

**Trust Board Meeting: Wednesday 14 May 2014**

**TB2014.50**

<b>Title</b>	<b>Patient Story</b>
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<b>Status</b>	For Information
<b>History</b>	Patient Stories are regularly presented to Trust Board and Quality Committee

<b>Board Lead(s)</b>	<b>Liz Wright, Acting Chief Nurse</b>			
<b>Key purpose</b>	Strategy	<b>Assurance</b>	Policy	Performance

**Executive Summary**

1. The Trust Board has made a commitment to present Patient Stories as part of each Board meeting. A positive patient experience has been chosen on this occasion however there are a range of organisational learning's reflected in this story.
2. This patient story presents the experience of a patient and his carer both of whom have a learning disability. The patient underwent cataract surgery at the John Radcliffe Hospital, Day Surgery Unit.
3. The story highlights the couple's positive experience because of the support of the ward sister, who is also the learning disability champion for the ward, and the Learning Disability Liaison Nurse. Reasonable adjustments were made for both the patient and his wife.
4. The Improving Health and Lives Public Health Observatory (IHAL)for people with a learning disability, Public Health England, has highlighted the health inequalities experienced by people with a learning disability and reasonable adjustments to improve their access, experience and outcomes of health care.
5. This story highlights the experience for people with a learning disability, and wider learning that can be drawn for supporting vulnerable people and their carers particularly with respect to the implementation of reasonable adjustments for patients with dementia, mental health problems, autism, cognitive impairment, and their family carers.
6. The outcome that was achieved for this patient and carer was a positive and successful experience of the Trust services.
<b>7. Recommendation</b>  The Trust Board is asked to note the contents of the story.

## Patient Story

### 1. Purpose

- 1.1. This patient story presents the experiences of a patient and his carer, both of whom have a learning disability. The patient had cataract surgery on a day surgery ward.
- 1.2. This particular story has been selected as an example of the potential for implementing individualised care and reasonable adjustments resulting in a positive experience for both the patient and the carer. The story identifies the processes and resources that contribute to a positive experience for people with a learning disability.

### 2. Background

- 2.1. Mencap, is the leading charity for people with a learning disability, published a report called "[Death by Indifference](#)" in 2007. This report identified 6 people who had died where the healthcare services did not address the significant difficulties that people with learning disabilities often faced when accessing healthcare in the UK.
- 2.2. In response to "Death by Indifference", an independent inquiry, led by Sir Jonathan Michael, published the report [Healthcare for All](#) (2008). The inquiry found that people with learning disabilities have higher levels of unmet health needs and receive less effective treatment and 10 recommendations were made to address these issues.

### 3. Information on learning disabilities

- 3.1. A learning disability is characterised by a significant reduction in ability to understand new or complex information, to learn new skills due to impaired intelligence with a reduced ability to cope independently due to impaired social functioning. This starts before the age of 18 years old, with a lasting effect on development. (Valuing People, 2001).
- 3.2. A learning disability is caused by the way the brain develops. There are many different types and most develop before a baby is born, during birth or because of a serious illness in early childhood. A learning disability is lifelong. A person might have a mild, moderate or severe learning disability, which will affect the amount of support they need in their day-to-day life. People with a learning disability find it harder than others to learn understand and communicate. A learning disability is not a mental illness. It is different to a learning difficulty, which is often used to describe conditions such as dyslexia.
- 3.3. Nationally, it is estimated that approximately 2% of the population have a learning disability. Within Oxfordshire there are approximately 2,200 people known to have a learning disability.

### 4. Health issues and learning disabilities

- 4.1. People with learning disabilities have poorer health than the general population, for the reasons that they may have genetic conditions and an inability to manage their own health. The health issues are often avoidable.

- 4.2. A [Confidential Inquiry in the premature deaths of people with learning disabilities](#), (2013) which was a recommendation from “Healthcare for All”, found that men with learning disabilities died, on average 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Recommendations from the confidential inquiry included the need to identify people with learning disabilities in healthcare and the need to change how services are delivered to meet individual needs; these changes are referred to as ‘reasonable adjustments’.
- 4.3. An example of the health disparity faced by people with learning disabilities is highlighted by IHAL in their report on the prevalence of visual impairment among people with learning disability. They found that people with learning disabilities are 10 times more likely to have serious sight problems than other people often due to their original condition. Six out of 10 people with learning disabilities will need glasses. (Improving Health and Lives, Learning Disabilities Observatory, 2011). This [short film from ‘SeeAbility’](#) illustrates the key issues and statistics related to eye conditions in patients with learning disabilities
- 4.4. The Improving Health and Lives Public Health Observatory ( IHLPHO) have described 5 determinants of health equalities experienced by people with a learning disability.
- Increased risk of exposure (and possibly greater vulnerability when exposed) to well established ‘social determinants’ of poorer health;
  - Increased risk associated with specific genetic and biological causes of learning disabilities;
  - Communication difficulties and reduced health ‘literacy’;
  - Personal health risks and behaviours;
  - Deficiencies in access to and the quality of healthcare and other service provision.
- 4.5. The reports referred to above highlight that people with learning disabilities have equal rights of access to the same investigations and treatments as any patient but that they may need to be delivered differently in order to achieve the same outcome. .

## 5. Specific resources in the Trust for people with learning disabilities

- 5.1. The Trust has appointed a Learning Disability Liaison Nurse (LDLN) to work throughout the Trust, with the aim of being a point of contact for patients, carers and staff, providing advice, resources and support. The LDLN role has been recognised by Tuffrey-Wijne et al in [Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals](#) (2013) as improving the safety, experience and outcome of healthcare for people with a learning disability. The LDLN can be contacted via telephone or email internally in the Trust, and details have been disseminated to learning disability services, self-advocacy groups and carers organisations; the information can be found on the [OUH Trust easy read website](#). The LDLN role also involves an educational element to ensure all staff have the training, resources and processes in place to effectively meet the needs of people with learning disabilities.

- 5.2. It has been recognised nationally that it is essential for people with learning disabilities to be able to document their needs and key health information, in order that it can be easily shared with all appropriate health care staff. The document is frequently referred to as a Hospital Passport and a copy of one can be found [here](#). A Hospital Passport is owned by the person and wherever possible should be completed at home with the support of those people who know them well. On admission to hospital it should be accessible and visible to staff and then returned to the person on discharge.
- 5.3. The Trust has 49 learning disability champions across all 4 sites, available at ward level to ensure that appropriate 'reasonable adjustments' are made for people who have a learning disability, enabling appropriate access to healthcare and treatment. Contact details are on the Trust's intranet learning disability site, where all information and resources relating to learning disabilities can be found.
- 5.4. A key area for improvement that is in progress within the Trust is that of the seeking consent from all adults who are known to the Learning Disability Teams in Oxfordshire, to place an alert on their Electronic Patient Record within the Trust. This work is still in progress, although for those people whose records currently have an alert on the system, this enables the Learning Disability Liaison Nurse to be aware when a person with a learning disability is admitted as well as providing a prompt for the clinical teams as to the reasonable adjustments that maybe required within their care.

## **6. The story is presented in appendix A**

## **7. Conclusion**

- 7.1. The patient story evidences the importance of identifying and responding to individual patient's needs and personalised care, and in particular those from vulnerable patient groups.
- 7.2. The learning from this story demonstrates the Trusts Values in to Action, to improve the experience and health outcomes for vulnerable people including people with dementia, cognitive impairment and mental health problems.

## **8. Key Actions**

- 8.1. There are a number of key actions as a result of the learning from this patient story:
  - 8.1.1. To review the capacity and training of learning disability champions with the aim for there to be a trained champion on every ward.
  - 8.1.2. To work towards a national easy read consent form in collaboration with the national networking group for Learning Disability Liaison Nurses (A2A), NHS England and Public Health England.
  - 8.1.3. To disseminate the "See Ability" easy read and video resources on the Trust intranet and the easy read internet page.
  - 8.1.4. To identify a pathway to enable the pre-operative assessment teams to forward a completed hospital passport to the Day Surgery ward prior to an admission.
  - 8.1.5. To develop a carers feedback form to analyse carers experience in conjunction with the easy read patients experience FFT feedback and

the audit of the clinical service provided by individual wards and departments.

- 8.1.6. To establish a peer forum for Learning Disability Liaison Nurses across Thames Valley and Wessex, to share good practice, service developments and learning to improve acute health services for people with a learning disability and their families.

## **9. Recommendation**

- 9.1. The Trust Board is asked to note the contents of the story.

**Liz Wright**  
**Acting Chief Nurse**

**May 2014**

Report prepared by:

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Ward Sister and Learning Disability Champion for Day Surgery Unit

Stephanie Ross

Learning Disability Liaison Nurse

**Appendix A**

Mr S was admitted to the Day Surgery Ward for cataract surgery supported by his wife who is also his carer. They have told their story to enable the Trust's clinical services teams to learn from patients' and carers' positive experiences.

The ward sister and the Learning Disability Liaison Nurse (LDLN) supported Mr and Mrs S through their care pathway and hospital journey. The key aspects of their experiences are highlighted below. These illustrate and acknowledge their perception of compassionate and personalised care and flexibility to include reasonable adjustments.

**Mr and Mrs S's experience** (taken from Mr and Mrs S's account)

- Mr S was anxious before his admission. Mrs S asked the LDLN to ring him, to **allay his fears**.
- Mr S's **Hospital Passport** was completed with him and his wife on the morning of his admission.
- Mr and Mrs S commented that they found everyone to be helpful. He reflected that it was **important to be asked** if he would like his wife to accompany him to theatre. Once there, as a result of being anxious he began to shake, but the **staff put him at ease** by talking with and supporting him with light hearted conversation. The **process was also explained** to Mrs S which she found helpful as she had not observed an anaesthetic being administered previously.
- Mrs S, who is a diabetic, was **supported by the ward sister to have lunch** whilst Mr S was in surgery. She also made Mrs S a cup of tea, and **stayed with her** to allay her worries.
- Mrs S **praised the aftercare** as brilliant. The ward sister accompanied her to the recovery room so Mrs S could be with her husband. In recovery, a **nurse stayed with Mr S** and helped him feel less anxious by chatting with both of them.
- Before they left the **ward sister showed Mrs S how to put drops in Mr S's eyes**. This was important to Mrs S as her husband could not do this, and she wanted to be confident in caring for him.
- Mr S was followed up with a telephone call when he was at home to ensure that they were both coping with the eye drops in particular

**Staff experience**

**Reasonable Adjustments:** More information on reasonable adjustments can be found [here](#). A Hospital Passport can be found [here](#).

- Mr and Mrs S contacted the LDLN and the ward sister and **together** they planned for the admission to identify possible issues and solutions. The **procedure, transport** to and from hospital, **arrival time** and **waiting times** were discussed (to arrive late morning and together) and agreed to **suit their needs**. A Hospital Passport was explained and the benefits of staff understanding Mr and Mrs S individual **needs as a patient and his carer** were discussed. The reasonable adjustments included **reserving a side room**, having a **named nurse** and using **local anaesthetic cream** prior to injections and other **strategies to reduce his anxiety**.
- Mr and Mrs S understood explanations in relation to the procedure however an easy read consent form was not available. Mr S had mental capacity and understood the contents of consent form 1, which included the procedure, and this was discussed with him by the clinician. (Nationally easy read consent forms are not available).
- The ward sister was able to allocate herself as Mr S's **named nurse**, to ensure continuity of care in order to **support both Mr and Mrs S**.
- The **Hospital Passport** was helpful in supporting staff teams, and would be more useful if **available prior to admission** to maximise the reasonable adjustments to care, treatment and emotional support to both a patient and their carer.
- Mr and Mrs S completed the easy read [Friends and Family Test](#). This is part of NHS England's 'Access for All' to enable all patients to give feedback on their treatment and care.

**What have we learned as clinical staff?****Identification of people who have a learning disability, to ensure reasonable adjustments are made**

- Review your patients' Hospital Passport prior to their admission in order to plan reasonable adjustments with your patient and their carer.
- Ward based learning disability champions on the ward, are able to provide and understand the reasonable adjustments required by your patients. Mr and Mrs S experience demonstrates the importance of this role. Find out about becoming a learning disability champion [here](#)
- There are clear benefits of having named clinicians and nurses to support before and during a patient's admission, who understands the potential issues, and can offer personalised care, continuity and build a strong therapeutic relationship with the patient and carer.
- The RCN have produced a guide for supporting people with a learning disability [Guidance for nursing staff](#)
- The Royal College of Ophthalmologists produced [Quality Standards for Services for Patients with Learning Disabilities](#) on 17 April 2014
- If a patient does not have capacity to consent please refer to the [Mental Capacity Act](#). If the patient does not have any family or friends refer to [Independent Mental Capacity Advocates \(IMCA\)](#)

**Provision of easy to understand information for people who have a learning disability**

- There is an easy read booklet with information for patients attending the [John Radcliffe](#) Hospital. It would have been helpful if there was an easy read leaflet available, with information specific to this admission. This is currently being addressed.
- Remember to ask if your patient or their carer would like easy read information. Mr S had not been given any easy read information on cataracts or cataract surgery. See Ability have [easy read information and films available](#). [Easyhealth](#) have many useful leaflets for patients and carers.
- The team used the Department of Health's [easy read consent guide](#). However the availability of an easy read consent form would enable Mr S to have more autonomy over the consent process.
- Mencap have produced an easy read guide about what to expect from [health services](#).

**Support to family carers of people with learning disabilities**

- We should take the opportunity to ask carers if they are aware of the support they can access through [Oxford Family Support Network \(OxFSN\)](#) and [Carers Oxfordshire](#). These services are able to offer peer support, grants and breaks information.
- Recognise carers needs in addition to your patient's needs. [The Carers Trust](#) and [Mencap both provide information](#).
- Supporting Mrs S who has [diabetes](#) was crucial to enable her to support her husband.

**Health inequalities**

- Develop a mechanism as part of safeguarding education to explore key aspects of care for people with learning disabilities such as they are more likely to have poor health than other people. [improving health and lives](#)
- It is estimated that 50,000 people with a learning disability who are known to health and social care services have a [visual impairment](#)
- This short film from 'See Ability', found [here](#), illustrates the key issues and statistics related to eye conditions in patients with learning disabilities

**Hearing the voice of people who have a learning disability**

- The easy read friends and family test form enabled Mr S to independently give his feedback about his care.



**Additional reading**

1. Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals:a mixed-methods study. 2013 / *Tuffrey-Wijne, N Giatras, L Goulding, E Abraham,L Fenwick, C Edwards and S Hollins* HEALTH SERVICES AND DELIVERY RESEARCH VOLUME 1 ISSUE 2013
2. Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities: Sue Turner, Stephen Kill & Eric Emerson 2012 Improving Health and lives Public Health Observatory
3. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report 2013. Pauline Heslop, Peter Blair, Peter Fleming, Matt Hoghton, Anna Marriott, Lesley Russ
4. Death by Indifference Mencap 2007
5. Healthcare for All: Report of the Independent INQUIRY into access to healthcare for people with learning disabilities Sir Jonathan Michael. 2008