1. INTRODUCTION

Identifying the issue

Epilepsy is recognised as the second most prevalent neurological condition with approximately 50 million individuals and their families worldwide 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 with the type, frequency and predictability of seizures varying from person to person. Appropriate medication, learning to recognise personal triggers, developing healthy ways to avoid them and maintaining good health and rest will help to reduce the impact epilepsy may have on an individual and their family.

Epilepsy impacts on people’s ability to be eligible to drive safely. After the initial diagnosis, the type, frequency and predictability of seizures directly affect the chances of a person with epilepsy obtaining or retaining a driver’s licence/permit. In surveys driving is listed as a first or second concern by people with epilepsy, after the wish to be seizure free. (Final Report: Epilepsy & Driving in Europe, 2005) Being directed to surrender a licence after diagnosis of epilepsy or a seizure can disrupt a person’s entire life, especially if transport is required to maintain employment or transport children. This can be an extremely stressful time for people with epilepsy and their families.

Driving with active epilepsy clearly poses an increased risk. Completing an application to operate a motor vehicle has legal implications as the applicant swears that he/she is able to safely operate a motor vehicle. Misleading authorities by falsifying an application for a driver’s license or not adhering to legal requirements may have both civil and criminal legal implications in the event of a vehicular accident. Although the rules for licensure for persons with epilepsy are codified by driving authorities, the actual risk associated with driving is less certain.

According to the Global Plan for the Decade of Action for Road Safety 2011-2020, nearly 1,3 million people dies annually as a result of a road traffic collision - more than 3,000 deaths daily - and more than half of these people are not travelling in a car. Twenty to fifty million more people sustain non-fatal injuries resulting 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 pertaining to epilepsy and driving exists in most countries in the world with current legislation in most countries permitting person with epilepsy who have controlled seizures to obtain a driving licence. Legislation regarding epilepsy and driving must 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 (Epilepsy Out of the Shadows, 2012).

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

“Uncontrolled Epilepsy”

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 person with uncontrolled epilepsy in denying such a person the right to drive. It also states that if a driver becomes aware that he/she is disqualified from holding such a license this must be reported within 21 days. There are several grey areas in the National Traffic Act 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 impact on quality of life and independence of persons with epilepsy.

Safe driving requires the driver to correctly identify threats and changes in the environment, interpret these changes and respond appropriately to avoid an accident. These threats and changes differ 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 (Berger et al, 2000).

Both new and older anti-epileptic drugs (AEDs) have the potential to control seizures, but may also negatively impact the ability to safely operate a motor vehicle by affecting the person’s physical abilities. Potential side effects of AEDs could affect the ability to drive safely, such as blurred and double vision, fatigue and even tremor.

It is understood well 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 of drivers with epilepsy continue to raise concerns, as does the role of physicians 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 on the one hand and the promotion of the optimal quality of life for persons with epilepsy on the other.

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, over time some individuals could gain seizure control and that the increasing use of new and positive medications could offer good seizure control to people with epilepsy. This allowed a gradual shift in community and government thinking. Perhaps it was possible for such individuals to be considered for a driver’s licence, and so the debate began about the required factors before it would be considered safe for both the individual and the community to have individuals with seizure history licenced and driving on the road. It was also a time when it was acknowledged that other medical conditions could also interfere with driving (Krumholz, 2009).

Early studies concluded that with a demonstrated period of seizure free living individuals could safely regain their driver’s licence and return to the road. Legislation addressing specific legal requirements has been enacted and national guidelines developed to give reasonable opportunities to individuals with epilepsy to drive. However, considerable conflict and debate continue about expanding driving legislation and standards. As such, the discussion regarding individual and public safety over the individual’s right to drive continues (Krumholz, 2009).

**Who can drive, who can’t and who decides?**

Several studies showed that, although epilepsy did pose some risk, this risk was relatively small especially when considered against other risks such as driving when under the influence of alcohol. One study on accidents 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 accident risk of persons with epilepsy 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 studies showed that, as with all potential drivers, people with epilepsy require additional regulation and may not always be well informed by medical practitioners. Guidelines and restrictions are justified to safely permit individuals with controlled seizures to drive.
The decision whether individuals with epilepsy should obtain a driver’s licence if their seizures were under control resulted in ongoing debate about what control meant. Legal rules and regulations were often confusing and complex and differed between states, territories and countries. For many years the required period that individuals needed to be seizure free before obtaining/retaining their driver’s licence varied from three months to ten years.

Further confusion exists about the process and requirements to determine who is medically suitable and acceptable as fit to drive. Discrepancies between countries, regions and territory regulations add additional stress and difficulty for persons with epilepsy. It is difficult to know how or where to start the process of assessing suitability to drive.

While medical practitioners are required to supply a professional opinion based on medical facts any decision regarding driver licence eligibility ultimately lies with the relevant licensing authority. Motor vehicle licensing authorities use a variety of benchmarks, indicators and statistics in developing standards for and limitations of individuals with epilepsy and other medical conditions. These include 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 issues relating to fear, lack of knowledge and a lack of understanding about the experience of people with epilepsy still continue today. Individuals denied access to 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 an assumed right internationally today and many aspects of life are very difficult to engage in without being able to drive.

Comparative research has shown the accident ratio rate for drivers with epilepsy to be far lower than for young drivers, older drivers and sleep-deprived drivers or those having consumed alcohol within the legal limit. It is interesting to consider that the community and licensing authorities accept the accident ratio rates for all the other groups except for persons with epilepsy (Final Report: Epilepsy & Driving in Europe, 2005).

**The question of compliance**

According to the Final Report on Epilepsy & Driving in Europe (2005) Belgian law requires a two-year period of seizure freedom, even after a first epileptic seizure. A group of neurologists estimated that 70% of their epilepsy patients who were not allowed to drive still continued to do so.

The Final Report on Epilepsy and Driving in Europe (2005) recommends that making laws more liberal will improve adherence. Liberal rules may persuade persons with epilepsy to undergo an assessment to adhere to the rules for several reasons:

- They have the prospect of getting their licenses back;
- They may accept the rules as reasonable;
- They drive legally;
- Shorter seizure-free periods will increase the reporting of seizures to their doctors; and
- They feel relieved of the responsibility and uneasiness of doing something that may endanger other people and themselves.
According to a study conducted by Berg et al (2000) there is a relationship between the social expectation or need to drive and the number of people with epilepsy that drives illegally. The number of experienced seizures and the availability of public transport for PWE will likely influence compliance with rules for driving. An understandable and convincing explanation of the risk-increase should be given to the patient/client and this will then increase compliance (Final Report: Epilepsy & Driving in Europe, 2005). Physicians should also educate patients about epilepsy which impair driving, and be attentive to increases in disability over time. Some impaired drivers avoid their responsibility to stop driving due to emotional and logistical concerns of immobility and dependence. The multi-disciplinary team providing services to PWE should also consider family support in this life-event. As family members can provide emotional support to the PWE, can reinforce the concerns expressed by the physicians and social workers etc..., can assist in articulating his/her concerns and can play a very important role in developing strategies for patient safety and welfare (Berger et al, 2000).

**Who should notify the driving licence authority on diagnosis?**

In most cases the driver 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 clarity in guidelines around this issue. Contrary to general community expectation the treating medical practitioner does not always inform the patient about his/her disclosure responsibilities.

The line between the doctor’s role as treating physician and 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 as this 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, question are raised regarding the medical practitioner’s obligation to report the issue to the licencing authorities.

### 3. RECOMMENDATIONS

- a) All legislation dealing with persons with epilepsy should first aim to promote their capacity to exercise autonomy and their right to live independently and be included in the community (Epilepsy Out of the Shadows, 2012).

- b) Legislation about epilepsy and driving and should attempt to balance the important economic and social value of driving with the risk to public safety from seizure-related road traffic accidents.

- c) Epilepsy South Africa should campaign to establish a South African Working Group on Driving and Epilepsy to work in partnership with the European Working Group on Epilepsy and Driving. The South African Working Group on Driving and Epilepsy should include a variety of experts: (i) Representatives of Epilepsy South Africa; (ii) traffic authorities (local and national); (iii) the Department of Transport; (iv) a neurologist; (v) a representative of the SADA Sub-Committee on Aviation, Public and Private Transport; (vi) representatives of the Arrive Alive Campaign; and (vii) persons with epilepsy.
Recommendations made in the Final Report on Epilepsy and Driving in Europe (2005) should be reviewed to enable using these international guidelines when drafting more liberal laws about epilepsy and driving in South Africa. Addenda A and B (attached) provides an overview of the regulations established by the Second European Working Group on Epilepsy and Driving (2005). The following recommendations require further discussion and debate by the proposed South African Working Group on Epilepsy and Driving:

- Epilepsy South Africa will need to determine whether it supports the concept of mandatory reporting or whether it intends advocating for self-reporting with the individual being responsible for their condition and the limitations it presents. Consequences may include 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 persons with epilepsy during the suspension period until driving rights are restored. Various literature sources object to mandatory reporting to authorities by the treating doctor as this is likely to encourage non-reporting of seizures to the treating doctor. Withholding information interferes with treatment and has the potential for 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 reporting is not the responsibility of the doctor, but the patient. Mandatory reporting is also considered as working against road safety because it discourages the declaration of symptoms. It is also recommended that the assessing physician should be legally protected regarding his/her advice about driving ability and reporting to authorities.

- Risk assessment should be based on the risk assessment of the individual (“R”: relative risk) rather than on the risk of the population as a whole.

- Dangers to the general population are low if people continue driving after a first seizure and the effect on the population of restricting driving may not outweigh the socio-economic disadvantages to persons with epilepsy.

- Many factors are at play in the ability to drive that cannot be easily quantified. An individual assessment by a neurologist is recommended for every person who has had one or more seizures.

- Decisions are based on the full consideration of relevant factors relating to health and driving performance, including medical reports provided by a treating practitioner. Such a system should be supported by a review process consisting of an expert panel of neurologists indemnified by the licensing authority.

- Epilepsy South Africa supports the development and promotion of better evaluation tools to assess driver safety. Training of state officials and medical practitioners is also required while the tools should be developed in cooperation with state transportation officials, medical experts and persons with epilepsy.

- Further research and planning is needed to help state officials evaluate road safety of drivers with medical conditions.
The South African government, NPOs and disability organisations need to do more to ensure alternative transportation for people no longer holding 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 persons with epilepsy and deficiencies in established methods of regulation, both of which also present future opportunities for scientific research and public policy change.

Promotion of public safety and transportation for persons with epilepsy 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 at risk of having an accident.

Epilepsy South Africa needs to strongly advocate on behalf of persons with epilepsy to improve regulations for drivers with epilepsy and seizures. Knowledgeable professionals can help define best practices through evidence-based guideline development and advocate for the welfare of persons with epilepsy.

On an individual basis professionals working with persons with epilepsy can provide informed opinions and constructive critique on regulators and policy makers as well as their patients and their families.

This position paper was adopted by the National Board of Epilepsy South Africa on 23 April 2016.
Table 1 Epilepsy Proposed Guidelines for Group 1

Group 1:
A licence may be issued or renewed subject to an examination by a competent authority to the state of epilepsy or other disturbances of consciousness its clinical form and progress (no seizures in the last 2 years, for example), the treatment received and results thereof.

Group 1 refers to categories A: motorbike and B: car


General rules

A person who has an initial or isolated seizure or loss of consciousness should be advised not to drive. A specialist report is required, stating the period of driving prohibition and the requested follow-up.

Drivers, assessed under group 1 with epilepsy should be under licence review until they have been seizure–free for at least 5 years.

If a person has epilepsy, the criteria for an unconditional licence are not met. The patient should notify the Licensing Authority.

It is extremely important that the patient’s specific epilepsy syndrome and seizure type are identified so that an adequate evaluation of the person’s driving safety can be undertaken (including the risk of further seizures) and the appropriate therapy instituted. This should be done by a neurologist.

Clinical situations | Advise
--- | ---
Provoked epileptic seizure | The applicant that has had a provoked epileptic seizure because of a recognisable provoking factor that is unlikely to recur at the wheel can be declared able to drive on an individual basis, subject to neurological opinion.
First unprovoked seizure | The applicant who has had a first unprovoked epileptic seizure can be declared able to drive after a period without seizures of six months, if there has been an appropriate medical assessment.
Other loss of consciousness | The loss of consciousness should be assessed according to the risk of recurrence while driving.
<table>
<thead>
<tr>
<th>Epilepsy</th>
<th>Drivers or applicants can be declared fit to drive after a 1-year period of further seizures.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Special Situations</strong></td>
<td></td>
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<tr>
<td>Sporadic seizures</td>
<td>If the period between the last seizure and penultimate seizure is more than 5 years, the last seizure may be considered in a similar fashion to a first unprovoked seizure for licensing purposes, subject to a neurological opinion.</td>
</tr>
<tr>
<td>Seizure without influence on consciousness, or ability to act without (ever) having (had) any other kind of seizure</td>
<td>The applicant or driver who has had seizures exclusively during sleep or seizures which have been demonstrated exclusively to affect neither consciousness nor cause any functional impairment can be declared fit to drive so long as this pattern has been established for a period which must not be less than the seizure free period required for epilepsy.</td>
</tr>
<tr>
<td>Seizures exclusively during sleep</td>
<td></td>
</tr>
<tr>
<td>Seizures because of physician directed change or reduction of AE therapy</td>
<td>Patients should be warned of the risk they run coming off medication, both of losing their driving licence and also of having a seizure, which could result in a road traffic accident. The patient may be advised not to drive for a period of 6 months after cessation of treatment. Seizure occurring during physician advised change or withdrawal of medication require 3 months off driving if previously effective treatment is reinstated.</td>
</tr>
<tr>
<td>After curative epilepsy surgery</td>
<td>1 year seizure-freedom</td>
</tr>
</tbody>
</table>
Table 2 Epilepsy Proposed Guidelines for Group 2

**Group 2:**

Driving licence shall not be issued to or renewed for applicants or drivers suffering or liable to suffer from epileptic seizures or other sudden disturbances of the state of consciousness.

Group 2 refers to categories C: truck and D: bus

Other countries Group 2 also includes taxi drivers, rental services with drivers, drivers for school transport, public transport and transport organised and run by employers.


<table>
<thead>
<tr>
<th>Clinical situations</th>
<th>Advise</th>
</tr>
</thead>
<tbody>
<tr>
<td>General conditions for all Group 2 drivers</td>
<td>The applicant should be without antiepileptic medication for the required period of seizure freedom; There has been an appropriate medical follow up; On extensive neurological investigation no relevant cerebral pathology has been established and there is no epileptiform activity on the EEG. The subject can only be declared able to drive subject to neurological opinion. The risk of having a seizure should be 2% per annum or less.</td>
</tr>
<tr>
<td>Provoked seizures, because of a recognisable and avoidable provoking factor</td>
<td>The applicant that has had a provoked epileptic seizure because of a recognisable provoking factor that is unlikely to recur at the wheel can be declared able to drive on an individual basis, subject to neurological opinion. An EEG and an appropriate neurological assessment should be performed after the acute episode. Someone with a structural intracerebral lesion who has increased risk of seizures should not be able to drive vehicles of group 2 until the epilepsy risk has fallen to at least 2% per annum.</td>
</tr>
<tr>
<td>First unprovoked seizure</td>
<td>The applicant who has had a first unprovoked seizure can be declared able to drive once 5 years freedom of further seizures has been achieved without the aid of anti-epileptic drugs, if there has been an appropriate neurological assessment. National authorities may allow drivers with recognised good prognostic indicators to drive sooner.</td>
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<tr>
<td>Other loss of consciousness</td>
<td>The loss of consciousness should be assessed according to the risk of recurrence while driving. The risk of recurrence should be 2% per annum or less.</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>10 years freedom of further seizures has been achieved without the aid of anti-epileptic drugs. National authorities may allow drivers with recognised good prognostic indicators to drive sooner.</td>
</tr>
<tr>
<td>Special Situations</td>
<td>Driving ban</td>
</tr>
<tr>
<td>Prophylactic ban</td>
<td>Certain disorders have an increased risk of seizures, even if seizures have not yet occurred. In such a situation an assessment should be done: the risk of having a seizure should be 2% per annum or less.</td>
</tr>
</tbody>
</table>
References


National Road Traffic Act, 93 of 1996