

Transport Review

Issues – People with epilepsy

1. Driving restrictions

Almost all people diagnosed with epilepsy are told initially they cannot drive, and lose their license. The period of time which they can reclaim their license varies from 3 months to an indefinite time, depending on the seizure control (if someone is not seizure free for 2yrs). The license can be revoked again at any time, if further seizures occur. This can result in:

- I. Restricted employment – many people with epilepsy are unemployed or underemployed, creating financial difficulties as a result
- II. Isolation, particularly socially - due to more expensive travel costs, and limited finances, many people limit themselves to essential travel only
- III. Increased dependence upon others. Many people with epilepsy who are unable to drive rely on public transport, taxi's and family and friends/colleagues for mobility.

2. Recognising epilepsy as a disability

People with epilepsy frequently are declined any mobility allowance or taxi subsidy as they do not fit the criteria for disability. In many circumstances, they are not allowed to drive, and riding a bike can even be considered risky if seizures are not fully controlled.

- I. Epilepsy is currently not recognised as a disability unless the condition is severe or quite disabling.
- II. Epilepsy is frequently unpredictable and prognosis is often difficult to determine. Therefore many people cannot prove they will be incapable of driving for certain periods, as they are never certain. This creates difficulties in obtaining many different types of welfare, not just mobility allowance or taxi subsidy.
- III. Current standards only apply to people with a physical disability - most clients with epilepsy are unable to get allowance or taxi subsidy, despite the fact they are not allowed to drive.

3. Accessibility to transport

There is often poor accessibility to public transport in many areas, particularly rural and remote regions. There are:

- I. Limited or no access in some areas. If you live in remote areas or even smaller towns and cities there is often no public transport options for getting to work, taking children to school or recreational activities or accessing medical appointments.
- II. Infrequent or inconvenient services resulting in long periods of time waiting for public transport or unnecessarily lengthy trips
- III. Some people with epilepsy cannot use public transport due to safety related to having seizures (eg having a seizure on a train platform and falling onto the tracks)

4. Costs

Many people with epilepsy are faced with financial difficulties. They also frequently encounter additional financial expenses due to:

- I. Medical and pharmaceutical expenses
- II. Loss of employment or employment changes
- III. Only receiving welfare - usually sickness benefits. It appears more difficult for them to get a disability pension. This in itself reduces their entitlements.
- IV. Increased dependence on taxis and public transport

5. Other arising issues

- I. Many of the above factors also can contribute to an increased risk of depression (and sometimes suicide) and other psychosocial issues. Clients report increased feelings of depression and feelings of uselessness due to inability to continue employment, inability to drive, financial difficulties and dependency upon others.
- II. Many people suffer anxiety, particularly about having a seizure in public. We have spoken to a number of clients who have had negative experiences and reactions when they've had a seizure on public transport.
- III. Because of the difficulties faced by people with epilepsy regarding obtaining their drivers license or entitlements to transport allowances, it is not uncommon for some people to *not* disclose to their Doctor or Driving Authority about their seizure control. Consequently, this puts people's safety and public safety at risk.

6. Gaps in coverage of requirements

Epilepsy (and possibly other "hidden conditions" or non-physical disabilities) are not recognised as a disability unless the condition is severe. Whereas all people diagnosed with epilepsy require to cease driving from a minimum of 3 months – 2 years (sometimes indefinitely). If seizures continue, even only 1-2 per year, the individual is unable to obtain his/her drivers licence.

Recommendations

1. Legislation should be implemented to recognise epilepsy as a condition eligible for transport support - where sufferers who are unable to drive have entitlements to mobility allowances or taxi subsidy schemes
2. National standards should be in place to avoid each state treating people differently
3. Currently the system accommodates mostly metropolitan or large regional centres and needs special categories and more flexibility for people in rural/remote and smaller regional centres.
4. In rural or remote areas, an allocated allowance or amount per person who is eligible to pay a third party (such as a friend/colleague) who provides regular transport - other than a taxi.