consultation with the board, eopd.ie members and the general public and this Policy shall stay in place until any alterations are formally agreed.

The Policy will be reviewed twice a year by the Board of Trustees, sooner if legislation, best practice, or other circumstances indicate this is necessary.

All aspects of this strategy shall be open to review at any time. If you have any comments or suggestions on the content of this policy, please contact the team at dpo@eopd.ie

EOPD.ie is a registered charity and a company limited by guarantee.
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Overview

Welcome to the EOPD.ie (Early Onset Parkinson's Disease CLG) Strategy document. In this document you will find details of how our charity is aiming to continue to be successful over the next 3 years and grow our peer support and membership, as well as to advocate on behalf of and to provide information to people living with Parkinson's Disease, their partners, families, friends and the communities in which they live

This strategy document was created following:

- Reflection and review of EOPD's impact over the last two years,
- An inclusive consultation in partnership with the EOPD community, and
- Workshops on strategic development attended by the Board of EOPD

Our Strategy

Vision

Everybody with Early Onset Parkinson's Disease has what they need to live a fulfilling life.

Mission

Our mission is to improve the lives of people who live with Early Onset Parkinson's Disease and support them to enhance their quality of life through information, advocacy and peer support**.**

Strategic Priorities

The main strategic priorities facing our organisation and community are as follows:

1. Education
2. Support
3. Advocacy
4. Advising on Research
5. Informing

EOPD Background

Early Onset Parkinson's Disease affects approximately 1800 (2019 estimated) people in Ireland. This figure is likely to be higher at present as Parkinson's is one of the fastest growing neurological conditions. The diagnosis is often received by people at the height of their career with mortgages still to pay and family to support and educate. The condition which affects people differently may lead to some having to step back from work causing financial worries, isolation and living on the poverty line due to the poor supports available. It is important that people do not feel that they are the only person going through this and that they have somewhere to turn to connect with others at the same life stage when faced with this diagnosis. It is therefore vital that a support group is highly visible in the community for Early Onset Parkinson's.

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There are three organisations in Ireland serving the needs of people with Parkinson's. There are:

- EOPD.ie
- Move for Parkinson's
- Parkinson's Association of Ireland

Our Services

Our primary focus is people living with early onset Parkinson's and share information on their journey through Education, work, and life.

We work with people with Early Onset Parkinson's Disease, their family members/loved ones as part of a range of key stakeholders including clinical and allied health care professionals and researchers. By co-operating with the medical, scientific, social, and caring professions we aim to promote scientific research into the causes of, cure for and management of EOPD.ie and the alleviation of its medical and social symptoms. We will provide opportunities for people living with EOPD to inform research by relaying the difficulties and obstacles to living well with EOPD encountered by people who are at varying life stages.

Our members include many who are navigating a health system which often sees Parkinson's disease as an older person's disease. Many of our members are working full-time without any support and some may not disclose their condition for fear of discrimination or termination of their employment. We aim to support those who wish to and need to continue in employment by providing guidance on adaptations and information on financial support. Many employers have benefited by getting support to enable valuable staff to continue in employment.

EOPD.ie will be an identifiable focal point for all the community, including family members/loved one's health professionals, researchers and the wider support community who have an interest in addressing issues particular to those who are diagnosed with EOPD. Some of our members are still in education, buying their first home, learning to drive and have young families. In enabling and assisting people to navigate these important milestones, we believe that it will benefit the public research community and help them to engage with the Parkinson's community in a dynamic, systemic, and creative way.

We will provide peer group support individually and collectively so that our Primary Stakeholders can know that they are not alone and can benefit from the experiences of others.

Exercise and physiotherapy have been demonstrated to be crucial in alleviating some of the symptoms of EOPD. We will share information about exercise class and work with other stakeholders to delivery classes.

We arrange information talks and presentations given by relevant experts including medical professionals, allied health care, community social supports, and others, specifically directed at EOPD to ensure we foster an inclusive model of support that is person centred.

Current EOPD Environment

The environment in which the charity operates is changing and some realities include the following:

- In Europe, 1.2 million people have Parkinson's disease (PD), with a total socioeconomic cost of €13.9 billion per annum, which will double by 2030. Current estimates are that 16,000 people live with Parkinson's in Ireland with 10% living with Early Onset Parkinson's and Juvenile Parkinson's

- No current therapy stops the progression of PD.

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- Parkinson's is a chronic neurological disease that affects over 10 million people worldwide. Its incidence is steadily increasing and is estimated to double by 2030.
- Current drugs treat the symptoms of Parkinson's, but do not prevent it from worsening.
- A greater focus on living independently in the community.
- A greater focus on the benefits on exercise, diet, speech and language and Physio services within the local community.
- Need to raise awareness on Early Onset Parkinson's and the impacts it has on people lives.
- Need to get involved in research.
- Explain the changes that may happen once someone diagnosed with Parkinson's and some of the possible impacts of the medication that helps control Parkinson's.

Board of Directors Response

The members of our board detailed are on our website www.EOPD.ie.

The EOPD charity needs to be agile, embrace the change ahead and as a Board maintain our focus on robust financial management and strong governance.

Within this document there is a three-year plan which gives more detail on the actions and activities that we will undertake. There is flexibility within our strategy to enable us to accommodate environmental changes and keep our vision moving in the right direction.

We will work with other local, national, and international organisations to ensure we maximise the potential for new and changing service offers. We want to reach out to more of our local community by offering services throughout Ireland via a partnership approach.

EOPD.ie is very much about teamwork and investing in our volunteers is a major part of our strategic direction, we see our team as asset to the charity and want to support and develop them to bring our strategic vision to life so that we can achieve our objective to be the first-choice organisation for young people in Ireland with Parkinson's

Strategic Priorities

1. Educate

Objective is to be a source of information for Early Onset Community.

Monthly newsletter: It would be helpful if members of the board or EOPD community would share with the working committee any interesting articles. It was discussed if there is a way to automatically gather the content and format it.

Core information modules: Discussion around the creation of an EOPD syllabus with 4-6 modules which could be presented and refreshed yearly. At least one should be in person. They would be around self-management and living well and could include, for example:

- Medical
- Self-management
- Therapeutic
- Wellbeing
- Exercises
- Diet

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Need to consider the audience for this; people having EOPD, professionals, friends, family. Pillars could be:

- Support people/family and friends
- Professionals
- People with the condition.

Board to propose the syllabus and modules for board to work on the content regarding support people.

Education for the medical and allied health care profession: There is a desire also to educate medical, allied healthcare and community professionals by speaking at conferences. This includes:

- GPs,
- Consultants
- Neurologists
- Allied health professionals
- Community network supports.

Conduct a small research survey to see how medical professionals would like to receive information and what information they are interested in. Seek to attend relevant annual conferences.

2. Support

EOPD's objective is to signpost people to the appropriate resources, and the website will be the cornerstone for disseminating this. Recorded events can be stored there also. There should be a maintained 'FAQ' section with question related to working with EOPD for example.

Given the importance of the website in the EOPD strategy, it's considered that their needs be some professional support here and possibly paid staff. The website needs to be kept up-to-date and designed with the user experience in mind. Each new member is offered a call back when they join up through the website, but the idea is that the community then supports each other.

3. Advocate

EOPD needs to advocate by regularly meeting and raising the needs of its members with key decision makers:

- Society at large
- Medical and allied healthcare professionals
- Government and policy makers
- Employers.
- HSE national patient's forum.

The networking strategy should be to identify the key people in these groups. Identify what EOPD wants from these people (support, understanding etc...) and maintain the relationships. As this is a key objective of EOPD it's considered that there should be a member of staff or a volunteer whose specific role is to co-ordinate and deliver the advocacy function on behalf of EOPD. There is a specific need to deepen the relationship with NAI. Identify the key decision makers impacting EOPD, e.g., HSE, Government and Pharma,

4. Advise Research

The goal is to be a centre where the research community ask EOPD.ie to inform members that research is happening and let them know how they can get involved. To be a source where EOPD pull together as much information on what research is happening in Ireland. Pull the research community together.

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One benefit of being a member of EOPD could be access to research studies. EOPD should contact the key researchers in Ireland (universities and hospitals for example) to find out what research is happening.

In addition, it can be highlighted to research organisations that EOPD has members willing to be involved in research. EOPD should lobby research organisations about potential research subject matters based on input from the members. It was mentioned that research doesn't only have to be in the medical domain, there can be research in Engineering for example around developing technology that aids with PD.

Currently all members with EOPD are asked if they want to take part in research during the sign-up. It was mentioned that it would be good to keep track of drug access outside of Ireland.

5. Inform

The objective is that people know what Parkinson's Disease is, and particularly early onset.

The first strategy involves targeting education co-ordinators of major organisations:

- Citizen's advice
- Gardai
- Fire Service
- Ambulance Service
- Counselling service of Ireland
- Social welfare
- Occupational Health
- Family resource centres
- Hse network teams
- Community groups

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