



Overview

First of all, we would like to thank the Committee for seeking submissions from people with disabilities and representative bodies in order to inform your important work. Our submission will focus on two key issues that have been identified to Epilepsy Ireland in our work serving people with epilepsy and their families. The submission will be formatted as follows:

- 1) About Epilepsy & Epilepsy Ireland**
- 2) Access to Free Travel for People with Epilepsy who cannot hold a driver's licence as a result of their disability**
- 3) Provision of Reasonable Accommodations for students with epilepsy during state examinations**

As outlined in our cover letter, we would like to stress that these are not the only two issues impacting on the lives of people with epilepsy and their families. However, we are identifying them to the Committee as we believe that they are matters that could be wholly addressed by the Committee within the lifetime of the current Oireachtas term.

Should you require any further information on this submission or in relation to epilepsy or Epilepsy Ireland, please do not hesitate to contact us by emailing pmurphy@epilepsy.ie.

1) About Epilepsy & Epilepsy Ireland

Epilepsy is a neurological disorder characterised by a tendency to have recurring seizures. Nearly 40,000 people in Ireland have epilepsy including 10,000–15,000 people who are living with uncontrolled seizures. For this group in particular, the consequences of epilepsy can be long-lasting and significant. It can affect the person's education, employment, social functioning, self-esteem and independent living. People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications and for many, the social stigma and economic impact that can be associated with it. Its individualised impact on those who live with it means that it is often considered as a hidden disability. There is also an increased risk of mortality associated with epilepsy with an estimated 130 epilepsy-related deaths in Ireland each year.

Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy. Since 1966, we have remained committed to working for, and meeting the needs of everyone with epilepsy in Ireland, their families and carers. Our key aims include:

- To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community.
- To raise awareness and to improve public understanding of epilepsy; and to advocate for the rights of those with epilepsy, their families and carers.
- To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals.
- To undertake, encourage, fund and communicate research into the causes of, cures for and management of epilepsy and into the social and psychological effects of the condition.



2) Access to Free Travel for People With Epilepsy who cannot hold a driver's licence due to their disability

Access to free travel has long been an issue for people with epilepsy and is something we firmly believe that the Committee could achieve real progress on. Despite public misconceptions that still unfortunately exist, people with epilepsy can drive and can hold a full driving license when they are seizure free in accordance with the *Sláinte agus Tiomáint Medical Fitness to Drive Guidelines*.

However, even if a person goes a number of years being seizure free, they can still experience breakthrough seizures. If this person holds a driving licence, they will automatically lose that license until they are at least one-year seizure free again.

Alongside this, there are those with epilepsy who unfortunately will never be able to gain control of their condition and therefore will not be able to drive as a result. In addition, owing to the unpredictable nature of epilepsy, there are others who make a conscious decision not to drive due to the unpredictable nature of epilepsy.

Therefore, many people with epilepsy depend on public transport and this can lead to significant financial costs for people with epilepsy as they aim to continue their work or education.

In the case of a person who may have temporarily lost their license due to a seizure, we believe that they should automatically be given access to Free Travel for the period that they are off the road due to their long term health condition.

We believe that if the state takes away with one hand, then they should accommodate with the other. We are aware of cases where a person with epilepsy has had to give up work due to the costs associated with public transport. As a result, they then depend on state welfare payments which can have an impact on their independence and can lead to a person becoming socially isolated. Automatic access to free travel for this group would help prevent this from happening in the future.

For the cases of people who have uncontrolled seizures and for those who make a conscious decision not to drive, they too will be faced with financial implications.

Some people, particularly those living with ongoing, uncontrolled seizures, will be able to access a free travel pass via qualifying payments such as disability allowance, invalidity pension etc. However, many will not qualify as they do not meet the strict medical criteria for these schemes.

What people with epilepsy need is for the Free Travel scheme to be uncoupled from other payments so they can apply directly for the free travel pass in order to help them with costs of travel which result from their hidden disability.

The Oireachtas Committee on Transport made the recommendation in 2018 that the Free Travel scheme be uncoupled from other payments so people could apply to avail of a free travel pass directly. In addition, a number of countries across of the globe have provisions in place to assist people with epilepsy with the cost of travel – including our neighbours in the UK.

Difficulties in accessing public transport can have a significant impact on a person with epilepsy's ability to continue employment or education and can lead to social isolation and a loss of independence. We believe that it would be cost effective for the state to put in place a mechanism



whereby people with epilepsy can access a free travel pass. We estimate that the proposal would expand the Free Travel scheme by less than 1%. Note that we are not proposing that all 40,000 people with an epilepsy diagnosis are automatically granted access to free travel, only that individuals prevented from driving are given access, limited to the period that they are so prevented.

Access to free travel would make a huge impact in the lives of many people with epilepsy and we believe that the Committee could investigate its provision under the implementation of Article 24 (Personal Mobility), Article 27 (Work and Employment) and Article 28 (Adequate standard of living and social protection) of the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

3) Reasonable Accommodations in State Examinations.

Under the current criteria for the Leaving Cert or Junior Cert examinations, if a student with epilepsy has a seizure before or during their exam and is unable to complete their exam, there is no provision to allow that student resit their exam at a later date.

With particular reference to the Leaving Cert, this can have a huge impact as that person will essentially have to wait until the following year to complete their examinations. Of the approximate 600 students with epilepsy sitting the Leaving Cert each year, at least one third have active, uncontrolled seizures.

There are a number of reasonable accommodations that may be applied for through the RACE Scheme. The purpose of the RACE system is to remove the impact of a disability on the student's exam performance and enable them to demonstrate their level of achievement. Unfortunately, existing accommodations (e.g. additional time, rest periods or a separate room) do not compensate for the often severe after-effects of a seizure which can include exhaustion, confusion, nausea, headache, disorientation or even temporary amnesia.

Therefore, existing accommodations do not adequately address the greatest concern that many students with epilepsy hold. The threat of a seizure is a constant worry that can, in an instant, destroy years of hard work. We work with families every year in this situation and for some, the fear becomes a reality with a single seizure forcing students to unnecessarily repeat their Leaving Cert a year later.

For a young person, this can be particularly difficult as they watch their peers' progress on to college while they are left in limbo waiting to complete their examinations.

Internationally, there are many examples where more appropriate accommodations can be provided where needed. We believe that in Ireland, there remains an outdated onus on the student needing to fit the system whereas the trend in other countries is for an individualised approach that attempts to fit the system around the student.

For many years, the Department of Education have been resolute in their position that no alternative arrangements could be made on this matter. However, in recent years, provision was finally made to cater for students who had experienced a bereavement during the state exams.



We believe that as result of this, there is now a clear pathway to allow students who may be impacted by a health condition or hidden disability such as epilepsy to be allowed to re-sit their exam at a later date the same year should they be impacted by their condition during a state exam.

There are a number of provisions within Article 24 (Education) of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) that the Committee can investigate to ensure that this situation is addressed in Ireland.

Conclusion

We have outlined to the Committee just two issues within its remit which have impacted on people with epilepsy for many years. These are priority issues that we believe can be addressed with renewed collaboration and political will.

We hope to be able to work hand in hand with members of the Committee to have these matters addressed and we would be delighted to provide further details to the Committee as required.