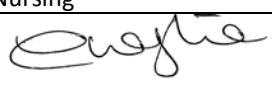


Date:	14 th December 2017
Meeting:	Governing Body
Item Number:	Item 2.0
Public/Private:	Public <input checked="" type="checkbox"/> Private <input type="checkbox"/>

Author: <i>(Name, Title)</i>	Chloe Nicholson Quality & Experience Manager
GB Lead: <i>(Name, Title)</i>	Catherine Wylie Director of Quality & Nursing
Director approval/signature (MUST BE SIGNED)	
Date:	6.12.17

Report Title:	Patient Story
Decisions to be made:	For information

Continue to improve the quality of services	<input type="checkbox"/>	Improve patient experience	<input type="checkbox"/>
Reduced unwarranted variations in services	<input type="checkbox"/>	Reduce the inequalities gap in North Lincolnshire	<input type="checkbox"/>
Deliver the best outcomes for every patient	<input type="checkbox"/>	Statutory/Regulatory	<input type="checkbox"/>

Executive Summary (Question, Options, Recommendations):
The Patient Story for the NLCCG Governing Body meeting, to be held on 14 th December 17, relates to a patient's experience of living with Motor Neurone Disease.
Motor Neurone Disease (MND) describes a group of diseases that affect the nerves (motor neurones) in the brain and spinal cord that tell your muscles what to do. With MND, messages from these nerves gradually stop reaching the muscles, leading them to weaken, stiffen and waste. MND can affect how you walk, talk, eat, drink and breathe. Some people also experience changes to their thinking and behaviour. However, MND affects everyone differently. Not all symptoms will affect everyone, or in the same order. Symptoms also progress at varying speeds, which makes the course of the disease difficult to predict.
MND is life-shortening and, at present, there is no cure. Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life. For further details on MND, please follow the link below to the Motor Neurone Disease Association website: https://www.mndassociation.org/?gclid=EAlalQobChMlmoivsdXv1wIVzJQYCh0f2wg6EAAYASAAEqlfE_D_BwE#

Equality Impact	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Sustainability	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Risk	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Legal	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Finance	Yes <input type="checkbox"/> No <input type="checkbox"/>	

Patient, Public, Clinical and Stakeholder Engagement to date									
	<i>N/A</i>	<i>Y</i>	<i>N</i>	<i>Date</i>		<i>N/A</i>	<i>Y</i>	<i>N</i>	<i>Date</i>
Patient:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		Clinical:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Public:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Charles' Story:

Charles is 65 years old and he was diagnosed with MND in October 2014. He lives in North Lincolnshire with his wife, who is a nurse, and he has a daughter, who is also a nurse.

Charles was born in Scotland, near St Andrews and grew up on a farm. He served in the Army for 33 years; he was very active and enjoyed an athletics career whilst serving in the military. He ran 100m, 200m and 400m for the army and combined services; he also ran at county level and was the Army's 200m champion for 2 years.

Charles has an MBA Management Qualification and, following retirement from the Army, moved onto a career in Telecommunications, Project Management and Consultancy work.

He also loved long distance running, orienteering and skiing. He was skiing when he first noticed the signs that something was wrong, he started to fall over and couldn't get up and started to notice that he didn't have full control over his legs and started to lose power/function in his muscles. He noticed that his physical abilities started to change, and he identified symptoms indicative of MND.

In light of his ailing health, Charles and his wife adapted their house, to suit his needs, at their own cost as Charles is not eligible for a Disabled Facilities Grant. Charles is now wheelchair bound, and is often in a lot of pain and discomfort, although he tries to manage these symptoms through gentle exercise and medication.

Following his diagnosis, Charles has helped out with MND global research projects and has supported the work of the MND Association. Examples of this include MRI scan research and EMG tests.

Charles is keen to support people that are living with and are affected by MND, and he suggests that the following should be prioritised by local health services:

- provide further support to carers
- provide further support to multi-disciplinary teams
- expedite the NHS procurement process
- review local patient transport services