

Submission to the Parliamentary Inquiry into Epilepsy and Related Healthcare Failures

Re: The Case of

I am writing this submission to share the experience of my brother, _____, who passed away at the age of 22 following failures within the medical system in responding to and managing his seizures.

_____ was an extremely vulnerable young man. He was low-functioning autistic and mentally functioned at the level of a child. This made him entirely dependent on those around him, including medical professionals, to recognise the seriousness of his condition and act appropriately in his best interests.

_____ experienced his first seizure approximately two months prior to his death. This was not a minor event it was severe and unmistakable. He lost consciousness, foamed at the mouth, and lost control of his bowels. Despite the seriousness of this seizure, there was no appropriate urgency, follow-up, or referral pathway initiated by the healthcare system. As his family, we trusted that the system would respond as it should. It did not.

Following this, _____ suffered a second seizure. During this incident, we experienced an extreme wait time of 10 hours for medical attention. What was most alarming, however, was the apparent lack of concern from medical staff. There was a noticeable complacency surrounding seizures, despite the known risks associated with them, including sudden unexpected death in epilepsy SUDEP.

We were not provided with timely access to specialist care. It was only after repeatedly advocating, pushing, and hounding doctors that we were finally given an appointment with a First Seizures Clinic. This referral should have been automatic after his first seizure. We later learned that the expected standard timeframe to be seen by a specialist is approximately 20 days.

Instead, we waited months.

Tragically, _____ passed away the night before his scheduled appointment an appointment that should have occurred weeks earlier. The delay in care, the lack of urgency, and the failure to follow established pathways meant that _____ never received the specialist assessment that may have saved his life.

This raises serious concerns about:

The lack of mandatory referral pathways following a first seizure

Failure to recognise and prioritise high-risk patients, particularly those who are vulnerable or unable to advocate for themselves

Excessive wait times that far exceed clinical guidelines

A culture of complacency around seizures within parts of the healthcare system

The burden placed on families to fight for basic care

_____ deserved better. Our family deserved better.

No family should have to lose a loved one while waiting for an appointment that should have been provided as a matter of urgency.

I ask this inquiry to consider stronger enforcement of referral standards, improved education around seizure risk, and accountability within the healthcare system to ensure that no one else falls through the cracks the way _____ did.

This submission is made in honour of my brother, _____, whose life mattered.

Sincerely,