Case Study

Listen to a patient

The sad story of a young person's death after surgery

For confidentiality reasons, the name of the client has been replaced in this account with the agreed name 'Sammy' – his beloved rescue dog, who now lives with his parents.

IHCAS
Independent Health Complaints Advocacy Service

healthwatch
West Sussex

Sammy's Story

Sammy presented for elective weight loss surgery at his local Acute hospital Trust. Before they agreed to put him forward for surgery, he had attended appointments for over four years. Staff were aware of Sammy's autism, and he endured months of injections and a strict diet regime, with lots of side effects.

On the morning of his surgery, he drove to the hospital, pulling his suitcase and walking unaided in the hospital, with the hope the surgery would change his life and get him feeling positive for his upcoming wedding.

Sammy underwent a 'Roux-en-Y: gastric bypass procedure' and according to the medical team, the surgery went well, and Sammy was taken back to the ward. With limited visiting on the ward, his fiancée arrived in the evening and Sammy reported that he was in a great deal of pain. He was violently vomiting and bringing up blood. Staff said that it was a reaction to the anaesthetic, and that he would feel better in the morning. Although the staff seemed surprised the anti-emetic drugs and pain relief were not working like they would expect.

The last text Sammy sent to his family read "worst night and morning of my life, pain is bad, and I can't stop being sick. Too unwell to message further unfortunately."

The Trust reported in the serious incident report, the National Early Warning Scores (NEWS2) were between 0 and 3, and with normal blood test results and observations, there was no need for further escalation of care. However, the pain scores documented did not consistently represent the analgesia requirements or reflect the reports from the family about Sammy's levels of pain. Considering this discrepancy, the family queried whether Sammy's autism and style of communication affected his ability to ensure the staff understood the pain he was in.

Early the following morning Sammy's **NEWS2 score** was **recorded as 11 (high)**, a MET (medical emergency team) call should have been triggered at 4.43am, instead reviews were done, and the MET call was not placed until 6.05am by the surgical registrar.

Clinical response to the NEWS trigger thresholds

NEW score	Frequency of monitoring	Clinical response
0	Minimum 12 hourly	Continue routine NEWS monitoring
Total 1–4	Minimum 4–6 hourly	• Inform registered nurse, who must assess the patient • Registered nurse decides whether increased frequency of monitoring and/or escalation of care is required
3 in single parameter	Minimum 1 hourly	• Registered nurse to inform medical team caring for the patient, who will review and decide whether escalation of care is necessary
Total 5 or more Urgent response threshold	Minimum 1 hourly	• Registered nurse to immediately inform the medical team caring for the patient • Registered nurse to request urgent assessment by a clinician or team with core competencies in the care of acutely ill patients • Provide clinical care in an environment with monitoring facilities
Total 7 or more Emergency response threshold	Continuous monitoring of vital signs	• Registered nurse to immediately inform the medical team caring for the patient – this should be at least at specialist registrar level • Emergency assessment by a team with critical care competencies, including practitioner(s) with advanced airway management skills • Consider transfer of care to a level 2 or 3 clinical care facility, ie higher-dependency unit or ICU • Clinical care in an environment with monitoring facilities

Sammy was rushed for an urgent CT scan which showed a haematoma blocking the bypass and was taken into surgery to remove the blockage and then transferred to intensive care. His family and fiancée were informed, and they rushed to the hospital and sat with him in ICU, talking to him and holding his hand, whilst he was in a coma. The family returned home and later that evening they received an urgent call to return to the hospital.

The family described this as a journey they will never forget. It was a 22-mile journey from hell, ending in them arriving to hold Sammy's hand as he passed away. His fiancée did not arrive in time to be with him.

The family were left in total shock as to what had gone so tragically wrong in the past 3 days.

Sammy's death was considered to have met the threshold for the Trust to start a serious incident investigation (SI), and the death was reported to the coroner. The family also submitted a complaint to the Trust and requested advocacy support from their local IHCAS team.

Sammy's fiancée wrote a statement about the events that she had witnessed leading up to when Sammy was taken back into theatre, twice after the surgery during the first evening, she voiced her concerns about the pain Sammy was in and was informed it was normal after bariatric surgery. When she returned the next afternoon, she was expecting Sammy to be feeling better as she had been informed the pain and vomiting should ease after 12 hours, but to her surprise Sammy was still being sick and was in a great deal of pain. She raised her concerns with the nurses, and these were dismissed, and she was informed that patient transport had been booked to take Sammy home. She again raised her concerns with the surgeon in the evening and was again informed that it was Sammy's body adjusting to the changes.

Sammy's Finance is also autistic, and she felt that she had been dismissed and that her autism played a part in the way the staff communicated with both her and Sammy.

A part of the SI investigation revealed that a bariatric physician who was not due to visit Sammy the day after his surgery, having seen Sammy in clinic over the past 4 years, decided to visit him post-surgery and had sufficient concerns to carry out a full examination and wrote in his medical files "NOT RIGHT" and possible CT scan "blockage," she also checked the drugs charts and messaged her concerns to the surgeon. The surgeon did review Sammy but did not do a full examination or check the drug charts, all of which would have alerted him to the unusual pain Sammy was in, and he reported "there was nothing out of the ordinary going on at this stage that would require further investigation or return to theatre".

The surgeon did not check the medical/drug records or carry out a full examination as his colleague had done earlier, therefore when making his assessment he was unaware of the levels of pain relief drugs being administered, or the pain Sammy was in. He did record that Sammy's very high body weight and autism, were taken into consideration as he felt Sammy would struggle a bit more with post-operative changes. The family were shocked and dismayed on reading the surgeon's report to the investigation that he had taken Sammy's autism into account as regards Sammy's ability to understand pain.

The family's view that was accepted by the investigation lead, that had action been taken when the physician raised the alarm about a possible blockage Sammy would most probably have lived. This was a huge, missed opportunity.

Once the SI report was sent to the family, this gave them the opportunity to understand what had happened in the days after Sammy had his operation.

Some of the findings/learning opportunities were:

- Autism may have contributed to the way Sammy interpreted and communicated pain. Because he was mobilising independently this may have caused the nursing team to underestimate the severity of the pain he was in.
- There was no evidence that Sammy had been asked whether any reasonable adjustments were required to support him during his admission to hospital in respect to his autism.
- Due to normal clinical observations and unremarkable blood tests first day after surgery, the surgeon did not feel there was a need for a CT scan or return to theatre.
- The need for an assessment of the use of anti-emetic drug use as a potential marker for the presence of any obstruction.
- The pain assessment scores were recorded as mild to moderate and not consistent with reports from the family.
- Fluid balance monitoring was not consistently completed.
- The surgeon confirmed the escalation of anti-emetic use without clinical benefit had not been communicated to him, and that reviews of electronic prescriptions is not routine practice.
- The sudden deterioration of the NEWS2 scoring should have resulted in an emergency call (MET call) which would have resulted in a faster senior clinical assessment and emergency resuscitative care.

Sammy's death was listed as requiring a full inquest, and 16 months later the family were at the coroner's court facing the staff from the Acute hospital Trust that had been present at the death of their beloved son.

This was such a traumatic experience for the family; the family feel that this case study will never be able to describe the pain, sadness, anger, and emotional state they felt, to be told after 2 days of inquest, that Sammy died of a rare but recognised complication of a medical procedure.

Recommendations

These are some of the recommendations from the Acute Trust:

- Consider early CT scan in the presence of clinical concern regarding unresolved pain and nausea.
- Training for staff to implement MET calls when there is a sudden deterioration in NEWS2 scores.
- Improve documentation.
- Education in the bariatric medical team to specifically assess the anti-emetic drug use as potential markers for the presence of an obstruction.
- Recognition of autism as a part of a holistic assessment and how it may impact upon an individual's recognition and response to pain from the beginning of the patient's journey.
- Importance of asking whether reasonable adjustments might be required to support individuals while they are receiving our care.
- Communication training for nursing staff to ensure time is taken to listen to concerns and when to respond in an effective manner, reassure patients and loved ones that we are listening and taking action.

At the end of the inquest and the NHS complaints process the family's statement to Coroner read:

"No words can adequately express the endless devastation, agony, and heartbreak we feel on a daily basis over the loss of our beloved son. Sammy was ripped from our lives that dreadful day. The wounds for us are still raw and jagged, and we cannot even imagine a time when they will be healed. We will miss Sammy, our beloved son, until our dying days. Our lives will be forever incomplete."

The family are also astonished that an NHS Trust agrees post the investigation and inquest that nurses are to receive training in monitoring fluids and doctors will be instructed in how to act in a medical emergency and to check drug records.

The **IHCAS Advocate** has been by the side of the family throughout the entire process, and at times it was just having someone to be in their corner.

"Whilst we thanked you after the inquest for all the help and support you gave us, we both felt we had not thanked you enough. We like many before us, were left disillusioned and feeling let down by the system. That does not take away from our appreciation of the support and guidance you gave us. Without your help the entire process would have been far more distressing and intimidating than it was."