

**Briefing: Case**

**Incident:**

Delay in patient's access to treatment due to the patient's disabilities, communication barriers and engagement with carers and family.

**Details:**

The patient was referred to the hospital by her General Practitioner (GP) on 17 October 2015; she was admitted to Ilchester Integrated Assessment Unit at 20:30 with diarrhoea and vomiting. The GP referral form provided information that the patient was known to be severely autistic; the carers' informed the GP that the patient had been agitated and difficult to communicate with, totally un-co-operative. The patient had been unwell for 1.5 days, the carers' reported that she was normally manageable and co-operative. The patient was seen by another GP 3 days previously, on 14 October 2015 and was diagnosed with Lower Respiratory Tract Infection (LRTI) (symptoms include shortness of breathe, weakness, fever, coughing and fatigue) and she was prescribed antibiotics.

On the 16 October 2015, she was seen by her GP and was prescribed clarithromycin 250mg twice a day and stemetil 5mg for vertigo, the GP was not able to examine the patient due to her severe autism. It was reported that the patient had been off her food for 1.5 days, intermittent heavy polycythemia pubra vera (PV) (a disorder in which too many red cells are produced in the bone marrow, without any identifiable cause) bleeds. 1 episode of epistaxis (nose bleed); she had also vomited 3-4 times in the previous week and had unable to keep down anything on this day. The patient took herself off to bed, she had wet pads/diarrhoea. The carers' reported that all of these things were totally out of character and she had deteriorated.

The patient's full time carers' were present on her admission and throughout the patient's admission. The patient's parents were kept informed of changes to their daughter's management plan. However, there is documented evidence to indicate the family and her carers' were not happy with the care being provided and felt that they were not being listened to and the management plan was not being acted upon sufficiently.

Due to the patient's autism, and the fact that she did not like to be touched, no observations were able to be taken. The consultant care was handed from one consultant to another consultant regularly. A range of consultants and doctors were involved in the patient's care.

A voice mail was left for Safeguarding Lead at the time over the weekend, which was picked up in the 19th when she was back in the office and the DoLS was put in place. It was clear from the discussion, that at that time, staff were not aware of who else they could contact or what the process was for out of hours to get a DoLS completed. The patient had been seen by the hospital social worker.

It was evident from the documentation and the conversation that plans for care that were made were not always followed through due to changes in clinical opinion, which was not always communicated between the staff, the parents or the care agency. The 'This is me' documentation was provided, which is the document that details how patients that have difficulties like to be treated. This document detailed the patient's needs, what she did like, and what she did not like and how she liked to be interacted with. This document was dated 19 October 2015.

On 19th October 2015, the care manager reported a decline in the patient's condition – they advised that the patient had previously undergone a planned operation to take her finger off after shutting it in a door, and that a general anaesthetic had been given to the patient on that occasion under physical restraint.

19th October 2015, the patient underwent another review of care plan. No tests had been carried out by this point and it was queried whether the patient had been given any food or fluids, there was nothing to confirm or deny that the patient had not been given food or drink, just an entry stating 'nil by mouth'.

20th October 2015, a new plan was put in place to give the patient sedation to undertake the necessary tests.

The patient had a rare condition that is difficult to immediately diagnose (noting it affects approx. one in one million) and it would have needed to be picked up early due to renal failure risk. By the time that the diagnosis was made it was too late for any different outcome.

It was also noted that if the condition had been identified earlier the treatment for this condition would have meant the patient undergoing plasma infusions three times a week intravenously.

This treatment would have been incredibly difficult for the patient to tolerate due to their autism and refusing to be touched. In addition, it is a difficult and technical treatment and for the patient it would have required three general anaesthetics every week which would therefore be a high risk option. It was discussed that this discussion and the possible end of life plan would have been a discussion that was needed earlier.

This condition (HUS) slowly affects the organs, which you can not physically see that happening easily in the way it presents. When the patient did undergo a GA they were then so unwell that effectively they did not wake up again.

At that time one consultant saw the patient one day and a different consultant would see the patient the next day. Consultant handed over on the Monday to the acute physicians with one plan and the following day review meant the plan was changed due to a belief the symptoms were related to constipation.

The Medical Director reviewed that case and noted that, in his opinion, the issues were due to clinical indecision, a best interest decision should have been made, and tests carried out but without the correct best interest decision in place this could have been seen as assault if bloods and observations taken by restraint. After a discussion all noted that if the patient had presented really sick (i.e. acutely unwell), then a GA would have happened, but because the way the patient was presenting is was felt it left the clinicians with this indecision and transfer of care around consultants.

It was also noted that if a clinician had been identified early on to take control of the care, they would have been able to lead a multi-disciplinary meeting (MDT) and decision making.

In addition the carers' noted the patient had been unwell for 2/3 weeks before admission with the GP requesting this admission. The carers would have been aware what was 'normal' for this patient and we should have listened more when they were saying that the patient's behaviour was out of character. Different consultant cover meant the communication with the parents or the carers was poor.

It was agreed the cause of death was

1a – Multi organ failure

1b – Haemolytic Uraemic Syndrome

1c - Severe Autism

The investigation also discovered that two meetings had been held with the patient's parents, on 2<sup>nd</sup> and 24<sup>th</sup> November 2015, together with a manager from the care agency, Head of Risk Management, Renal Consultant, Ward Sister and Risk Manager, Litigation and Claims. We were unable to identify any documented evidence of what was discussed or what actions were agreed at either of these meetings.

There was no evidence the family had been contacted since those meetings were held in November 2015.

New staff came in to post in January 2017, new Dorset Coroner came in to post February 2017.

Investigation in to this case commenced again in January 2017, nearly two years after the patient's death. No contact had been made with the family since 2015, and for then that communication back then was appalling. The family recalled that that their complaint had been 'lost' they had never received a response, and they had been made to feel that they had no right to complain anyway as 'they could not be bothered to visit their daughter'.

Understandably, communication with the family and the care agency was extremely difficult when contact was made in 2017. They had waited over two years for an inquest, and the Trust's investigation in to the patient's care. The family and the care agency were extremely angry.

## **CONTRIBUTORY FACTORS**

- Severe autism, unable to take observations
- Delay in completing the Mental Capacity Assessment and Best Interest Assessment upon admission. This led to a delay with sedating the patient to obtain baseline observations. This resulted to a delay in diagnosis to provide the patient with the most appropriate care and treatment.
- Change in clinical plan to not sedate, to obtain baseline assessments to obtain a possible diagnosis, and to act promptly on the plan.
- Poor medical and nursing documentation makes it difficult to clarify when concerns were identified regarding high blood pressure and reduced GCS (Glasgow coma scale). No reference documented in nursing records that when the patient was deteriorating this was escalated for a medical review.
- Parents and carers were voicing concerns regarding the change in patient and identifying her behaviour was not normal for her on admission. It is not clear if anyone took their concerns into consideration.
- The "This is me – my care passport" – is signed and dated 19th October 15 by the patient Care Manager, (not hospital staff). It clearly states in the passport that patient requires sedation and/or restraint for any nursing or medical interventions. This was not available at the time of the patient's admission.
- At the time of the patient's admission the in-house safeguarding service was not available, however, there was an on call safeguarding service available out of hours but this service was not used.
- Failure to act upon advice made by the Social Worker on 18th October 15 that a MCA and Best Interest Assessments were required, this advice was not acted upon.
- Failure to complete DOLs application upon admission.
- Failure to complete a MCA & Best Interest Assessments upon admission.
- There were a number of clinicians involved in the patient's care, and each clinician changed the care plan. There was poor communication and a lack of responsibility taken by a single clinician to oversee the patient's care at that time. There is now a single named clinician that will remain responsible for the patient throughout their admission.
- There was poor documentation throughout the patient's episode of care by nursing and doctors.
- There was a lack of Learning Disability and Mental Capacity advice available for staff.

## **Findings and Learning:**

- The Trust worked with the care agency to raise awareness of patients with autism across the Trust. They came in and presented training sessions for staff across the Trust. Family also attended this session. We also took the opportunity to launch 'Gemma's story'.
- The Trust undertook a big awareness campaign on Autism and the 'This is me Document' and 'Care passport' documentation
- Newsletter was sent to all staff trust wide to share the importance of listening to family/carers and following the information documented or information verbally given by the family/carers.
- This is Me / Care passport included in the Trust's induction programme and preceptorship programme.
- Safeguarding information is provided on induction, this includes contact details. There are also online training packages available to staff. Safeguarding training is mandatory and includes what to do out of hours.
- Browne Jacobson supported us with training sessions on the MCA
- Handover sheets amended to include information provided by other professional colleagues, to enable actions to be undertaken on the advice given.
- Reviewed how handover is provided to each shift and on Doctors ward rounds. This includes nursing documentation and any information from family/carers. These were audited.
- Documentation audits completed
- Appointed a Learning Disability and Mental Capacity Act Advisor.

## **Reflection/summary:**

- Understanding of compliance with legislation was poor. Clinical staff did not know their duties under the Mental Capacity Act 2005, including the Deprivation of Liberty Safeguards (now known as Liberty Protection Safeguards) or the Code of Practice for either. The trust did not have out-of-hours safeguarding expertise, in particular, at weekends.
- Clinical staff ought to have had access to the patient's clinical 'passport' and discussed her clinical care with her family and carers to establish treatment in her best interests, once her mental capacity had been assessed. For people without mental capacity to make a particular decision (for example the patient refusing assessment), clinical staff must involve family and carers in decisions in relation to serious medical treatment; in the absence of family or carers, clinical staff ought to instruct an Independent Mental Capacity Advocate or seek a declaration from the Court of Protection.
- Lack of awareness and lack of training to clinical staff resulted in this failure to comply with legislation