Trust Board Meeting in Public: Wednesday 14 March 2018
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### Executive Summary

1. This story highlights the value of **sensitivity, kindness and compassion from staff**, which made a significant difference to the overall positive experience of Mr M’s family when Mr M was diagnosed and treated for subarachnoid haemorrhage (SAH) at the John Radcliffe Hospital but sadly passed away.

2. The Trust Board is asked to reflect upon the following key areas for learning and improvement, as experienced during the three-week period (from the 3rd to 26th September 2017) of Mr M becoming ill and passing away, as related by his wife (Mrs L) and their son (Mr L).

3. Mrs L’s and Mr L’s story emphasises the following insights, which impacted on how the family experienced the Trust’s services when Mr M was treated and cared for at the John Radcliffe Hospital:

   - **The high value of the sensitivity, kindness and compassion shown by staff** in providing ‘holistic’ care and treating the patient within the context of his family including carers and relatives who are equally affected by the patient’s situation. This includes providing emotional and psychological support to the family member in the hospital.

   - **The value of effective communication and involvement of family and relatives** (especially when the patient is unable to communicate) in discussions about the patients’ care, treatment and the progress of their condition. Providing clear information about current care and treatment and enabling family members to take part in appropriate support alongside the nursing care team.

   - **The importance of maintaining communication between staff and family members to manage expectations**. This includes staff handover of information when patients are moved from one ward to another (e.g. from the intensive care unit to the high care area) and communicating what relatives/carers can and cannot do in differing environments.

   - **The vast importance of having private conversations with the next of kin** when discussing end of life care and the extra sensitivity required when raising the topic of organ donation.

4. **Recommendation**

   The Trust Board is asked to reflect on Mrs L’s and Mr L’s story and the learning and insights gained.

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1. A subarachnoid haemorrhage (SAH) is a sudden leak of blood over the surface of the brain. The brain is covered by layers of membranes, one of which is called the arachnoid. An SAH occurs beneath this layer. The blood vessels supplying blood to the brain lie in this space, surrounded by clear cerebrospinal fluid.

2. Presence of family during patients’ hospitalisation is strengthened by the perception of holistic care. Nursing, as a science and art, supports the idea of an anthropocentric and holistic care. Consequently, there is a need for continuous interaction between nurses and family, for the achievement of holistic care [22].

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Mrs L and Mr L’s story about Mr M

1. Purpose
The purpose of this paper is to relate the story of Mrs L and her son Mr L and their experience when their husband and father, Mr M, was taken to the John Radcliffe Hospital on the 26th September 2017, subsequently passing away within a three week period.

2. Background
2.1. The story was told to two members of the Patient Experience Team and a member of staff from the Neurosciences High Care Area at the John Radcliffe Hospital, at a pre-arranged meeting held on the 22nd December 2017. The location of the meeting was agreed with Mrs L at Banbury, Oxfordshire, which is midway from her home to where the Patient Experience Team is based. Mrs L and her son, Mr L, attended the meeting.

2.2. The story relates to Mr M who, prior to becoming ill, was a beekeeper, involved in archaeology and made bespoke guitars. He had a very vibrant personality. He had been away in August 2017, so family did not see much of him, because he was involved with an archaeological dig on a local Roman Villa site and away the weekend before helping friends in the Cotswolds.

2.3. There was a period of three weeks from the 3rd September, when Mr M became ill, to his passing away, at the age of 57, on the 26th September.

2.4. This story was produced by the Patient Experience Team, in partnership with Mrs L and Mr L, who agreed for their story to be used as a Patient’s Family Perspective, presented to the Trust Board or Quality Committee, so that learning and insights could be gained from the compassionate care provided to Mr M, and the kindness experienced by Mrs L and Mr L as family members.

2.5. Mrs L offered her willingness to speak to other members of staff about her experience, if it would help for learning and training purposes.

2.6. On the 3rd of September 2017, Mr M experienced headaches and began feeling sick. He asked for a massage and took painkillers, hoping to alleviate the pain, but these did not seem to help. Two hours later, Mr M was still feeling sick, so Mrs L called NHS 111 for advice. After a further 30 minutes Mr M was feeling worse, being sick and “not making sense” so Mrs L rang 111 again. The ambulance took an hour to arrive and Mr M was taken to Northampton General Hospital NHS Trust’s (NGH) Emergency Department, where it was determined that there was a bleed on his brain and he would need specialist support. The family were given the names of four specialist hospitals where Mr M might be sent: Oxford University Hospitals NHS Foundation Trust, University Hospitals Coventry and Warwickshire NHS Trust or Nottingham University Hospitals NHS Trust. Staff at NGH informed the family that Oxford would be the preferred option, but that there was no bed available at that time. However, by 10.40pm, a bed had become available and the team at NGH sedated Mr M for transfer by ambulance, accompanied by Mrs L.

2.7. Mr M arrived at the John Radcliffe Hospital in the middle of the night on the 3rd September and was operated on immediately. Mrs L was able to see Mr M at 2.00am, following his surgery, and at 5.00am he was looking a bit better. Mrs L went home and returned during visiting hours at 10.00am. The first few days were a “rollercoaster ride” but “staff were exceptionally kind and supportive”.
3. Mrs L and Mr L’s story

3.1. The story highlights examples of sensitivity, compassion and kindness in providing ‘holistic’ care:

“Once in Oxford at the John Radcliffe Hospital, the staff were exceptionally kind and supportive in a way that I have not seen elsewhere.” (Mrs L)

3.2. From the beginning, Mrs L described that she was given good explanations of what had happened. By 2.20am on the 4th September, Mr. M had had a scan which showed that he had had a subarachnoid haemorrhage (SAH). He then had an operation to drain the blood that had built up around the surface of his brain.

3.3. Mrs L mentioned feeling encouraged by what one of the consultants involved in Mr M’s case had said: “Let’s give [Mr M] a chance”.

3.4. Mrs L did raise an issue with having arrived during the night:

“However, because we arrived in the middle of the night, there was no one to tell us about visiting times and other information that family members should know about. Although there were notices, family members don’t see these notices, as we were ‘switched into a totally different mode’ and were very concerned about what might happen.” (Mrs. L)

3.5. Mrs L explained that she was keen to make notes about Mr M’s condition and treatment: “My life has gone out of control – what I can control is getting some information and getting it down and focusing on that.”

“When one of the consultants was talking to me the next day, I was taking down notes on my phone in order not to forget what was being said, so I could help, and the consultant asked whether I was texting and that made me feel a bit silly and angry. After that, I decided never to use my phone for note taking in front of other people, because I didn’t want to be accused of being rude.”

3.6. “This is an area where some training on customer service might be useful for the consultant or sensitivity in communication could be improved”. (Mrs L)

3.7. By the 6th September, Mr M was no longer sedated and a nurse explained that he was responding to commands.

3.8. Mrs L explained the family got to know the nurses at the ICU (Intensive Care Unit):

“The family got to know the nurses at the ICU (Intensive Care Unit), where the nurses would wave and acknowledge us. I was impressed with the professionalism and kindness in the relationship that the nurses demonstrated.” (Mrs L)

3.9. Mrs L said that the waiting area in the ICU was experienced as a warm and supportive environment, where families could talk to each other and provide support. The families they met there were also eager to know how Mr M was doing:

“Everyone was so excited for me when Mr M came around. There’s no way of contacting them, which is sad.”

3.10. The ICU waiting area enabled families to have a supportive community.

3.11. The story also highlights the value of effective communication and involvement of family and relatives:

3.12. On the 11th September, Mr M was transferred from the ICU to the Neurosciences High Care Area. Mrs L described the transfer between these units as “quite
awkward”. The ICU nurse who was accompanying Mr M to the High Care bed put the call bell in Mr M’s hand, saying that he should use this to call for help when he needed to. Mr M was wearing ‘mittens’ which meant that he could not use his hands to push the button. Mrs L said “She knew I was there and going to be there, but she didn’t say to me about the call bell.”

3.13. Mrs L explained that there were issues in the High Care Area around visiting hours: “I was told that I could visit at any time…at one stage the Ward Sister stopped me and [Mr L] entering the Ward out of visiting hours. I was very upset as I had just been told by one of the consultants that [Mr M] was one of the most seriously ill patients in the unit.”. She said that it was made clear by the ward sister that the family had to adhere to the visiting restrictions.

3.14. Mrs L wanted to be there for Mr M, but mentioned that the Ward Sister advised her to ensure that she slept well and looked after herself. She appreciated that this came from “good intentions”, but she felt that this “showed no understanding of my husband’s changed condition and empathy that I would wish to be with him if he was close to dying.”

3.15. The attitude and the way that nurses and staff communicate and involve the patient and their families make a huge difference to an otherwise emotionally intense atmosphere.

“From a family’s perspective, we wanted to help and therefore wanted to be involved, not only in discussions about the condition and progress of our family member, but also supported with information of what we could and couldn’t do, and being enabled to help.” (Mrs L)

Both Mrs L and Mr L particularly pointed out the positive attitude of one of the nurses (M), who they described as “cheeky” and who was especially kind to Mr M. In the particular context of the emotionally charged atmosphere that the family was under, (M) would say something that “made people laugh, she sang, she was really very sweet”.

3.16. Another key issue is the maintenance of communication between staff and family members, to manage expectations:

3.17. Staff handover of information when patients are moved from one ward to another (e.g. from ICU to the High Care Area) and communication with relatives/carers about what they can and can’t do is very important. Mrs L explained that after the move to the High Care Area, they did not receive a leaflet until the second day, which explained about the area’s day to day information.

3.18. Mr L raised the issue that his father’s transfer seemed inappropriate to him: “His behaviour made it an issue for him to be moved.” in terms of coming from somewhere where the nursing care was 1:1 and visiting hours were unlimited (ICU), to somewhere where nurses had several more patients to care for and visiting is restricted (High Care Area). Mr L suggested that “You need someone to explain it to you in terms of what will happen and how things work.”

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3 The staff who attended the meeting explained that ‘mittens’ are like soft boxing gloves and are sometimes used (under Section 5 and 6 of the Mental Capacity Act) to prevent life threatening occurrences with confused/restless patients who are trying to pull out their drains/tubes. If mittens are used, the reason will be documented in the patient’s notes.
3.19. Mrs L found it difficult that visiting was restricted in the High Care Area: “I wanted to be there to support [Mr M], thinking if I supported him and he was calm, it would be easier for the nurses and doctors. I massaged his feet and washed and creamed his hands. On occasion, we were told not to stay”.

3.20. By the 14th September, Mr M’s condition was rapidly deteriorating. There was concern that there might be an infection and the wound from the drain in his head was leaking, and the issue was raised with nursing staff. Mrs L said it would have been helpful if they had been told this potentially is expected and could be normal, and if the surgeon had been informed about the leakage, but the family was not updated about this.

3.21. The family saw several consultants and there was a discussion of a tracheostomy being put in, where a tube is put in through the neck to help with breathing. Mrs L explained that “You felt as though you were getting the best information from everybody.” One consultant informed the family that more serious interventions might be necessary.

“The words of one of the consultants “Let’s give [Mr M] a chance.” was very encouraging and compassionate.” (Mrs L)

3.22. By the 16th September, Mr M was back in the ICU and was sedated. On the 19th September, Mr M’s heart rate was irregular, and on the 20th the family were told that he had had two major strokes. The family was told that these were common complications within three weeks of someone having an SAH and there could potentially be further seizures. Mrs L and Mr L said they were able to see the scans carried out on Mr M and this helped to make what had happened clear.

3.23. Mrs L spoke positively around the information that was provided in terms of Mr M’s care and treatment:

“We were told what was happening with him and what could be done, however we were also told that there is still a great deal unknown about SAH.”

3.24. “By the 21st and 22nd September, the family knew that we were being gently supported with the knowledge that nothing could be done anymore and it felt that being cared for in that regard was hugely important.” (Mrs L)

3.25. By Friday the 22nd September, Mr M had become unresponsive and the family expected that he might pass away at any moment. Other family members had said their goodbyes and had left the hospital, so for Mrs L she was “Just waiting for it to happen”. Nurses were coming in and out to monitor Mr M and the morphine was keeping him comfortable.

3.26. By Saturday the 23rd September, the family were told that Mr M would be moved back to the Red High Care Area. The family was then given a side room to stay in during the night. They presumed they could stay there for a while. However, the following day they were told that the side room was needed for a patient and they had to move out. Mrs L explained that this confusion could have been avoided:

“We understood that those beds are precious but it would have been helpful if the family was told that you can go into this room for the moment but you might be moved out when there is someone who needs it more” (Mr. L).

3.27. There was a similar issue with communication between staff and the family after Mr. M passed away when Mr L stayed in the relatives’ room on ICU. In the evening, a nurse knocked and came in, surprised to find the room occupied and said, “I’m sorry,
we didn’t know you were in here.” Mr L felt that staff were “passive aggressive” when agreeing that he could spend another night in the room. He said, “I knew we couldn’t stay in the room for a considerable amount of time, as others would need the space, but it wasn’t very well discussed that there was a limit”

3.28. Mrs L also raised an issue with the differences between night and day time on the unit:

“Nursing at night was much better than during the day. During the day, sometimes we couldn’t find the nurse, and we felt left to our own devices over the weekend. This was when we felt we needed support and to speak to someone”.

3.29. Mr L explained that there was no communication to staff about Mr M’s status, such as a sign on the door to indicate that he should not be disturbed. Mrs L and Mr L related how someone came in and asked to tune the TV, someone else came test the fire alarm, and housekeeping asked to change the bin.

3.30. Mrs L talked about how this was a difficult time “We were wondering what was going to happen during the day that weekend, expecting that he would pass away within 24 hours, and were concerned he didn’t have enough drugs to keep him comfortable.”

3.31. Mrs L and Mr L gave praise to one member of night staff in particular: a nurse who was “so good” because he was “so sensitive and seemed to know what the family needed. He fetched me a mattress, so I could stay with Mr M, especially when he was making sounds that seemed like he was in pain”. (Mrs L)

3.32. After a weekend largely concerned about Mr M’s pain levels, the Chaplain and Palliative Care team came to visit on the Monday. In the afternoon, it became clear that Mr M was dying. Mr L was due to turn 21 the following week, and he was also starting his second year at university, so Mrs L suggested that he go home. After Mr L leaving, Mr M quickly declined.

3.33. Mrs L’s account raised issues around the need for having private conversations with the next of kin when discussing end of life care:

3.34. By the 22nd September, Mr M’s entire personality had changed, and he couldn’t move. Mrs L had a conversation with the consultant and explained that Mr M “had made his views really plain that he wouldn’t want to be alive at any cost”. So Mrs L asked the consultant what would happen now. The consultant explained that Mr M would be moved to a different area of care and various interventions would be withdrawn, but he would be on morphine to keep him comfortable.

3.35. In the conversation about end of life care, ten people were in a private room, including the consultant (who had introduced the End of Life Care Nurse), Mr M’s mother, Mr M’s sister, Mrs L’s father and sister and brother-in-law.

3.36. The End of Life Care Nurse then “started talking about organ donation and this really upset [Mr M’s] mother” who had to leave the room. Mrs L knew that Mr M’s view was not to have organ donation, but she hadn’t been asked the question before. Mrs L understood that the nurse needed a decision quickly, because the organs would have to be taken out within three hours of Mr M passing away. However, Mrs L explained that the subject could have been dealt with more appropriately:

“This could have been done a little kinder; for example asking me whether she could chat with me privately, which would have allowed me to express that Mr M’s view was not to donate his organs.” (Mrs L)
3.37. “On Monday the 25\textsuperscript{th} September, the Palliative Team came and the Chaplain came too. This was after having been left on our own during the weekend, except at night when C, a nurse, was there. The Palliative Care Team moved Mr M again to a room closer to a nurses station. He had been moved three times from Friday to Monday, but I was told that I could not take him home.” (Mrs L)

3.38. In the early hours of the morning, Mr M passed away. There were two nurses with him, as well as Mrs L.

3.39. Mrs L was given the number of the Bereavement Team to call, and when she did this the member of staff she spoke to was “very good”. Mrs L did explain that it is difficult to return to the place where your relative has died; for example, after meeting with the Bereavement Team, she went to the Pret à Manger café in the West Wing (as this was somewhere she and Mr L visited for a break when at the hospital) and happened to meet one of the family members she had met in the ICU. This person asked how Mr M was doing, which was hard to deal with. Mrs L said that it would be nice if family members could go somewhere else (away from hospital sites) to see the Bereavement team.

3.40. When asked about how they are both coping now, Mrs L said “He died too soon and I’ll struggle with that”. However, she has (three months on) gone back to work. She has accepted she needs support and is going to counselling. She acknowledged that there are lots of people who are kind and can provide support. She recognises that it’s a long and individual process that she is going through, but she is starting “to put the bees to bed and getting them ready for winter”. Mr L is back at University, studying to become a vet. As a family, it has had a great impact: “He’s a huge loss - we’re a little family, he’s a huge loss.” (Mrs L)

3.41. Mrs L offered to come and talk to staff, patients and family members or friends about her experience, if it helps to promote lessons and learning. She feels that the things they identified in their recommendations are not difficult to change.

4. Recommendations

4.1. Overall, in spite of the death of Mr M, the family thought their experience had been positive in terms of the compassion, kindness and sensitivity of care from most of the staff they met and who cared for Mr M. They also felt that staff had done all they could for him: “I feel he had the best chance he could” (Mrs. L).

4.2. However, there were things that the family would wish to change; these would be simple to change but would make a big difference to families. They recommended the following:

4.2.1. When a patient is moved from one ward to another, there should be appropriate discussion about the changes in environment, nursing staff per patient, and in terms of visiting hours, in particular. It would also be helpful for family members to be included in discussions around calling for help.

4.2.2. Allowances should be made for families of those who are critically ill or receiving end of life care, in terms of visiting hours.

4.2.3. Staff, including doctors, should undertake the ‘customer care’ training which is managed by the HR Department, in developing skills when speaking to relatives about sensitive topics; ensuring that they are sympathetic, understanding and clear in their explanations. However there are also excellent advanced communication courses led by the hospices which are available to all staff. Doctors are required to reflect on complaints as part of
their revalidation and appraisal process, and talk through the learning with their appraiser.

4.2.4. Staff should deal sensitively with relatives of those patients receiving end of life care when they are given use of a relatives’ rooms to spend the night. Where possible, all staff should be made aware of who is using the room and for how long. Families should be given explanations of the timescales these services can be used for.

4.2.5. Palliative care should be available 24/7, as the family felt alone during weekends when there were fewer members of staff to talk to or pose questions to.

4.2.6. Care, sensitivity and empathy are required when addressing the issue of organ donation by staff other than the organ donation team. Mrs L would suggest having private conversations with the most immediate next-of-kin and sensitively asking the family whether the patient had previously discussed their preferences or whether they carried a donor card.

4.2.7. Teams should speak openly with relatives about what is the norm in terms of visiting hours and being able to stay with their loved ones in hospital. Mrs L and Mr L explained that most of the nurses/staff/consultants were very supportive and kind. However, there were some instances where staff, including one Ward Sister, had inflexible approach to visiting hours. Mrs L felt it should be recognised that relatives want to be there to support not only their relative, but staff too, in terms of keeping patients calm and relaxed, for example. The Trust has already embarked on plans to develop open visiting within the trust and trialling this first in certain areas.

4.2.8. Handover conversations between staff need to be followed by face-to-face conversations with relatives. It should not be assumed that a receiving ward would explain to patients’ relatives about the processes of their ward being different to that of the patient’s previous ward. Teams need to give patients’ relatives the necessary time, and explanation, to prepare for the change in environment. This needs to be done by conversations and written information, as relatives are in an emotionally intense atmosphere, and cannot take in information as effectively as usual.

4.2.9. The leaflet given about what would happen when you go home following someone’s death, written by the Bereavement Team, was photocopied and did not look professional; staff should always use original versions of leaflets where possible (printed by the Print Room) and avoid making substandard copies. This has been followed up with the area that handed out the leaflet to ensure they get proper copies in the future.

Ms Sam Foster
Chief Nurse
March 2018

Report prepared by:
Liz Wright, Deputy Chief Nurse
Daisy Camiwet, Patient and Public Involvement Manager
Olivia Galloway, Patient Experience Project Manager
Naomi Roberts, Patient Information and Interpreting Officer (Proof reading and photo lay-out)
In attendance at the meeting:
Charge Nurse (Red High Care Area, Neuroscience Unit)