



## EPILEPSY AND DRIVING- A POSITION PAPER OF EPILEPSY SOUTH AFRICA DEVELOPED IN MARCH 2016

### 1. INTRODUCTION

#### Identification of the issue

Epilepsy is recognised as the second most prevalent neurological condition. Worldwide there are approximately 50 million individuals and their families living with a diagnosis of epilepsy. Epilepsy impacts all areas of an individual's life. There are significant social, economic, educational and employment ramifications and these place additional burdens on the family. Each individual's experience of epilepsy is unique and personal. No two people will experience epilepsy in exactly the same way. The type, frequency and predictability of seizures will vary from person to person. Appropriate medication, learning to recognise personal triggers and developing healthy ways to avoid them, and maintaining good health and rest will all help to reduce the impact epilepsy may have on an individual and their family.

Epilepsy impacts on people's ability to be considered safe to drive. After the initial diagnosis, the type, frequency and predictability of seizures directly affect the chances of someone living with epilepsy to obtain or maintain a driver's licence or permit. In surveys driving is listed as a first or second concern by people with epilepsy (PWE), after the wish to be seizure free. Being directed to surrender a licence after diagnosis of epilepsy or a seizure can disrupt someone's entire life, especially if you require transport to maintain employment or to transport children. This can be an extremely stressful time for people with epilepsy and their families.

Driving while having active epilepsy clearly poses and increased risky drivers. Filling out an application to operate a motor vehicle has legal implications. The applicant is swearing that they have the ability to safely operate a motor vehicle. Misleading the authorities by falsifying an application to drive or not following the law may have both civil and criminal legal implications should a car crash occur. Although the rules for licensure for PWE are codified by driving authorities, the actual risk associated with driving is less certain. Each year nearly 1.3 million people as a result of a road traffic collision-more than 3000 deaths each day-and more than half of these people are not travelling in a car. Twenty to fifty million more people sustain non-fatal injuries from a collision, and these injuries are an important cause of disability. Typically, statistics are not gathered for the number of car crashes due to medical reasons and the number of people with serious medical conditions on the road is unknown.

Legislation regarding epilepsy and driving exists in most countries in the world. Current legislation in most countries in the world permits PWE who have controlled seizures to obtain a driving license. Legislation regarding driving and epilepsy should attempt to balance the important economic and social value of driving with the risk to public safety from seizure-related road traffic accidents. Restrictions still vary from country to country and from region to region.

### **South African Legislation: National Road Traffic Act 93 of 1996**

#### **“Uncontrolled Epilepsy”**

According to Section 15(1)(e)(i) of the National Road Traffic Act 93 of 1996, states that "A person shall be disqualified from obtaining or holding a learner's or driving licence if such licence relates to a class of motor vehicle which he or she may already drive under a licence held by him or her; if he or she is suffering from one of the following diseases or disabilities :

#### **i) Uncontrolled epilepsy;**

Therefore a person with uncontrolled epilepsy may not be permitted to drive any motor vehicle, whether a light vehicle for private use or as a driver for passenger or goods conveyance.

South African Legislation on “epilepsy and driving” addresses the matter of a PWE having uncontrolled epilepsy that they are not allowed to drive. It also states that a driver if he/she becomes aware that he/she is disqualified from holding such a license than they need to report this matter within 21 days after having become aware of the disqualification. There are several grey areas in the National Traffic Law Act 93 of 1996 regarding guidelines for controlled epilepsy, guidance of control or remission of seizures and any discussions on seizure free intervals which should be a main determinant in the ability to drive.

#### **Statement of the position**

Epilepsy South Africa acknowledges that for many adults, the sudden loss or suspension of a driving licence for a significant period of time can adversely affect employment, education, and social participation. Driving restrictions impacts on quality of life and independence of PWE. Driving requires the driver to correctly identify threats and changes in the environment, interpret these changes and respond appropriately to avoid a crash. These threats and changes are different depending on the local environment, traffic congestion, and physical condition of the driver. Normal vision (acuity/visual fields), motor skills, reaction times, cognition, and judgment all impact the ability to drive. People with epilepsy, due to the nature of their condition, may have one or more impairments due to their condition.

Antiepileptic drugs (AEDs) both new and old, have the potential to control seizures but also may negatively impact the ability to safely operate a motor vehicle by affecting the patients' physical abilities. Potential side effects of AEDs exist that could affect the ability to safely drive, such as blurred and double vision, fatigue, and even tremor.

It is well understood that driving carries the risk of accident. Historically driving restrictions have been based more on expert opinion than sound scientific evidence, the appropriateness and applications of standard licensing drivers with epilepsy continue to raise concerns , as does the role of physicians should have in the process.

The organisation needs to review our current driving regulations, management guidelines, medical standards and evaluate whether there is a balance in the interests of public health and safety, and the promotion of the optimal quality of life for people living with epilepsy.

## 2. BACKGROUND INFORMATION AND CHALLENGES

“Driving” and “Epilepsy” have always been a difficult combination. Historically fear, poor knowledge and lack of understanding about epilepsy have led to decisions being made banning individuals with seizure history or epilepsy from driving under any circumstances. When developments in law required a driver’s licence to become compulsory, individuals with a history of seizure or epilepsy were initially excluded from obtaining a driver’s licence.

By the 1940’s it became obvious that, overtime, some individuals who suffered seizures could gain seizure control and that the increasing use of new and positive medications could offer good seizure control to people with epilepsy. This then allowed for a gradual shift in community and government thinking. Perhaps it was possible for those individuals to be considered for a driver’s licence, and so, the debate began about what factors needed to be in place before it would be considered safe for both the individual and the community to have individuals with seizure history licenced on the road. It was also a time when it was acknowledged that other medical conditions could also interfere with driving.

Early studies concluded that with a demonstrated period of seizure free living, individuals could safely return to the road with their driver’s licence. Legislation addressing specific legal requirements has been enacted, and national guidelines have been developed to give reasonable opportunities to individuals with epilepsy to drive. There continues to remain considerable conflict and debate about widening driving legislation and standards and the discussion regarding individual and public safety over the individual’s right to drive continues.

### **WHO CAN DRIVE, WHO CAN’T AND WHO DECIDES?**

Several studies were undertaken and the results showed that, although epilepsy did pose some risk, this risk was relatively small especially when considered against other understood risks such as driving when under the influence of alcohol. One study into accidents that had occurred involving drivers with epilepsy showed that, although there was a higher risk of accident for individuals with epilepsy, only 11% of these accidents occurred due to the epilepsy itself. The rest resulted from driver error at the same rate as seen in the general driving population.

Studies of large populations confirmed that the risk of PWE having an accident is not substantially higher than for other licenced individuals who experience medical conditions such as heart disease or diabetes. Yet, to date, there are few additional restrictions for individuals with these other conditions. Overall the studies showed that, as with all potential drivers, people with epilepsy require additional regulation and may not always be well informed by doctor. Guidelines and restrictions are justified to safely permit individuals with controlled seizures to drive. In deciding it was permissible for individuals with epilepsy to gain a driver’s licence, if they had seizures control, this resulted in ongoing debate about what control meant. The legal rules and regulations

that appeared were often confusing and complex and differed between states and territories. For many years the required period that individuals needed to be seizure free before obtaining or retaining their driver's licence varied from between three months and ten years.

Further confusion exists about the process and requirements to determine who is medically suitable and acceptable as being fit to drive. Discrepancies between countries, regions and Territory regulations add additional stress and difficulty for PWE. It is difficult to know how or where to start the process of accessing their suitability to drive. While medical practitioners are required to supply a professional opinion generated from medical facts, ultimately any decision regarding driver licence eligibility lies with the relevant licencing authority. Motor vehicle licencing authorities use a variety of benchmarks, indicators and statistics in developing the standards for and limitations of individuals with epilepsy and other medical conditions. This includes consideration of what constitutes acceptable risk and judging the likelihood of any individual being able to safely conform to the requirements of driving and driving regulations.

Unfortunately many of the issues regarding fear, lack of knowledge and a lack of understanding about the experience of people with epilepsy still continue today. Individuals denied access a driver's licences experience many additional problems and challenges that can further exacerbate the existing seizure condition. The ability to drive and hold a licence is generally assumed right internationally today, and many aspects of life are very difficult to engage in without being able to drive.

Research has shown that when comparing the accident ratio rate for drivers with epilepsy, the rate is far lower than for young drivers, older drivers and drivers who drive while deprived of sleep or having consumed alcohol within the legal limit. It is interesting to consider that the community and the licencing authorities accept the accident ratio rates for all the other groups except for those PWE.

## **THE QUESTION OF COMPLIANCE**

Belgian law requires a 2-year period of seizure freedom, even after a first epileptic seizure. A group of neurologists estimated that 70% of their epilepsy patients that were not allowed to drive still did so. The European second Working Group (2005) recommends that making laws more liberal, more people will adhere to it. Liberal rules may persuade PWE to undergo an assessment to stick to the rules for several reasons:

- they have the perspective of getting their licenses back;
- they may accept the rules as reasonable;
- they drive legally;
- shorter seizure free periods will also increase the reporting of seizures to their physician and
- they feel relieved of the responsibility and uneasiness of doing something that may endanger other people and themselves.

## **WHO SHOULD NOTIFY THE DRIVING LICENCE AUTHORITY ON DIAGNOSIS?**

In most cases it is the driver who has the legal responsibility to notify the appropriate transport authority. This is an area of confusion and concern as there is often a lack of clear clarity in the guidelines around this issue. Contrary to general community

expectation the treating medical practitioner does not always inform the patient about the responsibilities of disclosure.

The line between the doctor's role as treating physician and as law enforcer can be very problematic. Often medical practitioners prefer not to risk introducing any potential barriers or objections that may risk the doctor/patient relationship which could lead to doctor/patient breakdown. If a medical practitioner feels that the patient is likely to be a risk to themselves or others and suspects that the patient will not reveal relevant medical information to the appropriate authorities, the question raised is the medical practitioner obligated to report the issue to the licencing authorities?

### 3. RECOMMENDATIONS

- All legislation dealing with PWE should first aim to promote the capacity of PWE to exercise their autonomy and their right to live independently and to be included in the community.
- Establish a South African Working Group on Driving and Epilepsy and working in partnership with the European Working Group on Epilepsy and Driving. Review the recommendations made by the Second European Working Group on Epilepsy and Driving and using this international guidelines when drafting more liberal laws for epilepsy and driving. Below are a few recommendation of the Second European Working Group (2005):
  - The issue is mandatory reporting needs to be discussed further whether the organisation supports this or whether it advocates for self-reporting with the individual taking responsibility for the condition and the limitations it presents. Consequences, for example, may be the inability to get to work, loss of employment resulting in financial hardship, or difficulties in meeting family commitments. The organisation will also have to strongly advocate for government transport assistance to support the person with epilepsy during the suspension period until driving rights are restored. Various literature sources states that mandatory reporting to authorities by the treating doctor as it will encourage non-reporting of seizures to the treating doctor. The withholding of information interferes with treatment and has the potential for possible fatal consequences. Mandatory reporting breaches doctor-patient confidentiality, has the potential to erode the doctor-patient relationship, and serves neither patient nor

public safety. The European Second Workgroup (2005) also recommends that it the responsibility not of the doctor, but the patients whether he/she drives or not, and it his/her duty to report to authorities. Mandatory reporting is also considered as working against road safety because it discourages the declaration of symptoms of patients. It also recommends that the assessing physician should be legally protected as regards his/her advise about driving ability and if he/she reports or does not report the non-complaint patient to authorities.

- The risk assessment should be based on the risk assessment of the individual ("R": relative risk) rather than on the risk of the population.
  - The dangers of the population are low if people continue driving in a car after a first seizure and the effect on the population level of not letting them drive may not outweigh the socio-economic disadvantages.
  - There are many factors at play in the ability to drive that cannot be easily quantified. An individual assessment by a neurologist is recommended for every patient that has had one or more seizures.
- Decisions are based on a full consideration of relevant factors relating to health and driving performance, including medical reports provided by a treating practitioner; and such a system should be supported by a review process consisting of an expert panel of neurologists indemnified by the driver licensing authority.
  - Epilepsy South Africa supports the development and promotion of better evaluation tools to assess driver safety. Training needed to be conducted with state officials and also medical practitioners and the tools should be developed in co-operation with state transportation officials and other medical experts groups, to include physicians and also PWE.
  - More research and planning are needed to help state officials evaluate road safety of drivers with medical conditions.
  - South African government, NPO's and DPO's need to do more to ensure alternative transportation alternatives for people who no longer possess driving privileges as a result of driving laws.

#### 4. CONCLUSION

Considerable medical, epidemiological, and public policy research will be required to properly address the issue of driving and epilepsy. Current problems arise from gaps in

knowledge regarding driving risks for PWE and deficiencies in established methods of regulation, both which also present future opportunities for scientific research and public policy change. Promotion of public safety and transportation for PWE require good and reliable alternatives to driving a car. Some individuals will never meet the criteria to drive, and no society seeks to license individuals with uncontrolled epilepsy, who are at risk of having a driving accident. Epilepsy South Africa needs to advocate strongly for PWE and also to improve regulations for drivers with epilepsy and seizures. Involved and knowledgeable professionals can also help define best practices through evidence-based guideline development and can advocate for clients welfare. On an individual basis professionals working with PWE can provide informed opinions and constructive criticisms to regulators and policy makers as well as their patients and their families.