Firstly I would like to express my gratitude for the opportunity to participate and share the experience of living with epilepsy and the chance to make a difference for the thousands of Australians living with this condition.

As an introduction I am an unpaid carer for a loved one living with right mesial temporal sclerosis causing temporal lobe epilepsy , the most common cause of Focal seizures. The person I support lives with focal impaired, focal aware and tonic clonic seizures.

TLE caused by MTS is one of the most common drug-resistant epilepsy diagnosis, however despite there being a phenomenal amount of information and research surrounding this particular form of epilepsy there is still far too large of a stigma to offer adequate support and care to those living with this diagnosis.

Despite years of sudden onset panic attacks, mood instability, loss of consciousness and lapse in memory it wasn't until age 27 my loved one was diagnosed with epilepsy following 2 back-to-back nocturnal tonic clonic seizures. This in itself poses serious concern into the access to training our medical professionals receive as this diagnosis was missed for years. It wasn't until some months later after experiencing a influx of seizures that their GP made a referral for a MRI as at the time they were still waiting for assessment by a public neurologist which is when the true diagnosis was discovered. Scar tissue in the right hippocampus- mesial temporal sclerosis causing temporal lobe epilepsy.

As mentioned above this diagnosis is notoriously one of the most common types of medication resistant epilepsy and unfortunately one of the most misunderstood.

The temporal lobe is in control of many different functions and most primarily is in control of memory and mood.

Focal seizures originating in the temporal lobe can appear in many different ways- all it takes to understand this is a quick google search- however many medical professionals lack the training and understanding to properly support these seizures. I have witnessed personally the mistreatment in emergency settings of people experiencing focal seizures, including the forceful ejection from medical settings, refusal to treat and even so far as denial of diagnosis.

The stigma around this needs to change.

I am left curious as to how someone such as myself with no medical training has a more in depth understanding of the symptoms and correct treatment of temporal lobe epilepsy compared to professionals who study for years. There needs to be more in depth training in medical settings for professionals when it comes to seizure care and diagnosis, because far too many people are being brushed off until they progress to live changing symptoms.

Due to this fundamental oversight the impact breaches more than just the medical care of these individuals- they are losing their jobs due to lack of support , unable to work they are losing their homes, in a country built on the back of farmers and rural landscapes there are thousands of epileptic Australians unable to access transport because the public transport system for lack of better terms is rubbish. Epilepsy is not treated as a true and legitimate disability meaning people with impacted balance or memory can't access disability parking permits, people who are unable to access or safely use public transport independently aren't getting access to transport assistance. Epileptics are being expected to get a bus or walk home if they can't afford a taxi following a ED admission.

One of the most difficult aspects personally are accessing adequate mental health supports.

When I attended the emergency department with my loved one following a large seizure where days later they hadn't returned to their baseline, experiencing irritability, anxiety, mood swings and many more symptoms far too long to list we waited hours before a quick assessment was given and a diagnosis of generalized anxiety was given without any mental health assessments, tests and a refusal to allow escalation. Days later after living with the progressive worsening of these symptoms another google search exposed a common phenomenon of temporal lobe epilepsy- post ictal hypermania. Ther treatment and management of this is straight forwards and within a handful of days my loved one returned to their baseline self- but how was this diagnosis missed by someone trained to assess medical emergencies? Why was there a refusal to be assessed by a neurologist on shift?

These oversights in medical settings span far greater- emergency department doctors incorrectly siting information of what they believe a seizure to look like invalidating the individual experiencing them, the passive aggressive treatment as it is insinuated that they must be under the influence and faking their seizures and even down to the straight refusal to assist in a medical emergency.

I urge you to read the stories and experiences the many people impacted by the diagnosis of epilepsy will submit and plead you to take this opportunity to make a difference.

Mandate seizure training for ALL forms of seizures for medical professionals, offer more support to allow these individuals to get their independence back.

Take the opportunity to better the quality of life for these Australians.