

# Herald Sun

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ILLNESS

## Oliver McGowan: Mum's medication warning to Disability Royal Commission

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September 22, 2020 6:51pm

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Oliver McGowan never let his disabilities hold him back and aspired to compete in the Paralympics, but the teenager died after suffering an adverse reaction to antipsychotic medication.

His mother Paula McGowan believes the 18-year-old's death at a UK hospital in November 2016 could have been prevented.

"If Oliver had not had the labels of autism and intellectual disability attached to him, he would not have been prescribed psychotropic medications," Ms McGowan told the Disability Royal Commission on Tuesday.

After Oliver developed bacterial meningitis as a baby, he was left with a mild hemiplegia, focal seizure epilepsy and a mild intellectual disability. He was later diagnosed with high-functioning autism.

Ms McGowan, who is a special-education teacher, said Oliver's "steely determination" led him to become a school prefect, football player and runner.

"He had a full life expectancy and it was expected he would live an independent life with little support," she said.

In 2015, Oliver was hospitalised after a partial focal seizure and was given antidepressants, then a couple of months later he was given antipsychotic medication.

"Oliver did not have a diagnosis of psychosis or mental illness," Ms McGowan said.

The effect was catastrophic and Ms McGowan said she did not recognise her once-vibrant son, who was hallucinating and having up to 30 seizures a day.

“We walked into Oliver’s room one day and found him having an oculogyric crisis ... causing his eyes to roll upwards,” she said.

“He was left like this for six hours as the doctor at first believed it was behavioural.”

When Oliver was taken off the medication, his mood and seizure activity returned to normal.



 Oliver McGowan, 18, died at a UK hospital in November 2016. Picture: Supplied by the Disability Royal Commission

While hospitalised in 2016, Oliver was again given antipsychotic medication and had an adverse reaction, which resulted in him developing neuroleptic malignant syndrome.

Doctors said his brain was so badly swollen it was “bulging out the base of his skull”.

The family was told he would have no speech, language or way of communicating, would be tube-fed for the rest of his life and was paralysed.

“That beautiful smile, his sense of humour and words of wisdom were gone forever,” Ms McGowan said.

Oliver’s life support was turned off, and he died from a combination of pneumonia and hypoxic brain injury.

Ms McGowan, who now lives in Newcastle, NSW, told the royal commission there could be similar issues in Australia regarding over-medication and premature deaths of people with disability.

She said the focus should be on greater awareness, mandatory training among health professionals and support workers, and better communication with patients.

“It is wrong that we expect our doctors, nurses (and) social workers to suddenly know how to help a person with intellectual disability when they are in a sensory crisis,” she said.

“We wouldn’t expect them to go out and fix a car if they’ve not been given mechanical training, so why do we expect them to suddenly know how to treat and support our most vulnerable people?”

“They simply don’t have the skills to do so right now and it is affecting lives, it costs lives and it costs the quality of life.”

Ms McGowan also suggested Australia conduct national reviews into the deaths of people with disabilities.

“It is crucial to know how many deaths there are each year and how many of the people with learning disabilities who have died prematurely were taking psychotropic medications,” she said in her statement.

“Such reviews could examine whether people with learning disabilities are dying preventable deaths.”

Senior counsel assisting the hearing Kate Eastman said research suggested up to 60 per cent of people with intellectual disability were prescribed psychotropic medication to manage challenging behaviours, and only 30 per cent of them had a mental illness.

“This is a significant number when you recall that 1.8 per cent of the Australian population has an intellectual disability,” Ms Eastman said.

She said using psychotropic medication as a chemical restraint raised concerns, including an over-reliance as a first response to challenging behaviour, misuse or overdosing of medication, and side effects.

Psychiatrist Catherine Franklin said there had been international concerns about overprescription of psychotropic medication for at least 30 years.

Pharmacist Manya Angley said she reviewed the medications of one person, describing it as abuse and the most extreme case of psychotropic medication misuse she had seen.

A NSW woman, referred to as ABF, said her vulnerable brother had a “real sweet innocence” but people often held their breath around him or moved their children away because they believed he was violent.

She said she would like everyone to be better educated about invisible disabilities.

“As I support my brother to access his local community, I am struck by the absence of others with similar disabilities and I wonder whether and how they are accessing their community, or whether they are just shut away,” she said.

“I worry about how many others are being chemically, psychically and mechanically restrained, as well as how many others are regressing in developing their skill sets because of restrictions imposed by COVID-19.”

Raylene Griffiths, who has a disability and lives in a group home, said she would like to see more support provided.

The hearing will resume on Wednesday.

Originally published as [Teen’s brain was ‘bulging out of skull’](#)