



(Via Email)

25th August 2021

Minister Heather Humphreys TD,
Minister for Justice, Social Protection, Community and Rural Development and the
Islands
Department of Social Protection,
Áras Mhic Dhiarmada,
Store Street,
Dublin 1,
D01 WY03.

RE: Budget Proposal regarding access to Free Travel for people with epilepsy

Dear Minister,

I trust this finds you safe and well. I am contacting you regarding a longstanding issue facing people with epilepsy and one which I hope that you will be willing to address as part of your Department's negotiations in the context of Budget 2022.

The matter concerns access to the Free Travel Scheme for people with epilepsy, an issue you and your department will be familiar with from recent Parliamentary Questions. We note that replies have referred to our proposals as a budgetary matter in recent responses.

We have outlined below the key points of our proposals and why we are seeking this matter be addressed as part of Budget 2022.

Current travel & accessibility issues for people with epilepsy

Epilepsy is a complex, individual condition and people living with epilepsy face a wide range of challenges in living with the condition. Despite these challenges, the vast majority of people with epilepsy are more than capable of living a full life and in contributing to society through employment.

There are over 40,000 people living with epilepsy in Ireland today. 70% of people diagnosed with epilepsy can become seizure-free with the right treatment regime. For the other 30%, their condition will be more challenging due to the nature and impact of uncontrolled seizures.

In general, most people with epilepsy must be 12 months free of seizures before they can drive a motor vehicle in accordance with the Medical Fitness to Drive Guidelines. This has a number of implications:

1. Almost all new diagnoses of epilepsy in adults come with restrictions on driving. This typically occurs without time to plan or prepare and can lead to significant challenges and upheaval in a person's family, social and working lives at a time when they are learning to cope with a neurological diagnosis.
2. If a person with epilepsy who holds a license experiences a breakthrough seizure, they will once again lose that license for a further 12 months until they become one year seizure free.
3. Many of the 30% who are living with long-term uncontrolled epilepsy will never be able to hold a driver's license, often creating significant limitations on mobility and independence.

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Working to achieve a society where no person's life is limited by epilepsy.



4. There are a cohort of people with epilepsy who will make the conscious decision not to drive – despite meeting the criteria to hold a license– due to the unpredictable nature of their condition.

Therefore, there is a reliance and dependence on public transport for many people with epilepsy, as a direct result of their health condition and the State's (correct) decision to restrict their ability to drive. Through no fault of their own, this can lead to significant financial challenges for a person as they seek to maintain employment, remain socially active and meet family commitments.

Our Proposal

As a result of the above, Epilepsy Ireland is calling for two simple measures which we believe would jointly ease the considerable burden for people with epilepsy:

- 1) Extending Access to Free Travel
Provide automatic access to a Free Travel pass for those who temporarily lose their license for the period that they are "off the road".
- 2) Decoupling of Free Travel from qualifying payments
Establish the Free Travel scheme as a directly applicable benefit so that the needs of those in groups 3 and 4 above can be individually assessed for eligibility.

Rationale

These measures would be of huge benefit to those living with epilepsy who face unique accessibility issues because of their long-term health condition.

1) Extending Access

By providing those who lose their license with automatic access to a free travel pass, the state would be supporting that person to stay in employment or education; remain socially active & maintain their independence; and ease the significant financial burden that a person faces owing to their long-term health condition. Unfortunately, we are aware of many cases where a person with epilepsy has been forced to give up employment due to the transport challenges that they face and have ultimately ended up being supported by other, more costly, state welfare schemes such as Jobseekers Benefit. Our proposal therefore aligns with the ethos of your department in helping to ensure that individuals are supported in remaining in employment.

Internationally, there are examples of supports which have been established to mitigate the unique transport & accessibility challenges which are faced by people with epilepsy. In each jurisdiction of UK for example, there are differing systems in place for people with epilepsy – including in Northern Ireland where a half rate travel pass is provided. Further afield in Australia, a taxi subsidy scheme is in place to help support those with epilepsy who cannot drive because of their condition. These comparisons show that Ireland is lagging behind international practice when it comes to specific supports to help support people with epilepsy with the accessibility challenges they can face.

A further benefit is that the proposal promotes road safety by actively offering an alternative to those with active epilepsy who may be tempted to drive in breach of restrictions because they believe they have no other viable option.

Finally, there is strong support among legislators from all parties for what most see as a common-sense solution to an avoidable problem. There is also strong public support,



demonstrated in research conducted by Amárach Research on behalf of Epilepsy Ireland earlier this year, where 88% of 1,000 respondents said that they support our proposal.

The Free Travel scheme – with the necessary amendments – represents a ready-made vehicle to implement positive change in the lives of many people with epilepsy.

2) Decoupling of Free Travel from qualifying payments

Extending access, as described above, accommodates all those who hold a driver's license at the time of diagnosis. To assess the eligibility of those whose epilepsy has prevented them ever holding a license, we propose the establishment of a directly applicable route to Free Travel.

The Free Travel scheme is currently linked to other Departmental payments such as Disability Allowance & Invalidity Pension. Some people with epilepsy will already be able to access the Scheme as they will meet the criteria for these payments. However, the majority, including all those who remain in employment, will not.

If the Free Travel scheme was directly open to applications, this would enable a person's specific situation and needs (for example through medical information) to be assessed for access to the Scheme.

This 'decoupling' measure has already been recommended by the Oireachtas Committee on Transport in 2018.

Scope of the proposal

We are NOT advocating that all 40,000+ people with epilepsy in Ireland are provided with automatic access to Free Travel.

Our position is that those who are restricted from driving as a result of their epilepsy should be provided with Free Travel for the duration that they are off the road and that an access route to be benefit should be made available to those who will never be able to drive. We estimate the number of potential new beneficiaries to be 5,575 individuals. Further detail on these figures is provided in the attached appendix.

Please also note that we are not proposing that Free Travel eligibility be removed from current qualifying payments but rather a direct access route be established so that those who are purely seeking to access to Free Travel have a direct pathway to do so.

Cost of the Proposal

We note that there were 947,855 people availing of the Free Travel Scheme in 2020, and that expenditure on the Scheme amounted to €93.69m. The average cost per person is therefore €99.

Based on 5,575 new beneficiaries, the additional cost of our proposal to the Exchequer is €571,725. This represents an expenditure increase of just 0.6% on current expenditure.

Further detail on this is also provided in the attached appendix.



Comments on Departmental responses

Responses from the Department to date have highlighted several barriers to implementing this proposal.

1. Equal Status considerations

It has been noted that extending the Scheme to people with epilepsy cannot be considered in isolation and that moves to do so could result in challenges under the Equal Status Act.

As the national epilepsy patient organisation, our focus is on the community we support and represent. While we do not have specific expertise or remit in other disease areas, we support the general principle that all individuals restricted from driving by the State on foot of any medical condition should have access to Free Travel. If the state can automatically take away a person's license on health grounds, then the State can equally provide a free travel pass for the duration the person is off the road, subject to appropriate evidence being provided. Applications of this type could be streamlined through communication with the relevant driving authorities.

If the Department considers that there is likely to be a challenge over extending the Scheme, then this would suggest that the Scheme as it currently stands may be in need of review to determine its fitness for purpose and that it is not currently adequately addressing the needs of a far wider cohort of people with long term health conditions or disabilities.

In addition, establishing a route for eligibility to be individually assessed would not differ from any other existing Departmental scheme. Deciding Officers operating to consistent and objective criteria and with reference to the information provided as part of the application would be a fair and equitable decision-making process, with normal appeals processes in place should an applicant wish to have their eligibility reassessed.

2. Additional resources required to expand the scheme

The Department has referred to additional resources required to fund and operate an expanded Free Travel Scheme. Other than the information provided in the attached appendix on the direct costs associated with the condition of epilepsy, we do not have any information on the requirements that would be needed. Given that parliamentary question responses have made reference to this, we assume that the Department has a clear understanding of other disease areas/ disabilities which could qualify for an expanded Free Travel scheme (i.e. those which specifically result in driving restrictions) and of the resources that would be needed to fund and manage the Scheme. Therefore, we believe that the Department should seek these resources as part of Budget 2020.

Summary

If implemented, our proposals would address a longstanding issue for many people with epilepsy and their families.

Given the impact this would have in terms of increased economic activity; reducing isolation among a group of people living with a hidden and often stigmatising disability; and enabling people with epilepsy participate fully in society; we consider this to be a small, yet invaluable investment.

It would also represent an acknowledgement from the State of the unique circumstances which can face people with this often misunderstood and stigmatised condition. While



implementing this measure will not fully address all the challenges that people with epilepsy can face with accessibility and transport, it would be a significant step forward in improving the lives of many of those living with the condition.

We ask that as part of your Department's plans for Budget 2022, that you would give this issue your strongest consideration and seek to plan ahead to address this longstanding issue for people with epilepsy.

We look forward to your reply and would welcome the opportunity to meet with you and to work collaboratively with your department on developing and implementing a solution.

Please do not hesitate to contact me on should you require any further information.

Yours sincerely,

A handwritten signature in black ink that reads "Peter Murphy".

Peter Murphy
CEO, Epilepsy Ireland

CC:

Minister Pascal Donohoe TD; Minister for Finance.

Minister Michael McGrath TD; Minister for Public Expenditure & Reform.



APPENDIX: Estimated Cost of extending the Free Travel Scheme in Ireland

According to the Department of Social Protection Annual Statistics Report 2020ⁱ, there were 947,855 availing of the Free Travel Scheme in 2020. The Scheme has grown significantly in recent years. For example, there has been an 18% increase in numbers since 2014 when there were 799,672 people availing of the Scheme.

In 2020, expenditure on the Scheme amounted to €93.69m. On average therefore, the cost of enabling access to the Scheme is €99 (rounded) per person.

According to the Prevalence of Epilepsy in Ireland Report 2009ⁱⁱ (the most recent, and only such study undertaken here), approx. 10 per 1,000 adults (18y+) have epilepsy.

The Central Statistics Office estimatesⁱⁱⁱ that as of April 2021, the population of Ireland is 4.98m, of which 3.65m are 20 years old or more. Taking this to represent the 'adult' population, we estimate that there are currently 36,500 adults with epilepsy in Ireland.

The Epilepsy Model of Care published in 2016 by the HSE's Clinical Strategy and Programmes Division^{iv} states that in up to 70% of cases, seizures are well controlled by medication, while 30% of people continue to have regular seizures. Therefore, we estimate that **10,950** adults in Ireland have uncontrolled epilepsy. It is this group, those who would not be legally entitled to drive, that we believe free travel entitlements should be extended to.

This group of **10,950** is the maximum number of new beneficiaries that would enter the Free Travel Scheme as a result of our proposal. However, in practice this number would be significantly reduced because of the following factors:

1. Some will already have Free Travel as a result of being >66 years old. We estimate this number to be **3,250**, based on CSO population data by age; an epilepsy prevalence rate of 14-17/1000 in that age group (as per the Prevalence of Epilepsy in Ireland report 2009); and an uncontrolled epilepsy rate of 30%.
2. Some will already qualify for Free Travel as a result of having Disability Allowance or other qualifying state benefits. Unfortunately, there is no data available on how many people with uncontrolled epilepsy currently have a qualifying payment, but based on our experience of working with people with epilepsy, we estimate that up to 25% of those aged 18-65 with regular seizures would meet this criteria. Therefore, we estimate that **1,925** of this group already have access to Free Travel.

We therefore estimate that **our proposal would entitle a total of 5,775 adults with epilepsy** who do not otherwise qualify, to access the Free Travel Scheme.

This represents an increase of just **0.6%** to the total number of people with access to Free Travel in 2020.

At an average cost of €99 per person, our proposal would cost the Exchequer just **€571,725** per annum. Again, this would mean a **0.6%** increase to the total cost of providing the Scheme.

ⁱ <https://www.gov.ie/en/publication/802ec-2020-annual-statistics-report/>

ⁱⁱ <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2009.02417.x>

ⁱⁱⁱ <https://www.cso.ie/en/releasesandpublications/er/pme/populationandmigrationestimatesapril2020/>

^{iv} <http://www.hse.ie/eng/about/Who/clinical/natclinprog/epilepsyprogramme/>