



Early Onset Parkinson's
Disease Ireland

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EARLY ONSET PARKINSON'S DISEASE IRELAND

PRE-BUDGET SUBMISSION 2024



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INTRODUCTION

Early Onset Parkinson's Disease (EOPD.ie) is a registered charity, providing peer Parkinson's support and information, all over Ireland. We are a small but committed team with big plans for the future of the charity. As a new dynamic charity, we formed on the 7th December 2020.

Our aim is to assist people with Parkinson's, their families and carers, health professionals and other interested people by offering support, a listening ear and information on any aspect of living with Early Onset Parkinson's. Over 18,000 people in Ireland have Parkinson's Disease with 1,800 being diagnosed before 55. Our plans highlight the fantastic work that is done on a voluntary basis across the country. This work is done by volunteers, many of whom have Parkinson's or have a family member or a loved one with Parkinson's. Often family members are also working in caring roles.

The following EOPD.ie requests outlined in our Pre-Budget Submission 2024 are:

1) [Standardisation of HSE Technical Aids Grant](#)

Ask: Standardise HSE Technical Aids Grant Funding Assessment Model for all Community Health Organisations (CHOs) across the country and extend eligibility for the Technical Aids Grant to everybody living with Parkinson's. People with Parkinson's have the right to live an independent life and utilise a variety of aids and appliances to support them to do so. The Technical Aids Grant is an essential avenue to support people (aged under 65years) who are diagnosed with Parkinson's to purchase equipment that can enhance independence and boost self-esteem. However, the Technical Aids Grant administered by the HSE has no standardised eligibility criteria, assessment processes, or funding allocations for aids and appliances across the country. Consequently, many people with Parkinson's are unable to afford the cost of these aids and appliances and are either forced to wait for prolonged periods of time or must do without if they are over the age of 65, which undermines their right to living independently. As a result of inconsistent practices across Community Health Organisations (CHOs), there is extraordinarily little information available to guide people who need to apply for the Technical Aids Grant as to what the process entails.

2) [Reasonable Accommodation fund](#)

Ask: Review of reasonable accommodation fund for people with a disability who could remain at work for longer with support. Many people working in State-funded particularly



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Section 39 organisations can't apply for support, if the organisation is funded over 60% by the State.

3) Investment in dedicated Mental Health Services

Ask: Early Onset Parkinson's is seeking dedicated HSE funding of €234,000 per year to guarantee to establish an essential nationwide service. Receiving a diagnosis of Parkinson's at any age is life changing as it affects a person's sense of self and their independence.

4) Accessing Social Housing

Ask: Ringfence funding to the Disabled Persons Grant Scheme & Improvement Works which are administered by the Local Authorities to meet the bespoke requirements of an applicant who has a disability. According to research published by the Irish Human Rights and Equality Commission and Economic and Social Research Institute (ESRI), people with disabilities are more than twice as likely to report discrimination relating to housing and over 1.6 times more likely to live in poor conditions, such as living in damp housing, lacking central heating or living in an area with neighbourhood problems.

5) Review of Housing Adaptation Grant and Mobility Aids Grant

Ask: Review and update the Housing Adaptation Grant and Mobility Aids Grant to recognise the increased cost of building and recognise the additional cost of disability when determining grant payments.

The Housing Adaptation Grant for Older People and People with a Disability is available through local authorities when changes are needed to a home to make it more suitable for a person with a disability.

The Mobility Aids Grant which is also managed by the local authorities is designed to provide grants to address mobility problems in the home. This Grant does not cover more extensive works required but can cover works such as the installation of a level access shower.

It would be more cost effective to assist people in future-proofing their homes. Falls and issues with mobility will cost the State more in the long term rather than supporting people being proactive.

Each Grant scheme is covered under the Housing (Adaptation Grants for Older People and People with a Disability) Regulations 2007 Act and regulations in 2014. The maximum grant amount available was established in the 2007 regulations and was last updated in the 2014 amendments.



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Since 2014, the cost of building has risen sharply which means the cost of completing adaptation projects has continued to rise yet the financial supports available to people through these Schemes has remained stagnant. Therefore, the additional cost is left to the individual to cover, which is a barrier for many. Assistive technology in the home can greatly enhance the lives of people living with Parkinson's. Yet the Housing Adaptation Grant gives it no priority.

In 2021, the Cost of Disability Report indicated that the highest individual extra living cost that a person who is living with Parkinson's faces but cannot afford is in the area of adequate housing at €755 per annum. In general, this report states that the additional cost of disability for someone who is living with Parkinson's is between €9,805 – 10,565 per annum. This extra cost should be recognised as an additional burden when determining grant payments.



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6) Expansion of Criteria for Disabled Drivers and Disabled Passenger Scheme

Ask: Replace Disabled Drivers and Disabled Passengers (Tax Concessions) Regulations, 1994, with a needs-based grant aided vehicular adaptations scheme. VRT and VAT relief is available under the Disabled Drivers and Disabled Passengers Scheme for people who are either a disabled driver or passenger. This entire scheme has recently undergone a much-needed review in the context of a broader review of mobility supports. In February 2023, the National Disability Inclusion Strategy Transport Working Group published its report proposing replacing the scheme entirely with a need based, grant aided vehicular adaptation. EOPD.ie welcomes this move and urges the roll out of this approach promptly and for people who are living with Parkinson's or vision impaired to be eligible for inclusion in any new scheme.

7) Cost of Disability

Ask: Increase the disability allowance (€291.50) so people are not living in poverty.

8) Cost of Living Increase

Ask: The cost of living has risen drastically as result of inflation. However, for people living with a disability the impact has been greater. Energy prices have a huge impact on people living with a neurological condition as many are unable to regulate their temperature. Also, they may not qualify for Fuel Allowance, which is means-tested so many cannot afford to keep heat on. Their energy bills may be higher due to being at home for longer periods or need energy to power aids and appliances.



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9) Delivery in the community services

Ask: Fund the rental of halls, gyms, Parish centres, and club facilities for the delivery of exercise classes and social events for people with neurological conditions.

Many people with EOPD have significant costs attached to their rehabilitation and are funding this personally, one of the outcomes of this self-directive approach is a lesser impact on the allied health professionals in the acute and primary care teams. A tax allowance for exercise classes, Occupational Therapy and psychological counselling would be beneficial.



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EOPD.ie 2024 BUDGET PROPOSAL

Our nine budget proposals are based on the principle that we need the right care, at the right time, in the right place, and from the right person. EOPD.ie is asking the State to provide a complementary suite of supports in each main hospital to support neurologists as part of an Integrated Pathway in Parkinson's care in line with best practice.

Early Onset Parkinson's Disease Green book/Medical card issue

The call from us at EOPD.ie is to introduce a medical card to replace the green book. This would simplify and reduce the anxiety and stress that is caused when People living with Parkinsons are prescribed drugs that are not covered under the green book. Our community is then required to pay the additional cost. We are not calling for a free medical card but we would recommend that annual cap of €140 be placed on the new medical card.

CONCLUSION

We would welcome an opportunity to discuss any questions on this pre budget submission. We call on the government to delivery a person-centred model, and the role out of Slainte care plan.

Kieran Fallon

Chairperson

Early onset Parkinson's Disease CLG



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