Trust Board Meeting in Public: Wednesday 13 March 2019
TB2019.23

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<th>Title</th>
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<td>Status</td>
<td>For information and learning</td>
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<tr>
<td>History</td>
<td>Patient stories are presented to the Trust Board or the Quality Committee. This paper focuses on the lessons learnt from a patient story on End of Life Care.</td>
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<td>Board Lead(s)</td>
<td>Mrs Sam Foster, Chief Nurse</td>
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## Executive Summary

1. This paper explores the experience of the family and the lessons gained when the relative was on End of Life Care services by Trust. The story also highlights the importance of effective patient and family engagement including the family-centred approach that staff undertook in making joint decisions to support the patient’s choice and preferences of where to be cared for at the most difficult time during the End of Life.

2. The importance of family and the home setting for Sophia and her family was respected. Arrangements for transfer from Intensive Therapy Unit\(^1\) (ITU) to the family home for palliative extubation\(^2\) was well managed and commended by the family.

3. The importance of person-centred and compassionate approach of staff and the joint decision-making with the family on the care and treatment for Sophia which involved all relevant individuals, including Sophia.

4. **Recommendation**
   
   The Trust Board is asked to reflect on the content of Sophia’s story and the lessons learnt.

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\(^1\)Intensive care units (ICUs) are specialist hospital wards that provide treatment and monitoring for people who are very ill. … ICUs are also sometimes called critical care units (CCUs) or intensive therapy units (ITUs). [https://www.nhs.uk/conditions/intensive-care/](https://www.nhs.uk/conditions/intensive-care/)

Learning from Patients Feedback

1. Purpose

1.1. The purpose of this paper is to:

- Explore the experience of the family and the lessons gained when the relative was receiving End of Life Care services by Trust;
- Highlight the patient- and family-centred approach that the staff undertook in engaging with the family in making joint decisions to support the patient’s choice and preferences of where to be cared for at the most difficult time during the End of Life.

2. Background

2.1. This story was adapted from information shared by Sophia’s family as an example of how care can work well even at the end of life. At their request, her story has not been anonymised.

2.2. Sophia’s story was first told at the Clinical Commission Group Governing Body.

2.3. Sophia’s family have consented to her story being shared at Trust Board.

3. Sophia’s Story

3.1. Sophia had Downs Syndrome, severe pulmonary hypertension, scoliosis and hyperthyroidism. Despite this, she lived a rich and meaningful life.

3.2. Her immediate family was very important to her, as was her grandparents and cousins (especially on the Italian side of the family). Sophia regularly travelled to Italy to stay with her maternal grandparents. She swam in a small pool, whilst supported by an adult, and went to the seaside. Occasionally she stayed with her grandparents for several days without her parents.

3.3. Sophia enjoyed going to school, and benefited from mainstream education, supported by a Teaching Assistant, until she was 18. At 18 she made a successful transition to a Special School, which she settled into nicely.

3.4. Social integration was very important to Sophia. She went to a mainstream ballet class on Saturdays for many years and was a valued altar server in the Roman Catholic Church, where her family attended Sunday mass. She had a close bond with her school communities, both past and present, along with the church community. Sophia fully enjoyed the things she was able to do and took pride in them. Sophia liked routines and could be stubborn in resisting deviations from them.

3.5. She loved listening to music (whilst singing along also), watching DVDs, going to the theatre and the cinema, and dancing. She also enjoyed her curricular activities and was rightly proud of her own ability in a number of subjects, including reading and writing. Sophia also liked new things and loved school outings – one of the ways in which the curriculum had been beautifully adapted to provide enriching experiences for her. Sophia absolutely loved emotionally engaging activities which were not too strenuous from a physical

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3 Overactive thyroid - occurs when your thyroid gland produces too much of the hormone thyroxine.
point of view, such as going to the theatre, pantomimes, dance, musicals and concerts.

3.6. Overall, Sophia was very happy, greatly loved, and immensely admired by her family for her truly outstanding ability to bear the limitations imposed by her condition, whilst fully embracing and enjoying what she could and liked to do. Sophia was a very loving and much loved girl. She was very sensitive to the moods of others and showed quiet gratitude and affection towards those who were caring towards her. She loved young children, especially babies: if she had maintained sufficient good health after school and an opportunity could have been developed for her, she would have made a wonderful nursery assistant.

3.7. Sophia’s parents said ‘She rewarded affection like no one else we knew, which helps explain to us why she was so much loved by others who had the chance to get to know her’.

4. Lessons learnt and areas for improvement

The end-of-life care that Sophia received was agreed to be outstanding. The importance of family and the home setting for Sophia and her family was respected. Arrangements for transfer from ITU to the family home for palliative extubation were well managed and commended by the family. In gaining permission for Sophia’s story to be shared, her parents commented that the fact that Sophia was able to be cared for at home during the end of her life had been hugely important to them in the time since her death. Sophia passed away with her family, in her own bed, which had been moved to the living room of the house in which she had spent countless happy hours.

4.1. Decision-making around care and treatment was person-centred and involved all relevant individuals, including Sophia. There was good evidence of shared decision-making in relation to treatment choices. Having only just reached adulthood, decisions were still being jointly agreed between Sophia’s clinicians and her family. For example, discussions about Sophia’s pulmonary hypertension included active consideration of the information provided to patient and her family.

4.2. It was noted that Sophia's parents were very proactive and managed most aspects well. Transition to adult care was seen as disjointed and was successful because of the family’s coordination. During Sophia’s childhood, the Community Paediatrician provided a comprehensive health overview. The Paediatrician was unclear who would facilitate this in the Adult Services and had therefore struggled to handover. In this case, the Cardiology Service was identified as the lead.

4.3. The process of reviewing Sophia’s death was managed under the Learning Disabilities Mortality Review (LeDeR) process. This provided an opportunity for an extremely valuable multi agency review that has helped inform multiagency work.

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4 Learning Disabilities Mortality Review (National programme developed and coordinated by Bristol University to ensure the deaths of people with learning disability are reviewed and learning from them is implemented.)
5. Conclusion

5.1. The end of life care that Sophia received was agreed to be outstanding as the importance of family and the home setting for Sophia and her family was respected. Her parents stressed that the possibility given to Sophia of passing away at home, surrounded by the love of her family, in the house where she had been so happy, made a huge difference to them at the end of her life. They also requested that all staff involved were made aware of how much the family appreciated the care received at a most difficult time.

6. Recommendations

6.1. The Trust Board is asked to reflect on the lessons learnt to improve the patient experience from Sophia’s story.

Sam Foster
Chief Nurse