

**Trust Board Meeting: Wednesday 13 May 2015**  
**TB2015.47**

<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>Catherine Stoddart, Chief Nurse</b>			
<b>Key purpose</b>	Strategy	Assurance	Policy	<b>Performance</b>

## Executive Summary

1. Mr S was diagnosed with Motor Neurone Disease (MND) in 2012. This story describes the impact on his life and an episode in November 2014 when he had a serious chest infection and was at risk of hospital admission.

2. It is recommended that the board hear the story at its most powerful in the patient's own words via the video presentation.

<https://www.youtube.com/watch?v=kvne3cvwmbI>

3. This mechanism for telling a patient story is being trialled as part of the further development of patient stories for Trust Board.

4. This Patient Story was selected based on the criteria previously approved at Quality Committee for the selection of patient stories. It provides an opportunity for the Trust to learn from this patient's experience of care, particularly in relation to:

- The positive impact for the patient of being treated at home in the community rather than being admitted to hospital, in terms of their employment, independence, emotional well-being and recovery. To note that these factors were acutely important to him in maintaining his quality of life in face of a serious illness.
- The value of the immediate access and rapid domiciliary response of the specialist neuro-muscular respiratory physiotherapy service for a patient with a complex disease and the need for a dedicated service in the community.
- The importance of a patient being under the care of a MND Care Coordinator with oversight of his care.
- The potential preventative role of an Emergency Respiratory Plan and the reassurance it gives to the patient.
- This story provides an opportunity to reflect on the contribution that someone living with MND for several years can make to the community, to other patients with the same condition and to the NHS.

### 5. Recommendation

The Trust Board is asked

- to note the patient story; and
- to note the impact of specialist care in the community on patient experience, and on reducing the likelihood of acute hospital admission; and
- to note that consideration is being given to the expansion of services that could deliver a similar impact to the patient story.

## Patient Story

### 1. Purpose

- 1.1 The purpose of this paper is to provide the context and background to the Mr S's chest infection and the role of the MND Care Centre Co-ordinator and the Sleep and Ventilation Physiotherapist in helping to avoid hospital admission.
- 1.2 This story highlights the importance of:
  - The positive impact for the patient of being treated at home rather than being admitted to hospital, in terms of the impact on employment, independence, emotional well-being and recovery. To note that these factors were acutely important to him in maintaining his quality of life in face of a serious illness.
  - The value of the immediate access and rapid domiciliary response of the specialist neuro-muscular respiratory physiotherapy service for a patient with a complex disease and the need for a dedicated service in the community.
  - The importance of a patient being under the care of a MND Care Coordinator with oversight of his care.
  - The potential preventative role of an Emergency Respiratory Action Plan and the reassurance it gives to the patient.
  - This story provides an opportunity to reflect on the contribution that someone living with MND for several years can make to the community, to other patients with the same condition and to the NHS.

### 2. Background and context to the patient story

- 2.1. The Neurosciences Department has a positive approach to actively seeking and learning from patient stories.
- 2.2. The patient in this story told his story to the MND Care Centre Co-ordinator, the Sleep and Ventilation Physiotherapist, the Neurosciences Matron and the Public Engagement Manager. A short film accompanies this paper.
- 2.3. The Patient Experience Team co-produced this story with the patient and the clinicians involved to determine if a video story offers a better mechanism for exploring the patients perspective. This has been found to be the most empowering approach to developing a patient's story for presentation at the Quality Committee or Trust Board. The Patient Experience Team has found it to be both positive and productive in engaging with staff. All quotes from the patient are taken from the interview referred to above and an additional telephone conversation.
- 2.4. The Oxford Motor Neuron Disease Care and Research Centre offers multi-disciplinary care and support to patients and carers living with MND. The team working at the clinic include MND consultants, the centre coordinator,. Other team members are: a senior occupational therapist, a physiotherapist, a dietitian, a specialist speech and language therapist and a neuropsychologist.
- 2.6. The Oxford Sleep and Ventilation service is part of the Oxford Centre for Respiratory Medicine based at the Churchill Hospital, which investigates and treats patients with sleep-related breathing disorders. The unit currently

supports more than 10,000 obstructive sleep apnoea (OSA) patients on continuous positive airway pressure (CPAP) and provides home ventilation to more than 450 patients with ventilatory failure secondary to neuromuscular weakness, chest wall deformity, COPD or obesity.

- 2.7. After noticing his foot flapping on the pavement as he was running for a bus in 2011, Mr S went to his GP who referred him to a community podiatrist. Some months later Mr S saw the podiatrist who noticed that he had weakness and was stumbling and referred him to a neurologist. Eight months after Mr S's initial concern about his foot, he was diagnosed with Motor Neuron Disease in 2012. Mr S also has asthma.
- 2.8. Prior to his diagnosis he was a freelance project manager for the NHS and Local Authority specifically leading joint health and care projects. Since his diagnosis Mr S has had a range of roles, is NHS Patient Leader, health & social care project professional and is an MND Association Trustee. His current main role is the Project Manager for the Healthwatch Oxfordshire Hospital Discharge project.
- 2.9. Mr S is married to a musician and has two teenage children. He currently lives in Extra Care Housing (independent flats with a care team on site).
- 2.10. In November 2014, Mr S was returning home after attending a digital health event at the Said Business School. He was waiting for the last bus back to his Extra Care Housing. It was raining heavily and as he was becoming wet, he tried to get cover under the bus stop shelter but was unable to due to the size of the wheelchair. That evening when he got home, he started feeling very unwell and during dinner with his wife he began to have difficulty breathing such that he could not continue a conversation.
- 2.11. *"By early evening I realised I was feeling very unwell. I was having difficulty talking and eating and was choking. My wife was visiting for dinner and she said I should call the doctor."*
- 2.12. He phoned 111 and a few hours later the out of hours GP arrived and administered a nebuliser, course of antibiotics and steroids to help with the asthma. Mr S realised that it could be serious when the GP asked if he would like to be admitted to hospital that night. Mr S said that if there was a choice then he'd rather not be admitted.
- 2.13. Mr S spent the next day or two in bed but *"did not feel that he was getting what he needed"* and so he contacted a GP, at a practice where he'd recently registered, who advised to continue with the same treatment. By Wednesday he had spent two or three days in bed, still not feeling good, still coughing and he decided to contact the MND Care Coordinator. As she was talking to Mr S, the MND Care Coordinator noticed that he couldn't speak in whole sentences and that his speech was constantly interrupted by coughing, wheezing and breathlessness.
- 2.14. Realising that Mr S needed physiotherapy, the MND Care Coordinator phoned the single point of access team and spoke to the physiotherapist and explained that this was an urgent situation. The risk of not seeing him immediately was that he was unable to clear independently the secretions in his airway, making breathing more difficult and fatiguing. This can rapidly lead

to worsening ventilator failure which may have necessitated hospital admission.

- 2.15. People living with MND live in a state of fragile equilibrium. Any small change to their health can have a devastating effect on their well being. Most people with MND die from respiratory failure this is why it is so important to treat a chest infection quickly.
- 2.16. The usual response for the physiotherapy team is one week, however in this incidence they were able to visit the same afternoon. The community physiotherapist visited Mr S who recalls *“she was very prompt and clear straight away that she hadn’t seen anyone with MND before”*. She gave Mr S some exercises to do and also did some percussion<sup>1</sup> on him. These breathing exercises are very effective for patients with lung conditions but patients with neuromuscular conditions may not have the strength to do the exercises effectively.
- 2.17. The physiotherapist and the MND Care Coordinator liaised later that day and determined that Mr S needed support and intervention from a specialist physiotherapist. At this point the MND Care Coordinator contacted the ‘two person Sleep and Ventilation team’ who visited him the next day. Home visits are not something the team generally has capacity to do they support 450 patients who are ventilated.

Mr S said: *“I wouldn’t have been able to visit the team as an outpatient at this point as I wouldn’t have been strong enough to get to the hospital.”*

- 2.18. The Sleep and Ventilation Physiotherapist realised that Mr S needed specialist treatment for someone with a neurological condition and provided Mr S with a new Non Invasive Ventilation machine<sup>2</sup> and a ‘CoughAssist’<sup>3</sup> which simulates a natural cough. The Sleep and Ventilation physiotherapist trained Mr S how to use these machines and he said: *“this was the point where I felt things started to shift and get better”*.
- 2.19. With these new interventions, Mr S was able to avoid hospital admission and recovered at home with specialist peripatetic physiotherapy support over the following two weeks.
- 2.20. Mr S, the nurses and physiotherapists have concluded that without the intervention of the specialist physiotherapy at short notice and at home, Mr S would have been admitted to hospital and it probably would have been several weeks before he was discharged home. Mr S described the impact that would have had on his life:

*“(the impact on me) would have been huge. I had just taken on a role as project manager for Healthwatch Oxfordshire – and I would have had to*

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<sup>1</sup> Chest percussion, also referred to as chest physiotherapy, is an airway clearance technique that involves clapping on the chest and/or back to help loosen thick secretions. Doing this makes mucus easier to expel, or cough up.

<sup>2</sup> Non Invasive Ventilation (NIV) is a way of helping someone to breathe using a machine attached to a tight fitting mask that is worn over the face

<sup>3</sup> CoughAssist uses positive and negative pressure to simulate a natural cough. It is used for patients who are unable to cough or clear secretions due to reduced peak expiratory flow.

*contact Healthwatch and say you haven't got a project manager. That probably would have been 3-4 months critical work (that would have gone). Emotionally it would have been devastating because one of the things that has been most important to me, has kept me most sane has been to continue working to continue making a contribution, to be a patient lead.. etc. To feel I have a purpose. The alternative to that is — I would be looking at four walls, going slightly mad"*

- 2.21. About 2 weeks after the episode Mr S met the respiratory team and a Respiratory Action Plan was put in place. This is a document that has been very recently implemented and it is planned that it will be rolled out to all neuro-muscular patients at risk of respiratory deterioration. It is a traffic light system with clear instructions, held by the patient and on their healthcare records. It is also held on the respiratory ward in order that the out of hours doctors are able to provide well informed advice about whether a hospital admission or anything else is required. If a specialist neuro respiratory community service was also in place then physiotherapists would be available 8am-8pm seven days a week which would make this action plan even more effective and responsive. Feedback from patients who have it, find it very reassuring that they know what to do if the situation arises and prevent a situation from escalating.
- 2.22. Mr S said the Emergency Respiratory Action Plan is something *"I am so happy to have now... it says what normal state good looks like, early warning signs things that may start to alert me and what I should be doing. If I don't improve (it tells me) what I should be doing at that stage. Emergency situations that immediately I need to take action. Had it been in place, me and my carers would have known what was needed. There would have been a team I could have contacted. An out of hours doctor who came along would have had an OUH branded piece of paper. I think this is one of the most brilliant documents, credit to the team (who put it in place)"*.

### 3. Learning

This positive story offers an opportunity for learning in a number of areas:

#### 3.1. The importance of coordinated care

The Centre Coordinator participated in this story and the film. Her role at the MND centre is to provide a point-of-contact service for patients between clinic visits, and facilitates the communication of information between all those locally involved in an individual patient's care. She also provides emotional support for patients and their carers, and supports maintenance of care at home.

The importance of this role is demonstrated by the fact that Mr S thought of phoning his care coordinator when he was not improving. The Centre Coordinator knew about his condition and circumstances and got in touch with other appropriate services to ensure he got the right treatment quickly.

#### 3.2. The importance of treating in the community and avoiding hospital admission.

The clinical view is that the best place for people with complex neurological conditions is almost always at home in the community.<sup>4</sup> In the episode described in this story, Mr S's treatment at home resulted in avoidance of a potentially costly and lengthy hospital admission and a better experience for the patient. It meant that Mr S was able to continue to live independently with support, was able to continue in employment and avoided additional emotional distress.

### 3.3. The need for an Urgent Response General Neurology Team

Mr S has been working as the Patient Lead with the Centre Coordinator and the Sleep and Ventilation Physiotherapist on a business case for a new specialist rapid response service for people with long term neurological conditions who have a high risk of developing respiratory tract infections.

Oxfordshire has a high rate of non-elective admissions and one of the main causes are chest infections which, with urinary tract infections, account for the largest number of emergency admissions for people with neurological conditions. Emergency admissions are often associated with poor patient experience outcomes as well as high costs.

A business case for URGeNT (Urgent Response General Neurology Team) has recently been submitted to the Clinical Commissioning Group.

### 3.4. The importance of an Emergency Respiratory Action Plan

Mr S and other patients have described the importance of the Emergency Respiratory Action Plan which outlines clearly for the patient and carers what can be done to avoid a respiratory deterioration situation escalating and what treatment may be required. If the plan had been in place when this episode happened, Mr S and clinicians felt that the appropriate treatment would have been given more quickly.

### 3.5. The patient contribution

This story provides an opportunity to reflect on the contribution that someone living with MND for several years can make to the community, other patients with the same condition and the NHS.

## 4. Patient feedback

4.1 In order to provide context to this paper, the themes from complaints and the Friends and Family test from the Neurosciences Directorate for the three months (Oct-Dec 2014) surrounding Mr S's episode in the JR have been analysed:

4.2 **Friends and Family Test (FFT)** - There were 107 responses for Neurosciences Directorate, 96% of which were likely or extremely likely to recommend.

4.3 **Complaints data and Patient Advice and Liaison Service (PALS) data** – Between Oct-Dec 2014, there were 29 complaints and 80 PALS contact for the whole Neurosciences Directorate, mainly focussing on cancellations or delays for treatment and communication issues.

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<sup>4</sup> Proposal Urgent Response General Neurology Team (URGeNT). Authors: Rachael Marsden, MND Advanced Nurse Practitioner, Jane Freebody, Specialist Physiotherapist Neuromuscular diseases, Simon Lovett, Lead Physiotherapist Neuroscience ward, Julie Young, Lead Physiotherapist Sleep and Ventilation Service, Lesley Hoare Lead Physiotherapist Community Disability Service, Jo Bromley, Neuro Community Advanced Nurse Practitioner, Sue Barden

## 5. Recommendations

5.1. The Trust Board is asked

- to note the patient story; and
- to note the impact of specialist care in the community on patient experience, and on reducing the likelihood of acute hospital admission; and
- to note that consideration is being given to the expansion of services that could deliver a similar impact to the patient story.

**Catherine Stoddart**  
**Chief Nurse**

**May 2015**

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