PHSO Complaint Form - Mrs Paula McGowan and Mr Tom McGowan

Section 1: Can we look at your complaint?

Have you complained to the organisation? Y/N

Yes

Have you received a final response from them or completed their complaints process? Y/N

Yes

PHSO reference number: C2/01/4214

When did the events happen (date)?

6 October 2015 to 11 November 2016.

When did you become aware of the problem (date)?

6 October 2015 to 11 November 2016.

When did you complain to the organisation (date)?

9 December 2016 (meeting at South Gloucestershire Clinical Commissioning Group)

If you haven't been able to complain to us within a year of becoming aware of the problem, please use this space to tell us why, giving as much detail as possible.

N/A

Are you taking, or planning to take, legal action about your complaint? Y/N If yes give details

No

Section 2: Who are you complaining about?

Complaint 1 against Bristol Children's Hospital (University Hospitals Bristol NHS Foundation Trust)

Complaint 2 against National Hospital for Neurology (University College London Hospitals NHS Foundation Trust)

Complaint 3 against Southmead Hospital (North Bristol NHS Foundation Trust)

Section 3: About your complaint

Briefly tell us what your complaint is about

Our son Oliver had meningitis in early childhood and suffered brain damage as a result. He was autistic with mild learning difficulty, and suffered from epileptic seizures.

Oliver had a wicked sense of humour and was incredibly close to his older brother and sister. His disabilities did not hold him back. He had a steely determination and a can do attitude. He was a talented footballer and athlete and he harboured a realistic ambition of becoming a Paralympian. He was gentle and a natural leader who became a school Prefect. He attained several GCSEs and BTEC qualifications and went on to attend National Star College in Cheltenham, an independent specialist

further education college for people with physical disabilities, acquired brain injuries and associated learning difficulties. Staff there said how friendly and kind he was, supporting and enabling others students who were less able than himself.

Our complaints cover the use of antipsychotic medication at Bristol Royal Hospital for Children in 2015 and 2016, Oliver's care and treatment including use of antipsychotic medication at the National Hospital for Neurology in 2016, and Oliver's treatment at Southmead hospital in 2016 where he was admitted due to seizures and where he died after developing Neuroleptic Malignant Syndrome as a result of being given antipsychotic medication in order to manage potentially challenging behaviour when coming out of sedation.

Oliver died on 11 November 2016 at Southmead hospital due to Neuroleptic Malignant Syndrome, as a direct result of the administration of anti-psychotic medication despite Oliver's and our expressed wishes and warnings, and despite evidence of a history of sensitivity / serious adverse reactions to anti-psychotic medication. We are convinced that Oliver's hospital care was characterised by an inappropriate emphasis upon physical and chemical restraint in response to symptoms which were closely related to the impact of the hospital environment for a person with autism and learning disabilities, and Oliver's adverse reactions to medication. We believe that this led to his death, which was completely preventable. We are shocked that this could happen within the NHS, and that we as parents were not listened to when we tried to speak up on Oliver's behalf about his wishes not to be given antipsychotic medication, and about our own concerns having witnessed his reactions to antipsychotics in the past.

In making the decision to give Oliver Olanzapine, doctors did not follow the Mental Capacity Act 2005 properly and consult with the professionals who knew Oliver well and who understood his needs, which we asked them to do. Oliver was sedated for a couple of days so there was time to do this and explore alternative ways to manage potentially challenging behaviour as Oliver came out of sedation. The doctors should have done this, particularly as the decision to administer Olanzapine was against Oliver's and our wishes. But they didn't. We would also like to draw the Ombudsman's attention to NHS England's 2016 report on Stopping the Over-Medication of People with Learning Disabilities and/or Autism (STOMP). It is clear to us that the approach recommended by NHS England was not followed in the hospitals about which we have complained. The hospitals concerned have failed to provide adequate answers to our questions or accept that they were at fault. Lessons must be learned and the hospitals concerned need to acknowledge what happened and where they went wrong.

At the end of this document we have attached a list of relevant documents which can be supplied to you in due course to support this complaint, however at this point we attach a letter dated 9 February 2017 from Dr Razak, Oliver's Consultant Psychiatrist in the community learning disability team, who supports our view that Oliver's condition was misunderstood by other clinicians and that there was no evidence of mental illness / psychosis. Dr Razak shares our concern that "people working with [Oliver] might jump to the conclusion that he had a history of mental illness which in my opinion was not the case." Dr Razak's opinion is that the focus of treatment should have been on the management of Oliver's epilepsy.

Timeline- see separate Timeline document

Complaint 1 against Bristol Royal Hospital for Children (University Hospitals Bristol NHS Foundation Trust)

In response to the UHB Trust's response to our complaint we would like to ask PHSO to investigate the following matters:

(1a) Inappropriate treatment with antipsychotic medication

During an admission to BRHC in November / December 2015, for treatment of seizures, Oliver was prescribed anti-psychotic medication (Olanzapine). We saw that this had a dramatic effect, making his seizures worse and affecting his blood pressure and increasing agitation. We expressly forbade the use of Olanzapine to Dr Gilbert who was dismissive of our concerns and prescribed another antipsychotic. We begged him to stop the antipsychotics. Oliver was placed on Section 2 of the Mental Health Act but no bed was available. He was eventually taken off antipsychotic medication and quickly returned to his baseline self; allowed home on Section 17 leave and discharged off the Section 2 by CAMHS within days.

Oliver was readmitted to BRHC on 1 April 2016 following further seizures. We expressed concerns about Oliver's previous adverse reactions to antipsychotics, and passed on information about Oliver's autism and his previous adverse reaction to antipsychotics. The discharge summary dated 29 December 2015 highlighted in bold text the warning: **'sensitive to psychotropic medication**' and yet the first thing BRCH did when he presented in A&E in April 2016 was to give him antipsychotic medication. We asked for antipsychotics not to be used. However, antipsychotic medication was again used (Haloperidol). This brought about Oculogyric Crisis, and increased Oliver's agitation and seizures. We note that BHRC's response states that the doctor thought there might be a psychotic illness and also that antipsychotics were used for treatment of 'acutely disturbed behaviour'. We believe this is wrong on both counts – it is clear to us (as borne out by subsequent events) that Oliver did not have a psychotic illness and that this was a misdiagnosis. We also consider that it is quite wrong to use antipsychotics as a chemical restraint when this was against the wishes of Oliver and his parents and there was a history of adverse reaction to these medications. The history and our opinions and wishes were dismissed and disregarded.

(1b) Why were our concerns about antipsychotic medication not taken seriously?

This complaint overlaps with (a) above. BRCH justify their use of antipsychotic medication by reference to 'clinical judgement'. We are not doctors but as his parents we had a wealth of knowledge and expertise about Oliver's condition of autism and his behaviour. During the December 2015 admission BRHC have acknowledged that we reported to them that the Olanzapine was making Oliver worse and that they therefore discontinued it. However the doctors prescribed another antipsychotic, Haloperidol, and then added another antipsychotic, Aripiprazole. As BRHC have acknowledged, this resulted in Oliver 'showing increased agitation and looking more dishevelled'. We again expressed our concern about the use of antipsychotics which we felt were harmful to Oliver. We do not understand why Dr Gilbert was so committed to the continuing use of antipsychotics despite our objections to their use. We observed that antipsychotics made Oliver more agitated and their response was just to give Oliver more medication. We believe this was a very wrong approach.

During the April 2016 admission Dr Gilbert again prescribed an antipsychotic, Haloperidol which resulted in a severe reaction and an Oculogyric Crisis. This should have rung alarm bells about the use of such powerful medication with Oliver. While BCHRC claim that they listened to our

concerns, they clearly did not take them seriously enough to take Oliver off antipsychotic medication. This in turn influenced the National Hospital for Neurology who cited BRCH's prescription of antipsychotics as a justification for their continued use on admission to NHN. We are struck by the fact that the BRCH decision to continue using antipsychotics was communicated to NHN and influenced their treatment decision, but our persistent objections and concerns about the use of antipsychotics were disregarded by both BRCH and NHN.

(1c) Lack of information given about side effects

We were not given information about side effects of antipsychotics by BRHC doctors but had to look for this information ourselves. We tried to discuss this with BRHC staff but we were given no explanation. BRCH say this was due to 'pressure of events' and also to their opinion that 'no other treatment was available'. That should not have prevented the proper giving of information to us. BRHC apologise that we were 'not provided with more information.' We do not consider this is a full and sincere apology because it is qualified by saying that doctors 'did not feel they had any option' and that they were covered by 'BRHC guidelines'. We feel this illustrates an unfortunate attitude towards our needs and right to information, and our concerns, and that the hospital continues to be dismissive and defensive.

(1d) Failure to consider Neuroleptic Malignant Syndrome, or carry out a blood test

We do not accept BRCH's statement that Oliver had 'none of the characteristics of NMS.' We note that BRCH also state that they 'did not consider a diagnosis of NMS' and that there was 'no evidence' of NMS. We now know that Oliver died of NMS caused by antipsychotic medication. We simply do not accept BRCH's statement. There was evidence of increased seizures, and effects on blood pressure and heart rate, and difficulty urinating. There was an Oculogyric Crisis. We observed increased agitation. We passed on our observations and expressed our concerns about the adverse reactions to antipsychotics. All these factors constitute 'evidence' which should have prompted great caution. We believe there was enough evidence to have considered at least the possibility of NMS and to have carried out further investigations in response, e.g. Creatine Kinase testing. BCHRC say he was not tested because 'the clinical team did not consider a diagnosis of NMS.' We are very concerned that this was not considered and that in response to our concerns we experienced Dr Gilbert as condescending and dismissive.

(1e) Questionable legality of the use antipsychotics against our wishes

We made it abundantly clear on several occasions that we did not want Oliver prescribed antipsychotics. We believe there was a misunderstanding of Oliver's autistic behaviours. We had also observed that Oliver reacted badly to antipsychotics and we were concerned that they might be harming him. It is a complete distortion of the truth that we were 'willing to allow' Dr Sharples to use antipsychotics. We were <u>not</u> asked for our consent, and as BRCH has already acknowledged, we were not given any information about adverse effects so there was no attempt to gain our informed consent. Doctors were so committed to the use of antipsychotics that they chose to ignore our concerns, failed to properly consult and inform us, and just went ahead against our wishes and those of Oliver.

(1f) Why was Oliver left in Oculogyric Crisis for over 6 hours?

We are not satisfied with BRCH's explanations about this. We believe that staff failed to make a correct and timely diagnosis of the adverse reaction to antipsychotic medication. We ourselves noticed that Oliver had a protruding tongue, and we therefore question BHRC's statement that

there was a 'very low risk of tardive dyskinesia' – it is not clear that the consultant who gave this opinion (Dr Tallis) had actually examined Oliver. We continue to feel that this episode was not responded to with sufficient urgency. Dr Sharples is 'sorry that we feel there was a delay' but we are concerned that BRCH have not acknowledged that there was any delay.

Complaint 2 against National Hospital for Neurology (University College London Hospitals NHS Foundation Trust)

In response to the UCLH Trust's response to our complaint we would like to ask PHSO to investigate the following matters:

(2a) Excessive use of physical restraint

In response to our complaint, UCLHT claim that the restraint used was 'proportionate to the risk that Oliver posed to himself and others' and refer to his 'violent' and 'aggressive behaviour'. They refer to 'a number of assaults … on [ourselves]'. We dispute UCLHT's account as being inaccurate and a misrepresentation. Oliver was not at all aggressive on his arrival at the hospital; the problem was that he was experiencing seizures and he also had a number of autistic behaviours which staff did not seem to understand. It is not true that Oliver assaulted us and we find it distressing to see this being used a justification for the excessive physical restraint. The hospital failed to understand that they needed to provide an environment which was suitable for Oliver's needs and instead of managing him appropriately and calmly they misinterpreted his seizure episodes and his disorientation, and used excessive physical restraint which only made him more frightened and distressed, which was misinterpreted as aggression. We saw how Oliver reacted differently to different staff depending on how they treated him. UCLHT's explanation is a self-fulfilling prophesy based on mismanagement.

UCLHT refer to our 'assertion' that Tim Buckley told us that Oliver had been restrained by 8 staff and state that this did not happen and that Tim Buckley did not substantiate this. This is again a misrepresentation. It was us who observed 8 staff restraining Oliver – we told Tim Buckley about this, not the other way round. We reject as untrue UCLHT's assertion that 8 staff were not used as we saw this ourselves. We also saw security staff taking the lead in restraint, rather than being 'directed and supervised' by nurses.

We are very concerned that UCLHT assert that on admission Oliver had 'hallucinations' and 'delusions' which they describe as 'psychotic'. This shows a complete failure to understand the nature of Oliver's ASD and OCD behaviours. Oliver had a longstanding obsession with Faze Temperrr. It was normal for Oliver to talk about this as part of his usual internal monologue. This was <u>not</u> a symptom of psychosis (as other doctors who knew Oliver can attest).

(2b) Supervision during personal care

We believe that it was inappropriate for female staff to be involved in attending to Oliver in the shower and toilet, and that this reflected UCLHT's misunderstanding of Oliver's behaviour. It exacerbated his agitation. We question why it was necessary as during previous hospital admissions he had been allowed to shower alone with no problems.

(2c) Staff action in preventing parents sitting close to Oliver

We dispute the UCLHT account that Oliver spat at his mother and punched her in the neck and attempted to strangle her. This is untrue. Oliver pushed me (Oliver's mother) and I am used to

this behaviour and was not in fear of him. The staff reaction to this was excessive and escalated the situation. I was removed from the room. Again this shows that staff misunderstood Oliver and failed to listen to us or acknowledge our expertise as his parents. This was wrong.

UCLHT refer in their response to Oliver being transferred to a PICU in Salisbury under the Mental Health Act. We must point out that Oliver's behaviour calmed very quickly on the PICU and staff there told us that he was not mentally ill and that the use of the Mental Health Act had been inappropriate and he did not need to be there. Oliver was treated with respect on the PICU and staff were able to talk with him without the use of restraint. This clearly demonstrates that Oliver's distress and agitation at UCLHT was a response to the environment and his management. Dr Razak, Consultant Psychiatrist, also shares our concerns that the use of the Mental Health Act was inappropriate and that there was no evidence of any mental illness

(2d) Inappropriate and excessive use of medication as a chemical restraint despite parents' objections and evidence of sensitivity / adverse reaction

We were concerned that staff at UCLHT was not prepared to discuss medication with us. There was already evidence from a previous hospital admission to BCH that Oliver had developed an ocular crisis in response to haloperidol. We dispute (and do not fully understand) UCLH's statement: "Ms Frank does not recall him having any adverse reaction to medication investigation".

As we have said above, Oliver's behaviour was misunderstood by UCLHT and they wrongly diagnosed psychosis and prescribed strong anti-psychotic medication against his wishes and our wishes. We doubt the lawfulness of this. We were very concerned that he was sensitive to medication and that this was used inappropriately as a chemical restraint – UCLHT have acknowledged that it was in part used to treat 'challenging behaviour.' From UCLHT's own account there were some abnormal blood test findings which should also have resulted in great caution. We observed that on the medication Oliver had worrying symptoms including sweating profusely, high blood pressure, increased seizure activity, and confusion. This should have resulted in stopping the substantial amount of antipsychotic medication that was given. UCLHT state that there were 'no clinical indications of NMS'. We dispute this – there were worrying signs and we believe that staff did not have sufficient awareness of the risks and had closed their minds to the possibility that medication was harming Oliver.

(2e) Misuse of the Mental Health Act and placement in PICU (28/5/06)

UCLHT justify the use of detention under the Mental Health Act by stating that Oliver was 'suffering from a psychotic disorder.' We dispute this and maintain that the assessment by PICU doctors, and the medical history, shows that this was a wrong diagnosis. At the PICU Oliver was granted leave and taken off the Section. PICU staff found no evidence of psychosis. We question UCLHT's account that on the journey to the PICU Oliver assaulted staff. We were not told this at the time so we doubt the truth of it now and consider that this may be a retrospective justification for the inappropriate Section.

Complaint 3 against Southmead Hospital (North Bristol NHS Trust)

In response to the North Bristol Trust's response to our complaint we would like to ask PHSO to investigate the following matters:

(3a) Use of antipsychotic medication despite our objections and concerns

Oliver and ourselves were opposed to the prescription of antipsychotic medication because he was not suffering from a psychotic illness and this medication had in the recent past caused him serious physical problems including Oculogyric Crises, increased seizure activity, behavioural disturbance, sweating, increase of blood pressure, hallucinations, drooling and problems urinating. We impressed this upon the doctor on 22 October 2016, and provided a folder of documents supporting this concern. We note that, as a result, 'Antipsychotic Medication' was written in red in the 'Allergies' box on all of Oliver's ICU Patient 24hr Care Charts and his original Drug Chart to highlight the increased risk. We now know that Dr Luke Canham circulated his notes via email on 23 October 2016 at 01:59 to Dr Mohan after Oliver was admitted stating "he has a number of intolerances not least of which was all forms of antipsychotic" medications.

We find it completely unacceptable that despite the information we gave about past history and his reactions, our communication of Oliver's wishes not to be given antipsychotics, and our strongly expressed concerns, Southmead doctors subsequently prescribed the medication, and that this led to our son's death when he reacted badly to the medication, as we had feared. We believe this was a direct failure to understand Oliver's needs and presentation, and to take sufficient account of his history or our views. None of the doctors involved in this decision consulted with the Community Learning Disabilities Team who were responsible for Oliver's care following transition fr om the Child to Adult services and who visited Oliver in ICU, and knew and understood his complex needs. This lack of wider consultation with relevant professionals goes against the Mental Capacity Act 2005 and the adult safeguarding principles in the Care Act which calls for local partners to work together to prevent harm and promote dignity, empowerment and choice.

The Safeguarding Report (34) states: "*The best interests decision making process included conversations with the Consultant Neurologist and the ICU Consultant. All consultants involved (either through documentation in the patient's records or during the course of the investigations) have confirmed that they were very aware of Oliver's parents' concerns and that they were taken into account in their decision making.*" We do not accept that our views were 'taken into account' - the evidence points in the opposite direction. The Safeguarding Report (47) goes on to state that "*With all things considered, it may have proved helpful to the parents if a face to face meeting had been arranged with all the relevant Consultants involved in the decision making to introducing olanzapine (ICU, Neurologist and Neuropsychiatrist).*"

The Safeguarding Report (46) cites uncritically the approach of the doctor's concerned that *"if there was a dispute around the patient's best interests, it may have been helpful to seek Dr Razak's (Consultant Psychiatrist Learning Difficulties Community Team, South Gloucestershire) views on introducing olanzapine, if practical and appropriate. (The clinicians involved do not consider there was such a dispute).*" We consider that this admission is quite shocking and disregards the obvious point that the Community Learning Difficulties Consultant who knew Oliver best should have been consulted in any event, particularly in view of our strongly expressed concerns. This needs to change.

It is important to note that it was 'practical and appropriate' to consult more widely with relevant professionals. The decision being made was how to manage potentially challenging behaviour as Oliver came out of sedation, in order to ensure this happened safely and Oliver didn't pull tubes out etc. Oliver and us were against the use of antipsychotics and alternatives should have been properly explored, for example non-pharmacological approaches to managing behaviour – including use of mechanical restraint, and also seeing if just having us there when he woke was enough to calm him down (he was weak as he was recovering from pneumonia which

he had developed following admission so we think it unlikely he would have had the strength to be very challenging).

There was time to consult more widely as we had asked them to do, as Oliver was under sedation for a couple of days and he was stable – this was not an 'emergency' situation. The safeguarding lead at the hospital had come to see Oliver and us and he had left some soft wrist cuffs, a non-pharmacological approach, which could have been used to stop Oliver pulling tubes out, but the doctors did not consult with the safeguarding lead who had expertise around supporting people with a learning disability and autism, and this alternative was not used or even considered (this was clear from the evidence during the inquest).

The neuropsychiatrist, Dr Monica Mohan, who prescribed the Olanzapine should have consulted with those who knew Oliver well and those who had expertise in learning disability and autism, but she only consulted with the ICU consultant and the neurologist, neither of whom had met Oliver before. At the inquest the coroner did not have an independent expert with expertise in learning disability and autism and non-pharmacological approaches to managing challenging behaviour who could have commented on alternatives to using antipsychotics in this situation. He had an independent expert who confirmed he did not have this expertise; he was a pharmacist. Unfortunately, our requests to have Dr Razak and the hospital safeguarding lead at the hospital called as witnesses were rejected. Therefore, at the inquest there was a missed opportunity for the coroner to hear more about good practice in supporting someone with Oliver's needs and the alternatives to antipsychotics which could and should have been explored.

We are alarmed that the Trust doctor, Dr Mohan, wrongly believed that Oliver had been '*presenting with psychotic thoughts for the last few years',* and that she referred to '*suicidal and self-harming thoughts'*. This is quite untrue. Oliver was not suicidal and had never made any attempts or plans to take his own life. We note the Royal College of Psychiatrists guidance: *'Treatment - Ictal psychotic phenomena should be treated by optimisation of anti-epileptic medications with the aim of better seizure control. They do not warrant Antipsychotic Medications...Antipsychotic drugs can reduce the seizure threshold...Among the Atypicals, Risperidone and Olanzapine have greater propensity to affect the seizure threshold.'*

The Trust Root Cause Analysis Report and RCA Review Report both appear to confirm that antipsychotic medication was given because hospital doctors interpreted Oliver's symptoms as evidence of psychosis. The reports assert this was a reasonable judgement. It was not**.** The Learning Disability Consultant (who knew Oliver best) is clear that not only was there no evidence of psychosis, but there was a real danger of Oliver's presentation being misinterpreted as psychotic. Yet this consultant was not consulted, a point which the RCA reports fail to acknowledge. Neither were we properly consulted.

(3b) Failure to react swiftly to NMS

We are concerned that, in spite of an intolerance to all antipsychotics in the past, the Trust was slow to aggressively treat the signs of Neuroleptic Malignant Syndrome (NMS). There was a case of NMS in the Trust in 2016 so staff should have been more vigilant and heeded the Trust's own recommendation to "obtain a full history of previous mental health medication." Despite Oliver showing signs and symptoms of NMS (noted by Dr Campbell in the medical notes on 27 October as 'NMS?', this was not discussed with us until 30 Oct 2016 by which time irreversible brain damage had occurred.

We are concerned that immediate and urgent action was not taken to prevent brain damage in response to increasingly worrying symptoms. Oliver's appearance changed with blue pallor around his eyes and mouth – this was dismissed as *'probably the lights in his room';* muscular rigidity was reported to the doctors but again dismissed. Severe hyperthermia, tremor, increased seizures (different in nature to his usual epileptic presentation) were all present. These differences caused us great concern that something untoward was occurring in Oliver's brain and we discussed this with the ICU doctor on 27 October 2016 but our concerns were dismissed. At the inquest the independent expert said that there were clear signs of NMS on 28th October but a brain scan was not arranged until 30 October 2016. The Trust doctor said he was *'just dotting the i's and cross the t's* but was not expecting to see anything on the scan.' When the scan showed severe brain damage Dr Campbell said to us *"we did not spot this soon enough and did not react quickly enough."*

Once NMS was confirmed on 28 October 2016, there was no attempt to treat Oliver's raised temperature which then resulted in hypothermic brain injury which then ultimately led to his death. Paracetamol was withdrawn and there was no attempt to aggressively treat his temperature until 30 Oct 2016 by which time the prognosis was "appalling".

(3c) Swelling and tissue damage on Oliver's right hand / arm

The Trust's complaint response reveals that there were repeated errors in the treatment given:

- The wrong type of dressing was used on 23/10 and 31/10 - the Trust has acknowledged that this would have led to deterioration and further skin breakdown.
- In addition, on 29/10 another type of dressing was inappropriately used. Also on 29/10 when the cannula site was described as 'sloughy' Inadine was inappropriately used.
- No photo of the tissue damage was taken until 4/11, which was too late.
- Advice was not sought from or given by the tissue viability team.
- There were frequent changes of dressing without explanation in the notes. If the correct dressings had been used, and left in place "the wound may have had a chance to improve more quickly".
- There was no proper planning or wound assessment.

The Trust has given an apology for these failures.

The investigation, carried out at our request, has revealed a catalogue of poor practice and inappropriate treatment, poor planning and assessment, and failure to refer to specialist practitioners. This shortfall in basic physical care (despite our expressed concern at the time) raises the possibility of similar lack of alertness and competence of staff in relation to other areas of Oliver's treatment.

(3d) Failure to adhere to our request to be called in when Oliver came off sedation

We asked to be contacted any time of day or night so that we could be present when Oliver came off sedation. This was because we were worried that he may become agitated and we could help to support him. This was agreed, but it did not happen. The Safeguarding Report acknowledges this:"*This should have been taken into consideration and parents told of when sedation holds were taking place or due to take place. This would be normal practice in a paediatric ICU and the relationship is one of a similar level of emotional care if not physical care. This was an oversight on the part of the ICU team, for which they apologise and acknowledge the need to handle similar situations differently."*

We note the apology but no proper explanation has been given as to why staff ignored the agreement. We believe this is a significant issue because it appears to reflect not just poor communication but an underlying unwillingness on the part of clinicians to engage with us, listen to us, and involve us in decision-making around Oliver's needs and treatment.

(3e) Management of Oliver's temperature

Oliver's raised temperature was managed with anti-pyretic medication until 29/10/16. The Trust has apologised for a discrepancy in the records on 28/10 when intra-venous paracetamol prescribed on the drug chart was not signed for as having been administered. We are very concerned that this points to the drug not having been given.

Use of a 'Bair Hugger' was commenced later on 28/10 when Oliver's temperature had reached 40. However, this had little to no effect – the air was warm rather than cool and on two occasions we found that the nurse had forgotten to turn it on causing his temperature to rise. It was not until 29/10, when Oliver's temperature had risen to 40.5, that a cooling mattress was used. His temperature continued to increase to 41.5 before eventually decreasing. The Trust acknowledges that "*sustained temperatures above 40 can lead to cell injury and above 41.5 can lead to irreversible cell death*."

In its complaint response the Trust says it had no guidance on starting cooling in cases of sepsis or NMS. It says *"it is not clear whether earlier cooling was indicated or whether it would have had any effect on the subsequent outcome."* We consider that this is a highly unsatisfactory conclusion because it appears that Trust staff did not know what they were doing. It appears that there should have been clear guidance for staff to refer to and that the lack of guidance is the Trust's responsibility. The Trust's statement appears to suggest that it is possible that earlier cooling was indicated and that it may have had an effect on the subsequent outcome.

The Trust offers an apology for clinicians "not having properly communicated their thinking and treatment options." But the basis of this apology is not explained - from the foregoing it appears that this was not a failure of communication with us but a failure of Trust systems and of clinical competence and judgement.

The coroner's independent expert (pharmacist)said in his report that if the coroner wanted an expert opinion on symptomatic treatment of NMS such as hydration, nutrition and reduction of fever he should ask an ICU expert. However, the coroner did not engage an independent expert in ICU, so we do not believe this was not fully explored at the inquest.

We continue to have a number of unanswered questions about the effectiveness of the treatment Oliver received once NMS was suspected. The independent expert's report says that the mortality rates for NMS are between 5 and 20 percent. It says that some studies have documented lower mortalities associated with atypical compared with typical antipsychotics drugs. Olanzapine is an atypical antipsychotic.

(3f) Use of excessive physical restraint in A&E

The Trust Safeguarding report acknowledges that "*Oliver's recent difficult experiences of hospitals over the past year caused him additional anxiety for this admission*", and also that

up to the time of admission Oliver had not needed to be restrained by police officers who came in with him.

When Oliver arrived at Southmead A&E on 22 October 2016 we were told that they had no documentation regarding his additional needs, despite a Learning Disability Liaison Nurse having proactively given information in advance. We note from the Safeguarding Report (para 25) that "*There is system in place for adding alerts onto patient record to bring the special needs to the attention of those caring for them. The alert did not get added in this case*."

Oliver was scared and confused as he was experiencing a seizure and A&E was a busy and noisy environment. Our attempts to explain how best to de-escalate Oliver's anxieties were ignored and Oliver we were shocked to witness Oliver being held down on a bed by force with a police officer shouting into face, saying "I don't care what his illnesses are, I expect respect". People around him were all talking at once. Police have apologised to us - although NHS staff were responsible for managing the situation but completely failed to exercise leadership or skill in doing so. Staff seemed completely lacking in experience and awareness about how to manage a young person with Oliver's additional needs and our expressed concerns, and the information we gave, were brushed aside.

The Safeguarding Report states (para 28): "*There is currently no formalised awareness training on meeting the needs of those with Autistic Spectrum Disorders. This has been identified as a need in the organisation prior to O's death."* Despite this admission, the Safeguarding report dismisses our perceptions about restraint used. The report states that medical records indicate that Oliver was '*aggressive / very aggressive'*. It is clear to us that he was treated accordingly as a troublesome and aggressive patient, and that his additional needs were not understood. We are not satisfied by the information that there were '*no records of inappropriate restraint*'. We directly witnessed the staff's inexperience and failure to manage the situation appropriately. This, together with the type and level of restraint used and general atmosphere of excitation, had the effect of escalating Oliver's fear and distress. We didn't agree Oliver was aggressive, he did not attack or attempt to attack any other patients).

The use of physical restraint upon Oliver in these circumstances was a reaction to the levels of stress he was experiencing in an unfamiliar and frightening environment. In view of his autism, the emphasis should have been on stress reduction to prevent the need for excessive restraint. Staff failed to exercise reasonable skill and judgement but resorted to levels of physical restraint which heightened Oliver's anxiety and fear; this was in effect a 'self-fulfilling prophesy'. The Trust acknowledges no failing but states that "*There is currently no formalised awareness training on meeting the needs of those with Autistic Spectrum Disorders."* This reflects our own observations about staff responses: we believe there is a general lack of awareness of the needs of young people with autism and complex health issues in the hospital. It appears that not only do staff not have sufficient awareness and skill in relation to autism and complex needs, but staff also lack awareness of this deficit and treat all challenging behaviour in the same way whatever its cause, labelling it 'aggression'.

We note that the Trust's RCA Review Report makes a finding that: "*The apparent lack of a clear crisis plan for approaches to behavioural disturbance in Oliver's case was noted. The panel considered that it would have been helpful for there to have been an agreed plan between the different health and social care professionals, Oliver and his family, including those services who might become involved during a period of crisis, such as the ambulance*

service and police, regarding what steps should be taken in different types of crisis. This should then have been communicated to all those involved, been easily available at times of crisis, and reviewed and updated regularly, particularly following any crises."

Concluding comments

We would like the Trust to acknowledge and learn from the mistakes it made so that other people with learning disability / ASD will receive skilled, appropriate and safe treatment in future. We strongly dispute the Trust's apparent conclusions that all the decisions made by its doctors were correct. We note that the Trust responses (spread across multiple documents over a very prolonged period) do not look at what happened in a 'joined up' way. There are connections between Oliver's treatment on admission, his reaction to this, and a lack of understanding of his complex needs and history.

Oliver arrived in A&E because of seizure activity. We knew that his behaviour was due to the seizures and would pass when the seizure stopped and he did not have a mental illness that needed to be treated; it was the epilepsy that needed to be treated. We believe the inappropriate noisy environment and excessive restraint exacerbated his behaviour. We understood why he was sedated as it was an urgent situation and they needed to do a brain scan. The doctors in A&E listened when we told them not to give Oliver antipsychotics. At this point we thought everything would be fine. However, once sedated, the neuropsychiatrist made the decision to give him Olanzapine in order to manage any potentially challenging behaviour as he came out of sedation. Because of a lack of expertise around autism and learning disability and serious failures of communication, including a failure to consult with those who had the necessary expertise around Oliver's needs and how to manage them, trust staff pursued a course of action that was NOT in Oliver's best interests. Our pleas for antipsychotics not to be used, and for them to consult with those who understood Oliver's needs, were ignored with tragic consequences. When Oliver's condition deteriorated our concerns were dismissed until it was too late. Things must change and there needs to be justice for Oliver.

NOTE: Attached to this form are the following documents:

1. PHSO form - completed complaint form

2. Timeline produced by Mr Tom McGowan

3. Letter from Dr Razak 9/2/17 - important supporting clinical opinion

4. NBT letter of complaint - original written complaint to NBT

5. RCA Review Report pack {part of NBTs complaint response)

6. RCA Review action plan

7. NBT interim letter of response (part of NBTs complaint response)

8. Safeguarding investigation (part of NBTs complaint response)

9. Trust letter to Mr and Mrs M (part of NBT's complaint response)

10.Complaint responses from Trust 1 (UBHT)and 2 (UCLHT)

We would also like to refer the Ombudsman to the following additional supporting documents which can be supplied in due course:

- Inquest witness statement of Thomas McGowan (on behalf of him and Paula – Oliver's parents)
- Bristol Children's hospital notes
- Southmead notes (the copy the coroner received from Southmead was missing a number of key pages – Original Drug Chart,)
- Yellow folder (information supplied by Oliver's parents to the hospital)
- Email Sent 23 October 2016 01:59 (Dr Luke Canham to Dr Mohan).

Did the organisation answer all of the issues you raised in your complaint? Y/N

No

If no please tell us the issues they did not address.

No. We are not satisfied with the responses provided – please see above.

How far have you been affected by what has happened?

Our son has lost his life. We have lost our son.

Section 4: Putting it right

If we are able to take on your complaint, what would you like us to achieve for you?

We may recommend that organisations explain and apologise, change their procedure and, if appropriate, pay some compensation. Please use this space to explain what you want to happen as a result of your complaint.

The Trust to acknowledge and learn from the mistakes it made so that other people with learning disability / ASD will receive skilled, appropriate and safe treatment.

All doctors and hospital staff are to receive mandatory training in autism and learning disabilities, and understand and implement reasonable adjustments. Training and refresher training should be at least annual and recorded

Awareness of and commitment to take action to address the widespread overmedication of people with learning disabilities and autism, including stopping inappropriate chemical restraint. Understanding what good support looks like and non-pharmacological approaches to managing behaviour that challenges – See NHSE STOMP programme.

Expertise of families must be recognised. They often know the person's needs best. Many people with complex needs have pages and pages of hospital notes added to over many years, which include accurate information as well as lots of inaccurate information. Doctors must listen to families and consult doctors who know the person well when making decisions. They must follow the Mental Capacity Act which is there to empower and protect patients, and ensure that when a person lacks capacity, a decision is made that is truly in their best interests.

Section 5: About you

Title Mr and Mrs

First name Paula and Thomas

Surname McGowan

Address 7 Manor Gardens, Lechlade, GL7 3EQ (preferred method of communication via email)

Daytime telephone number 07463257772

Email address paula.mcgowan@live.com

Contact method: email

Is there anything we can do to make it easier for you to access our service? Please correspond through email

Are you making a complaint for someone else? Yes

Section 6: Complaining for someone else

Who is the service user? Thomas Oliver McGowan d.o.b. 29/4/98

Has this person died (date)? Yes. 11/11/16

Section 7 Authorisation

Please look at my complaint

I agree that you can get all the relevant papers so that you can investigate this complaint under the Parliamentary Commissioner Act 1967

Form submitted on behalf of Mr and Mrs McGowan by:

Tony Drew, Independent Health Complaints Advocate, Swan Advocacy

tony.g.drew@swanadvocacy.org.uk

Signature: Tony Drew

Date: 15 June 2018

If you are complaining for someone else they must sign below if they can:

Signature: P McGowan

Date: 15 June 2018

Please email your form and the organisation's final decision letter to:

Phso.enquiries@ombudsman.org.uk

Customer Services
Parliamentary and Health Service Ombudsman
Millbank Tower
Millbank
London
SW1P 4QP