

Trust Board Meeting in Public: Wednesday 9 March 2016
TB2016.23

Title	Ms S Patient Story
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Status	For information
History	Patient stories are regularly presented to Trust Board and Quality Committee

Board Lead(s)	Ms Catherine Stoddart, Chief Nurse			
Key purpose	Strategy	Assurance	Policy	Performance

Executive Summary

1. The purpose of this paper is to tell the recent story of Ms S who came into the John Radcliffe Hospital for a Magnetic Resonance Imaging (MRI) ¹ scan under general anaesthetic. Ms S is autistic and attended with her parents who were interviewed for this story.
2. This story provides an important opportunity to: <ul style="list-style-type: none">• Demonstrate how careful planning, preparation and good communication can result in an improved experience for patients with a learning disability, their carers and staff.• Highlight the importance of care coordination and the positive impact when all areas of the system work together. In this case a number of individuals were particularly important in ensuring it was a positive experience:<ul style="list-style-type: none">- The Learning Disability Liaison Nurse in communicating with the parents, her expertise in understanding the needs of people with learning disabilities and the specific needs of this patient as well as ensuring those needs were communicated to relevant staff members.- The role of the Ward Clerk in liaising with clinicians to ensure preparations were undertaken and the patient's needs understood.- The expertise of the nurse and anaesthetist who cared for Ms S.- The importance of PALS in liaising with the team to ensure an appointment was arranged quickly.• Recognise the importance of involving and listening to carers and ensuring that carers of adult patients are enabled to be fully involved.• Highlight the positive impact of patient centred, holistic care facilitated through a coordinated approach.
3. Recommendation The Trust Board is asked to read and reflect on the patient story and acknowledge the learning.

¹ This is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Patient story

1. Purpose

1.1 The purpose of this paper is to tell the recent story of Ms S who is on the autistic spectrum and attended the Day Investigation Unit in Neurology for an MRI scan with a general anaesthetic. The story includes the perspective of her parents who are her carers and staff involved with her care.

2. Background

2.1 The Patient Experience Team produced this story through an hour long conversation with Ms S's parents at their home. The staff perspective was obtained through conversations with the Learning Disability Liaison Nurse, the Ward Clerk and the Nurse who cared for her on the day.

2.2 This story provides an important opportunity to:

- Demonstrate how careful planning, preparation and good communication can result in an improved experience for patients with a learning disability, their carers and staff.
- Highlight the importance of care coordination and the positive impact when all areas of the system work together. In this case a number of individuals were particularly important in ensuring it was a positive experience:
 - The Learning Disability Liaison Nurse in communicating with the parents, her expertise in understanding the needs of people with learning disabilities and the specific needs of this patient as well as ensuring those needs were communicated to relevant staff members.
 - The role of the Ward Clerk in liaising with clinicians to ensure preparations were undertaken and the patient's needs understood.
 - The expertise of the nurse and anaesthetist who cared for Ms S.
 - The importance of PALS in liaising with the team to ensure an appointment was arranged quickly.
- Recognise the importance of involving and listening to carers and ensuring that carers of adult patients are enabled to be fully involved.
- Highlight the positive impact of patient centred, holistic care using a coordinated management approach to care.

2.3 The presentation of patient stories gives an opportunity to represent real life examples of the Trust's values in action, both from a positive and negative standpoint. This story gives Trust staff an opportunity to reflect on clinical and non-clinical work with patients and their families; and the critical role we all play in supporting healthcare to run smoothly.

3. Ms S's story

3.1 Ms S who was 20 years old at the time and had been referred for an appointment for an MRI with a general anaesthetic around 6 months previously. Ms S requires MRI scans approximately every year in order to monitor her neurological

conditions which are Chiari Malformation² and syringomyelia³. Ms S's parents had contacted the Patient Advice and Liaison Service in December 2015 about the delay. PALS were able to contact the team who were able to find her an appointment within a month. This shows the importance of the role of PALS in picking up issues for patients and liaising with the relevant staff.

- 3.2 Ms S came into the John Radcliffe Hospital at the end of January 2016 for the scan in the Neurology Day Investigation Unit.
- 3.3 The PALS Supervisor, after having contact with the family, was aware of the needs of the patient and felt the support of the LD Liaison Nurse would be helpful who was then contacted.
- 3.4 The LD Liaison Nurse contacted the family in early January and spoke to the parents in order to ensure that the care provided would be as person centred and as supportive as possible to Ms S and her parents offering a coordinated approach to the care.
- 3.5 The LD Liaison Nurse then communicated the key points, verbally and in writing to the Ward Clerk who liaised with the nurse and anaesthetist. Included in the communication from the LD Liaison Nurse was a written check list of key points, some stickers and photos of boy bands which Ms S liked.
- 3.6 The aspects of care that Ms S's parents highlighted were important were and for which subsequent preparation was made were:
 - A side room was allocated to Ms S in order to keep her calm.
 - She was first on the list so she did not have to wait which in the past her parents had found had made her more anxious to the point where it was sometimes not possible to complete the procedure.
 - She was not required to put on a gown, stockings or wrist band, all of which her parents knew she would be able to tolerate. She arrived in leggings and a T-shirt which she wore for the scan.
 - Her parents had ensured that she was not wearing any jewellery or metal so it did not need to be taken off.
 - She did not want to lie on a trolley and preferred a bed so she was taken to theatre in the ward bed and brought up in the same bed.
 - The anaesthetist and the nurse were prepared for Ms S's parents helping to restrain her when the cannula was inserted. The anaesthetist was calm and knew that Ms S liked a certain musician and discussed this with her. In the past, Ms S's parents have found that clinicians have become anxious if Ms S becomes distressed and clinicians have sometimes suggested doing the procedure on another day. However, everyone – the parents, the anaesthetist, the nurse – were all aware that Ms S's behaviour was usual for her and would not be different on another day.

² A Chiari Malformation (sometimes called an Arnold Chiari) means that the lower parts of the brain have been pushed downwards towards the spinal cord so they are below the entrance of the skull, resulting in a range of symptoms such as headaches, niche pain and dizziness.

³ Syringomyelia is a disorder in which a cyst forms within the spinal cord.

- Everyone involved knew that Ms S liked boy bands and were able to chat with her on this topic. They also knew she expected stickers for attending and these were given. In addition, she brought an iPad, games and her phone. Ms S knew she was “going for a magic sleep”.

“This was the best experience we have had. The role of the LD Liaison Nurse was so important as she coordinated the care with everyone. It went so well that she was able to eat and have a drink in hospital as soon as she woke up from the scan. Usually this isn’t possible and we have to take her home before she will eat.” (Ms S’s parents)

“If we have as much information as possible we can avoid things developing into a crisis. I knew she liked boy bands so I had something to talk to her about and could build up a relationship.”(Nurse)

4. Conclusion

4.1 There is an opportunity for learning from the following positive aspects of Ms S’s care:

- Ms S’s parents were listened to, fully consulted and involved with her care and were able to remain with her or close to her at all times.
- There was excellent preparation and communication between Ms S’s parents, the administration and clinical staff.
- The many little details of care, including having access to a side room and staff knowledge of Ms S’s likes and dislikes made a significant positive impact on the experience.

4.2 Ms S’s parents felt the following would be helpful to ensure that all patients with learning disabilities were able to benefit in the same way.

- There are leaflets available outlining the role of the LD with information on how she can be contacted for support.
- Leaflets are disseminated to carer organisations.
- If possible, the same clinicians are able to treat at each appointment. Ms S remembered the anaesthetist positively from a previous visit and this helped her relax.

5. Recommendation

The Trust Board is asked to reflect on the patient story and the learning.

Catherine Stoddart

Chief Nurse

March 2016

Report prepared by:

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