

Trust Board Meeting in Public: Wednesday 9th November 2016
TB2016.99

Title	Mr S and Family - Patient Perspective
--------------	--

Status	For information
History	Patient perspectives 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 Mr S whose wife Mrs S was diagnosed with dementia and passed away three years ago at the John Radcliffe (JR) Hospital. This story is accompanied by a film.
2.	This story provides an important opportunity to: <ul style="list-style-type: none">• highlight the impact of a patient story film for staff learning;• ensure that the Trust hears the important lessons about dementia from relatives and carers who have intimate, first hand and long-term experience of supporting their loved ones;• understand and highlight the work the Trust is undertaking to support people with dementia and their relatives.
3.	Recommendation The Trust Board is asked to reflect on the patient story and the learning.

1. Purpose

- 1.1 The purpose of this paper is to introduce the patient story film in which Mr S describes his wife's diagnosis of dementia, her care and treatment. The paper also outlines the Trust-wide work on improving the experience of people with dementia.
- 1.2 The film movingly tells the family's story. It is recommended that the Trust Board views this prior to the meeting via the link https://youtu.be/_6R4XWRD6qw¹. Mr S and his daughter will be attending the Trust Board meeting.

2. Background

- 2.1 This story was produced by the Patient Experience Team in partnership with Mr S and his daughters and the Quality Improvement Nurse Educator for Dementia. The direction and production was by an independent filmmaker and it was filmed by Oxford Medical Illustration.
- 2.2 The main purpose of this film is to increase understanding and empathy in staff for patients living with dementia and their relatives. In doing so, it is hoped that the film will facilitate holistic and compassionate care and support staff to support to build meaningful relationships with patients and their families. The film will be shared with partners across Oxfordshire such as the Clinical Commissioning Group, Oxford Health NHS Foundation Trust, Health Education England – Thames Valley and Age UK.
- 2.3 The family are keen that this film is used to help the Trust to improve the care of patients living with dementia and have agreed for it to be publically available on YouTube. Several groups of staff have already been shown the film and have found it powerful and moving. Mr S has also spoken about his experience at several Grand Rounds.
- 2.4 The Trust is extremely grateful to Mr S and the family for giving significant amounts of time and energy to allow this film to be made. As the key points are outlined in the film, this paper only briefly outlines the chronology of Mrs S's diagnosis and care. The paper provides an opportunity to outline the work the Trust is undertaking around dementia care, which is not included in the film.

3. Mr and Mrs S's story

- 3.1 Mr and Mrs S met at their local Sunday school, married in their twenties and had two children. During their retirement they were involved in a range of activities including travel, becoming yoga teachers, members of a church and volunteers at Sobell House. They lived in Oxfordshire at the time of Mrs S's diagnosis.
- 3.2 Mrs S was diagnosed with dementia in August 2008 at the age of 83. Mr S wanted to care for her himself at home and did so for four years until it became too difficult, mainly due to lack of sleep. At that point Mrs S moved to a Care Home known to her and her family. In October 2013, and after 15 months there,

¹ Please note this needs to be viewed by copying the link into Google Chrome. It cannot be viewed on Internet Explorer.

she fell and was treated at the John Radcliffe Hospital (JR) but very sadly died shortly after undergoing an operation.

- 3.3 Overall Mr S found the care his wife received was very good. In the film, Mr S identifies two things that he found were particularly important to recognise when caring for someone with dementia:

“one, don’t ask questions and two, they are always right.

You’ll have a much easier time caring for someone with dementia if you follow these two rules” Mr S

4. Supporting people living with dementia, and their carers

- 4.1 The Trust has a monthly Dementia Information Café, open to staff, patients and visitors, to provide a forum for information and advice. Representatives from Alzheimer’s Society and Carers Oxfordshire, and dementia leads/champions from the Trust provide support to attendees. The café is advertised widely across the Trust and on the intranet/internet.²
- 4.2 The Patient Experience and Engagement Team is currently working with carers of those with dementia, among others, to create a ‘Carers Charter’. This will clearly outline the Trust’s commitment in identifying and supporting carers, including a pledge that staff will be equipped to do so.³ Videos such as Mr S’s will be vital tools in supporting this type of training. It is hoped that once the charter has been disseminated and implemented, carers will have a more positive experience when using our services.
- 4.3 The Trust’s Dementia Steering Group, chaired by the Clinical Lead for Dementia and the Deputy Chief Nurse, meets quarterly to monitor progress against targets and projects and to set out action plans.
- 4.4 The Trust’s Dementia Strategy 2014-17 was approved by the Trust Board in November 2014.⁴ Key elements of the strategy are:
- Early assessment using the modified FAIR model (Find, Assess, Investigate & Refer)
 - Implementation of personalised care (refer to 4.6 for an example)
 - Leadership
 - Education (refer to 4.5)
 - Information, support and environment
 - Data Evaluation and Research
- 4.5 The training modules for dementia have been updated and the Trust is now working towards all staff having achieved Tier 1 Dementia Awareness Training. There are further developments and projects relating to Tier 2: Dementia Knowledge and Tier 3: Dementia Expert being completed with completion dates in 2017.

² <http://www.ouh.nhs.uk/patient-guide/carers-information.aspx#dementia>

³ This is a joint project across Oxfordshire, with Carers Oxfordshire, the Oxfordshire County Council, Oxford Health NHS Foundation Trust, the Clinical Commissioning Group, and the Young Carers Service. A number of other voluntary and community organisations are involved.

⁴ <http://www.ouh.nhs.uk/about/trust-board/2014/november/documents/TB2014.121DementiaStrategy2014-17.pdf>

- 4.6 'Knowing Me' documents are used across wards in the Trust; these are patient 'passports' and are completed by family members and carers to give staff members important individualised information about the person under their care. The form includes non-clinical information such as how the person takes their tea and what name they like to be called. 'Knowing me' was developed in Partnership with Oxford Health NHS Foundation Trust, as part of the Dementia Leadership Programme in Association with the University of Worcester.
- 4.7 There are nine Dementia Reminiscence Machines, (DRM), across general medicine wards in the Trust; these computers are pre-loaded with dementia reminiscence therapy technology and can be used as a distraction tool, a source of activities and general stimulation for patients. One feature favoured by staff is the video option where a carer or family member/friend can record a short message to be played to the patient in times of anxiety to reassure them that they are safe.
- 4.8 As a Trust we continue to work towards achieving Dementia Friendly Environments. This includes the improving physical spaces, the use of signage and patient and carer information. A project recently completed in the Emergency Department demonstrates the use of art to support and encourage staff and patients to use reminiscence.
- 4.9 Other initiatives include a one year pilot measuring the impact of introducing three Activity Co-ordinators who will focus on patients with cognitive impairment in Acute General Medicine and Gerontology wards at the JR Hospital. We are also working with community groups, such as Women's Institutes, to provide dementia-friendly resources such as comforting knitted muffs "twiddlemuffs"⁵.

5. Conclusion

- 5.1 This paper accompanies the film which will be a valuable training tool. The main purpose of the film is to understand Mr and Mrs S's life story encouraging empathy for those who are living with dementia and their carers'. The film also helps staff reflect on the impact of specific communication skills and activities that help improve the experience of patients with dementia.
- 5.2 The Trust has a range of ongoing work streams to raise staff awareness and improve practice, through the use of technology, resources and training.

6. Recommendation

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

Catherine Stoddart

Deputy Chief Executive and Chief Nurse

Report prepared by:

Olivia Galloway, Patient Experience Project Manager, Caroline Heason, Head of Patient Experience, Monika Rybacka, Quality Improvement Nurse Educator for Dementia and End of Life Care, and Rachel Taylor, Public Engagement Manager.

⁵ A **Twiddlemuff** is a double thickness hand muff with bits and bobs attached inside and out. It is designed to provide a stimulation activity for restless hands for patients suffering from dementia.