

# Justice for all

Teenager Oliver McGowan died when medical staff would not make reasonable adjustments for his autism and learning difficulties or acknowledge his requests. His mum, Paula, is campaigning to ensure this never happens again.

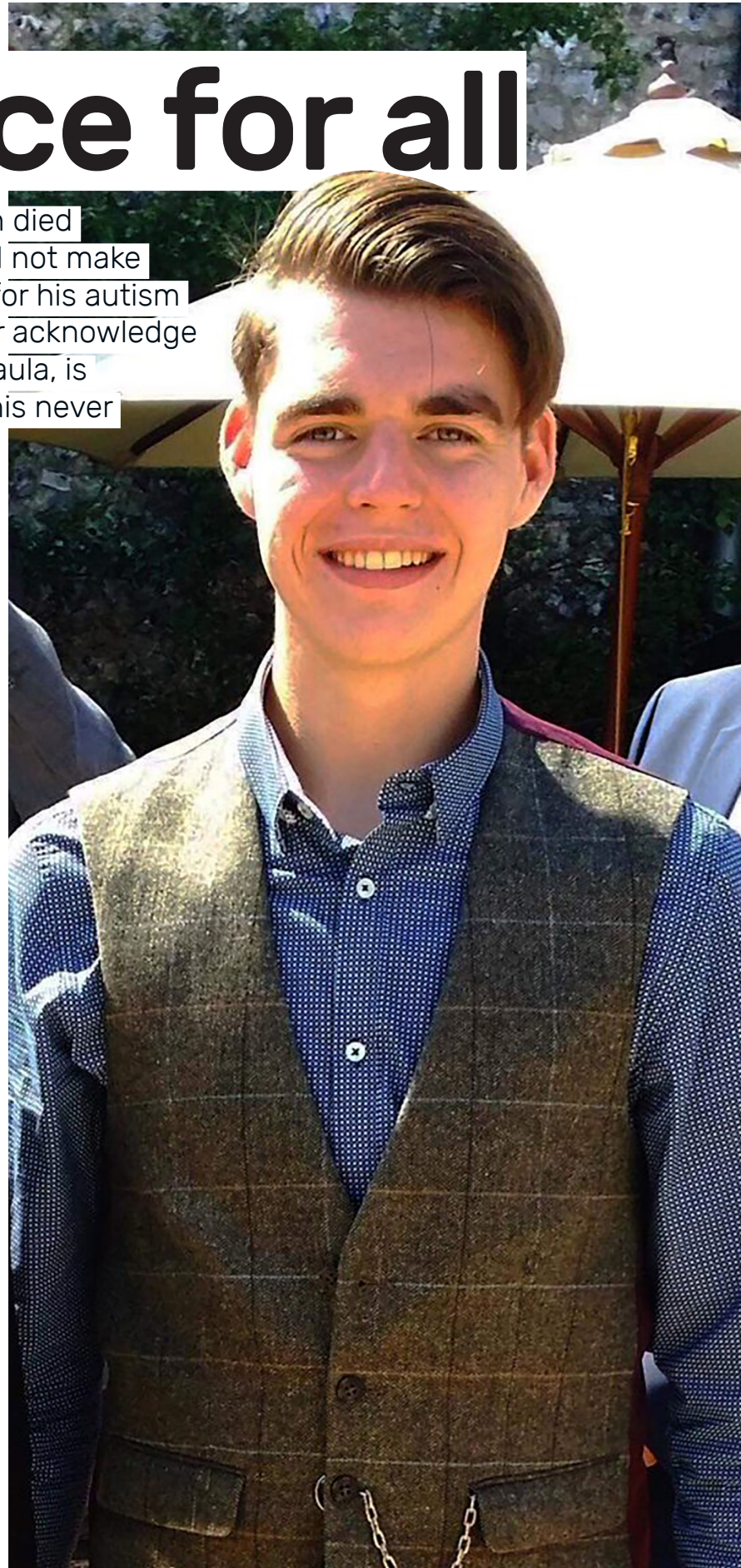
WORDS BY KATIE CAMPBELL

Oliver McGowan had the world at his feet. 18 years old, he loved his family. People were drawn to him; he was warm, funny and witty. He saw the good in everybody, he was determined and faced every challenge head-on. He was mild-mannered, hated arguments and loved to help. He was a school prefect and had a position on his college's council. Oliver was fit, healthy and active: he loved to play football, played for Cerebral Palsy England's football squad, and was training to be a Paralympian, running the 100m and 200m in athletics.

Oliver McGowan, a teenager with a full life expectancy, is dead.

On 22 October 2016, Oliver had a simple partial seizure. He had a prolonged absence type seizure and was taken to hospital. He asked the paramedics not to give him antipsychotics; he had been given Olanzapine at the Bristol Children's Hospital before, and the change in him had been dramatic. Oliver had mild cerebral palsy, autism, very mild learning difficulties and epilepsy; his family were careful to ensure that he had a full medical passport, which detailed how to make reasonable adjustments for him, and his sensitivities and allergies.

Police brought him in to Southmead Hospital in Bristol; there was no problem, he liked to walk when he had a seizure, and the police were there to keep him safe. Paula, Oliver's mother, gave the nurse his passport. She saw them put it in a drawer, unopened. Speaking with the neurologist who would care for Oliver, Paula reiterated



her concerns. He read the passport and acknowledged Oliver's sensitivity to antipsychotics and benzodiazepines.

Oliver was then given benzodiazepines. Where it would sedate most people, Oliver's sensitivity meant it made him hyper and incredibly anxious. He had another seizure and went to walk around; a police officer threw him down on the bed and lay on top of him. The doctors and nurses spoke to him in medical jargon, scaring and confusing him.

It was then that Dr Monica Mohan asked his parents: "How are we going to treat Oliver's psychosis?"

Oliver was not mentally ill, and he did not have psychosis. His patient passport contained a letter from the Bristol Children's Hospital that stated this explicitly, and under the assessment of the senior consultants there, they found him to be sound of mind and able to make his own decisions. Three other psychiatrists who saw Oliver confirmed this. Oliver was chattering about a video game blogger he liked; in Paula's opinion, the doctors mistook this for delusions, when it was in fact a symptom of his autism.

The teenager's parents explicitly forbade her from giving Oliver antipsychotics. While Oliver was intubated for a scan, he was administered with Olanzapine, the very antipsychotic he had a reaction to in the Bristol Children's Hospital.

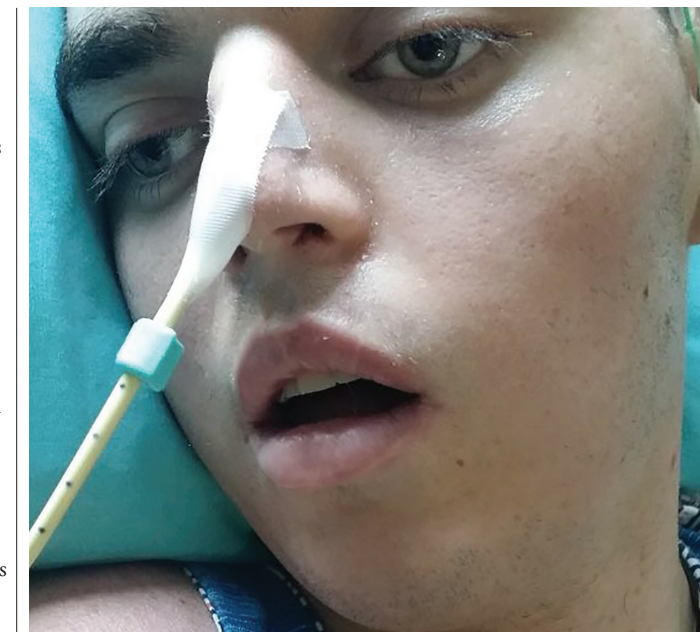
The family complained; they were ignored. They asked the doctors to stop; they were ignored.

Oliver began having chronic seizures and his temperature skyrocketed to 43°C as his liver was functioning incorrectly.

Oliver's brain was being, in his mother's words, fried in his skull: he was developing neuroleptic malignant syndrome – a side effect of antipsychotics to which he was sensitive. His brain was so badly swollen that it was bursting out of the bottom of his skull. He was rushed into surgery to have a shunt inserted.

Oliver's brain was so badly damaged that if he woke up, he would be deaf, blind, and unable to feed without a tube. With the doctors, his parents agreed to have his life support turned off. He survived for four days, having myoclonic seizures. Oliver died on 11 November 2016, after being admitted to hospital with nothing more than a seizure.

At the inquest into his death, the



INTUBATED: Oliver was given Olanzapine while intubated, triggering the NMS that made his brain swell out of his skull.

coroner refused to open the scope of his investigation to include information from the Bristol Children's Hospital that showed Oliver was sensitive to antipsychotics. He would not allow a jury, nor would he allow Oliver's community psychiatrist or his safeguarding officer who recommended doctors do not use Olanzapine, or another doctor who assessed his mental capacity.

Called to the stand, Dr Mohan said: "I took [the family's] concerns about Olanzapine, but I would choose it again because it's one of the medications we use in an acute setting."

Despite this, consultant in clinical pharmacology, Dr Nigel Langford, told the inquest that it was "possible" Oliver would not be dead had Olanzapine not been prescribed, a stance which Oliver's family adamantly support.

Dr Canham spoke to Oliver's family when he was admitted and remembered both reading about the teenager's sensitivity to antipsychotics and his parents' express forbidding of their use.

"I explained I would not be using antipsychotics," he said. "I made it very clear to my colleagues...both verbally and in typed correspondence about the concerns the family had about the use of antipsychotics."

Dr Howard Faulkner, a consultant neurologist who also treated Oliver, told the inquest: "It is untenable to me that we would have a conversation with the family saying we could not use antipsychotics and I

**“OLIVER'S BRAIN WAS SO BADLY DAMAGED THAT IF HE WOKE UP, HE WOULD BE DEAF, BLIND, AND UNABLE TO FEED WITHOUT A TUBE.”**

don't have a recollection of that."

Dr Faulkner informed the inquest that the teenager was suffering from ictal psychosis related to his seizures.

"I remember them being concerned about the side effects of antipsychotic medication," he said. "I don't recall at any point being asked to stop the Olanzapine... my understanding at that point was they accepted he needed to be on it in the short term."

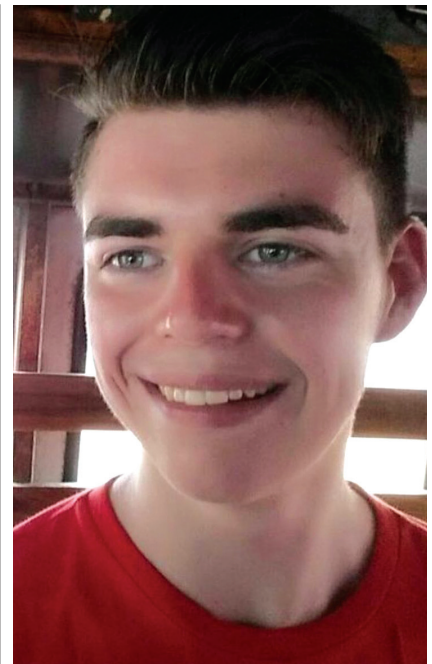
He said it was his understanding that Oliver was not allergic to antipsychotic drugs: "Oliver clearly didn't like them," he said. "In my experience, few patients like them."

The result of the inquest was that Oliver's death had been caused by his double pneumonia and NMS, but found no issue with the care he was given. His family were devastated.

While others might find themselves ►



**“I SAT DOWN ONE DAY, AND I KEPT THINKING – WHAT WAS THE CATALYST TO OLIVER’S DEATH? WHAT WAS THE START OF THE JOURNEY? THEY DIDN’T UNDERSTAND HIS AUTISM.”**



**RISING STAR:** *Oliver had been training to be a Paralympian before his untimely death at Southmead Hospital, Bristol*

defeated, the McGowans would not take the results of the inquest lying down.

“I sat down one day, and I kept thinking – what was the catalyst to Oliver’s death? What was the start of the journey? They didn’t understand his autism,” said Paula.

Oliver’s normal, autistic behaviour was confused for mania. Paula watched in the tense environment as medical jargon was thrown at her son by medical professionals who did not understand reasonable adjustments. She was shocked to find that doctors and nurses do not receive training in how to make reasonable adjustments for people with autism and learning difficulties.

Mencap offer an opt-in service to provide medical professionals with education on how to make reasonable adjustments for people with autism and learning difficulties, but it’s not mandatory. There are guidelines in place, but they’re not enforced. Guidelines are at discretion, Paula notes, but if it’s mandatory, the level of care has to be employed.

Paula wants prescriptive training introduced right from the start, beginning during education, and have learning disability nurses given a place within

hospitals to ensure doctors and nurses know who to turn to if they are unsure of how to make reasonable adjustments for a person.

“The Oliver McGowan Mandatory Training in Autism and Learning Disability Awareness” is how Paula wants it to be known to provide her son with the legacy he deserves. Doctors and nurses have privately approached Paula telling her how much they want this training, and she is adamant that it isn’t the fault of the doctors that they haven’t received this training. “If they haven’t received the training and they come across something that’s alien to them, what are they supposed to do,” Paula asks?

Paula McGowan is exhausted. She cannot stop shouting about the petition she has started in Oliver’s name. If she stops shouting about the petition, people forget. For Oliver, and for disabled people everywhere, she cannot stop pushing the petition.

Over 30,000 people have signed it – after 10,000 signatures Parliament are supposed to discuss it. Paula has heard nothing from them. At the time of writing, the McGowans have been waiting 40 days for a government response.

In a statement the Parliamentary Committee said: “The delay relating to this petition has been raised with the relevant government department. The committee expects a response to be provided as a priority.”

Paula will be making a complaint to the judicial service. She has gone to the health ombudsman with Oliver’s case. His case is also in front of the NHS Learning Disabilities Mortality Review. Oliver’s story is being used to make a point to doctors up and down the country in relation to STOMP – Stopping the Over-Medication of People with a Learning Disability, Autism or Both – and to illustrate the terrifying statistic that 42% of deaths of people with learning disabilities are considered to be premature, per CIPOLD.

Oliver’s death was tragic, and has devastated his family, friends and community. Through his death, his family are pushing to ensure that no other family has to experience their anguish. The least we can do is put our names to their petition. ■

#### ■ SIGN THE PETITION

Visit [petition.parliament.uk/petitions/221033](https://petition.parliament.uk/petitions/221033) or search “Oliver McGowan petition” to lend your voice to the campaign.