



Epilepsy Ireland: committed to meeting the needs of everyone with epilepsy

**26 March is Purple Day
and Epilepsy Ireland CEO,
Peter Murphy, discusses
the condition and the
work of the organisation
across the country**



Epilepsy is more common than you might think. Over 37,000 people in Ireland over the age of five have epilepsy, making it one of the most common neurological conditions but, despite its prevalence, it remains a much misunderstood and often stigmatised hidden disability.

The word 'epilepsy' is used to describe a group of disorders, all of which are characterised by recurrent unprovoked seizures involving abnormal electrical activity in the brain. About one in every 20 people will have a seizure at some time during their lives.

For decades, the terms partial and generalised seizures were used to describe types of seizures. Partial seizures were those starting in one area or side of the brain, while generalised seizures were those occurring in both sides of the brain at the same time. In 2017, The International League Against Epilepsy revised its classification of seizures. The new classification is based on three key features: where seizures begin in the brain,

level of awareness during a seizure, and other features. This means that terms such as simple partial seizure and complex partial seizure are now replaced with Focal Aware and Focal seizure with impaired awareness respectively.

Epilepsy affects people of all ages, but is more prevalent in children, adolescents and those over 65 years. It is also more common in people with an intellectual disability. In about 60% of cases, no specific cause can be identified. In the remaining 40% of people, common causes include head injuries, strokes, brain infections, birth defects and genetic conditions.

With anti-epileptic drug (AED) treatment, up to 70% of people with epilepsy can achieve seizure control, while surgery or vagus nerve stimulation, as well as the ketogenic diet in children are also options that may be considered. Deep brain stimulation, cannabinoids and personalised therapy targeted to specific genetic mutations, are just three areas of current research that offer hope for the future.

However, there are at least 10,000 people in Ireland living with uncontrolled seizures, and for this group in particular, the consequences of epilepsy can be long-lasting and significant. It can affect the person's education, employment, psychological and 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. 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 work

Our support services, delivered through our offices in Dublin, Cork, Dundalk, Galway, Kerry, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore are the core of our work and will be of interest to pharmacists across the country.

Our team of Community Resource Officers are key contacts for individuals or family members with epilepsy and depending on the need of the individual, can provide one-to-one support and advocacy, outreach services, educational programmes and self-management programmes. We also organise regular events and support groups in communities across the country.

STEPS is our six-session self-management programme for people with epilepsy. It supports people on a range of issues including seizure management, lifestyle issues, triggers and safety planning, managing moods and thoughts, communications and planning for the future. This course will help adults with epilepsy to meet others, manage their epilepsy and improve quality of life. We also offer a STEPS programme for parents as well as Innerwise, a follow-on programme designed to address stress management,

anxiety, wellness and personal confidence through meditation and personal development.

We also provide facilitated support sessions for those recently diagnosed with epilepsy, called the Living Well with Epilepsy Toolkit. The Toolkit is a comprehensive introduction to epilepsy management and includes handy resources such as a seizure diary, safety checklist and an epilepsy knowledge checklist. Demand for our services has grown by almost 40% over the past three years due to these new programmes and to strong links with clinical epilepsy services nationwide.

Another important service which continues to grow is our training programme in Epilepsy Awareness and the administration of Buccal Midazolam (BM) for healthcare professionals and those working in education or care settings. Over 2,000 people attended our training courses in 2018 and we also began providing BM demonstrations for parents and carers.

Epilepsy Ireland's award-winning Training for Success course is currently recruiting for the upcoming one-year term starting in August 2019.

Based at the Institute of Technology Sligo, this one-year full time QQI Level 5 Access Programme has helped over 250 young people with epilepsy achieve life and career goals since its inception in 1998.

Our newly revamped website, www.epilepsy.ie, contains useful information for pharmacists and their patients alike, including a range of new epilepsy information booklets and our Epilepsy Management App for iPhone and Android, which can be downloaded from the site. The app helps record information about seizures (including video), identify potential triggers and seizure patterns, set important reminders, send emergency texts, organise medical appointments and measure missed medications.

In 2019, we hope to develop a new comprehensive guide



Purple Day 26 March

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. Iconic buildings around Ireland will be lighting up purple to mark the occasion and we are inviting people to wear purple and host events in support of epilepsy awareness on this day.

To get a Purple Day wristband and for more information, visit www.epilepsy.ie or email info@epilepsy.ie.

to epilepsy for healthcare professionals, in association with our clinical care colleagues and we would welcome input from pharmacists who would like to contribute to the development of this important resource.

Likewise, if you are aware of a patient who would benefit from any of the supports outlined above, please do refer them to Epilepsy Ireland or contact us for more information.

Improving public understanding of epilepsy, supporting epilepsy research and advocating on behalf of people with the condition are also key objectives of our organisation. One of the most important issues in recent times relates to reducing the risks associated with in-utero exposure to sodium valproate. Children exposed to valproate in utero are at a high risk of serious developmental disorders (in up to 30 – 40% of cases) and congenital malformations (in approximately 10% of cases). While there is no official Irish data available, the FACS (Foetal Anti Convulsant Syndrome)

Forum estimates, based on international data, that at least 400 children in Ireland have been affected since the 1970s.

In February 2018, the European Medicines Agency put in place new risk minimisation measures which are being implemented in Ireland by the Health Products Regulatory Authority (HPRA). Epilepsy Ireland welcomes the strengthened warnings and educational resources which have been made available, which include patient and professional guides, alert cards, pharmacy posters and shelf barkers. These, and additional measures such as pregnancy prevention programmes, PL and SmPC updates, on-box and blister warnings, as well as reducing valproate pack sizes, will all combine to help to reduce the incidence of Foetal Valproate Syndrome in the years to come.

The role of pharmacists in educating and counselling patients will be a critical component in achieving this, building on the long-standing and vital role played by the profession in epilepsy care for generations in Ireland.