

Media Release

New WHO report identifies discrimination as key barrier to quality of life for the 250,000 Australians living with epilepsy

Discrimination and stigma still adversely affect Australians living with epilepsy, according to a new World Health Organisation report, *Epilepsy: A public health imperative*¹ released on 24 June at the 33rd International Epilepsy Congress held in Bangkok.

Currently 250,000 people in Australia are living with epilepsy. The report showed that in an Australian study, 47 percent of people living with epilepsy who were currently employed reported unfair treatment while in the workplace.² This is despite Australia being a high income, developed nation.

The report highlighted that in all parts of the world, including Australia, people with epilepsy are the target of discrimination and human rights violations. This discrimination and the associated stigma, can discourage people from seeking treatment and can adversely affect quality of life, employment, finances and social inclusion leading to isolation and poverty.

Wendy Groot, President of Epilepsy Australia said, "We know that almost half of people with epilepsy are discriminated against in the workplace. This can be due to a number of reasons such as being refused a job because of fears associated with employing a person with epilepsy, being isolated from tasks or workgroups through discrimination by colleagues, or by being terminated because an employer learns the person has epilepsy even though they may have held that job with no adverse consequences for some time," said Ms Groot.

"This important global report has found that even in Australia, where access to medical services for diagnosis and treatment are higher than in lower-resourced nations, people with epilepsy still experience discrimination and violations of their human rights. This discrimination can affect a person throughout their entire life, including lower education outcomes, limited employment opportunities, financial hardship and poor mental health."

"The report also found that dispelling the myths surrounding epilepsy that still persist today is the first step in reducing stigma that causes this discrimination," she said.

In Australia it is estimated that one million people will have epilepsy at some stage in their life. Epilepsy causes recurring seizures, often without warning.

The report is a collaborative effort between the World Health Organisation, the International League Against Epilepsy and the International Bureau for Epilepsy. A number of Australian medical and non-profit experts contributed to the report, including Graeme Shears, chief executive officer of the Epilepsy Foundation, one of the member organisations of Epilepsy Australia and a service provider in Victoria and New South Wales.

Mr Shears said programs such as Epilepsy Smart Schools, an initiative of the Epilepsy Foundation, have been developed to overcome discrimination by supporting schools to provide a safe and inclusive educational environment for students living with epilepsy.

"Epilepsy Smart Schools aims to reduce stigma and discrimination, as well as risk, by managing students' epilepsy better, training teachers and those with a duty of care within schools about epilepsy and raising

¹ Epilepsy, A Public health imperative, World Health Organisation, 2019.

² Bellon M, Walker C, Peterson C, Cookson P. The "E" word: epilepsy and perceptions of unfair treatment from the 2010 Australian Epilepsy Longitudinal Survey. *Epilepsy Behav.* 2013;27(1):251-6.

awareness of epilepsy among school communities. It is a positive step in reducing stigma in school communities, being the first crucial stage in a person's life, hopefully leading to flow-on benefits as students age and move into the workforce," he said.

The objective of the World Health Organisation report was to raise the prioritisation of epilepsy on the global agenda, to describe a public health approach that addresses its high burden, and to advocate for crucial actions that address gaps in epilepsy knowledge, care and research.

The report found that proper diagnosis and treatment are key and can eliminate seizures in around two-thirds of people living with epilepsy. However, in low-resourced countries, gaps in access to treatment means around 75 percent of people with epilepsy are not receiving the care they need. The risk of death in people with epilepsy is also three times that of the general population.

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