

Date:	8 th February 2018
Meeting:	NLCCG Governing Body
Item Number:	Item 2
Public/Private:	Public <input checked="" type="checkbox"/> Private <input type="checkbox"/>

Author: <i>(Name, Title)</i>	Chloe Nicholson, Quality Manager
GB Lead: <i>(Name, Title)</i>	Catherine Wylie, Director of Nursing and Quality
Director approval <i>(name)</i>	Catherine Wylie, Director of Nursing and Quality
Director Signature (MUST BE SIGNED)	

Report Title:
Patient Story – Briefing Note
Decisions to be made:
Members are asked to review and note the content of this report, and consider the recommendations provided.

Continue to improve the quality of services	<input checked="" type="checkbox"/>	Improve patient experience	<input checked="" type="checkbox"/>
Reduced unwarranted variations in services	<input checked="" type="checkbox"/>	Reduce the inequalities gap in North Lincolnshire	<input checked="" type="checkbox"/>
Deliver the best outcomes for every patient	<input checked="" type="checkbox"/>	Statutory/Regulatory	<input type="checkbox"/>
Purpose (tick one only)	Approval <input type="checkbox"/>	Information <input checked="" type="checkbox"/>	To note <input type="checkbox"/> Decision <input type="checkbox"/>

Executive Summary (Question, Options, Recommendations):	
<p>The Patient Story for the Governing Body on 8 Feb 18 relates to a carers experience of Congenital Myotonic Dystrophy (CMD), in North Lincolnshire.</p> <p>This story has been submitted to the CCG via the CCG’s Patient and Community Assurance Committee (PCAG).</p> <p>The PCAG (hereafter, the group) provides independent assurance that patients and the public of North Lincolnshire have the opportunity to contribute to the understanding, design, delivery and on-going review of local health service. The group provides an independent review of patient and public involvement plans and comment and feedback, as appropriate, on their suitability for the purpose of improving the health and wellbeing of the local population, local communities and individuals.</p> <p>This story includes five recommendations that have been identified by the service user.</p>	
Recommendations	<ol style="list-style-type: none"> 1- To provide further support to carers 2- To improve local knowledge and awareness of CMD 3- To improve staff communication at NL&G 4- To improve Continuing Healthcare process at North Lincolnshire CCG 5- To improve local processes for communicating with patients, specifically in relation to the management of healthcare referrals
Report history	This is the latest update to support this agenda item.
Equality Impact	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Sustainability	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> The report highlights areas of concern and pressure in relation to some services provided in North Lincolnshire, and the CCG.
Risk	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> The report highlights risk in relation to communication and involvement of service users.
Legal	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>

Finance	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	This report makes reference to delays within the NLCCG Continuing Healthcare payment process.
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<i>Patient, Public, Clinical and Stakeholder Engagement to date</i>									
	<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 checked="" type="checkbox"/>	<input type="checkbox"/>	29/01/18	Clinical:	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Public:	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>		Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

NLCCG Governing Body

February 2018

Patient Story – Briefing Note

Introduction

The Patient Story for the North Lincolnshire Clinical Commissioning Group (hereafter, the CCG) Governing Body meeting, to be held on 8th February 18, relates to a carers experience of Congenital Myotonic Dystrophy.

This story has been submitted to the CCG via the CCG's Patient and Community Assurance Committee (PCAG).

The PCAG (hereafter, the group) provides independent assurance that patients and the public of North Lincolnshire have the opportunity to contribute to the understanding, design, delivery and on-going review of local health service. The group will provide an independent review of patient and public involvement plans and comment and feedback, as appropriate, on their suitability for the purpose of improving the health and wellbeing of the local population, local communities and individuals.

Background Context

Myotonic Dystrophy is a long term genetic disorder that affects muscle function. Symptoms include gradually worsening muscle loss and weakness. Muscles often contract and are unable to relax. Other symptoms may include cataracts, intellectual disability, and heart conduction problems.

Myotonic Dystrophy is an inherited condition, and the commonest muscular dystrophy of adult life, affecting around 1 in 8000 adults.

Many children are also affected by the condition, either at birth or later. It is also by far the most variable neuromuscular disorder in terms of severity, age at onset and different body systems affected.

The scientific name for Myotonic Dystrophy is "Dystrophia Myotonica".

A's Story

A is a professional and lives in North Lincolnshire with his wife and family. A's story reflects his and his wife's experiences of caring for their son, B in North Lincolnshire. B is 18 years old and has Congenital Myotonic Dystrophy (hereafter, referred to as CMD).

Diagnosis

B was diagnosed by a Neurologist in Sheffield Children's Hospital when he was 15 years old, following a severe illness. A feels that B would have been diagnosed sooner if there had been a greater understanding and awareness of this condition, in North Lincolnshire. This delay in diagnosis caused a lot of strain and stress to A and his family.

Awareness and understanding

CMD is complex; B has approximately 20 different conditions, which are managed by several clinicians. In light of this, A and his family often require the support and input from specialist health services across England.

Due to the complexity of his condition, B frequently accesses Paediatric services at Scunthorpe Hospital when he has an acute problem, as his cognitive function is that of a 7 year old.

However, B is often transferred to Sheffield Children's Hospital for specialist input, due to the limited level of expertise in this specific condition at Scunthorpe Hospital.

B's care is co-ordinated by the Neuromuscular Complex Care Centre (NMCCC) in London, with further expertise provided by the Consultant Paediatric Neurologist at Sheffield Children's Hospital.

Over the last two years, in preparation for B's 18th birthday (and as such, transfer to adult services) Sheffield Children's Hospital has worked in collaboration with the NMCCC to undertake a full handover of B's care to NMCCC. This transition has been successful and B's current care package covers a range of services, including breathing, feeding and swallowing support, breathing physiotherapy and physical physiotherapy.

A and his family have accessed various NHS services to support B, including acute and specialist services, and community based services. Throughout each of these experiences, A and his wife have retained their role as (informal) co-ordinators of B's care. This has proven to be imperative when accessing local services, where awareness and understanding of B's condition is limited.

A and his family have expressed their concern in the approach taken by Northern Lincolnshire & Goole NHS Foundation Trust (NL&G) to manage B's care, when an acute admission is required. These concerns relate to the level of knowledge and understanding of CMD, with some members of NL&G staff, and the communication of B's requirements between staff at the point of handover.

Missed referral letters

A and his wife discovered, through conversations with staff at the NMCCC that referral letters sent by the NMCCC to B's local GP practice and the local hospital were missing. It transpired that several letters has been lost in the North Lincolnshire health system, and whilst the impact on B was managed, through perseverance by A and is wife, A remains concerned that communication and administration of patient information in the local health system is flawed. To mitigate any risk to B, A and his wife are in regular contact with the NMCCC and the Neurology team at Sheffield Children's Hospital.

Community services

B received fantastic support from a Paediatric Community Nurse, and a Complex Care Advisor provided by Muscular Dystrophy UK. These individuals provided excellent support to the family, by advocating for B and advising other NHS staff on his needs. These individuals were also aware of B's specific requirements and worked *with* A, his wife and B to provide care, advice and support.

Continuing Healthcare

As B is now 18 years, he is eligible for funding under the NHS Continuing Healthcare rules. A and his wife have worked closely with the North Lincolnshire CCG Continuing Healthcare team to agree a suitable package of care, and this process appears to be near completion.

However, A and his wife experienced delays with the CCG's Continuing Healthcare process. In response to this, A and his wife have met with the Continuing Healthcare team to review the case and the position appears to be improving, although payment remains outstanding.

Conclusion

To conclude this story, A would like to highlight the following issues, which are based on his and his family's experiences of local NHS services, in order to enact change and improve patient's experiences.

1. Provide further support to carers

Carer support is imperative, the carer needs to be supported to ensure that they are able to continue to advocate for the patient, as they are often the most informed of the patient's needs. Healthcare professionals should ensure that carers are effectively communicated with and remain a core part of the care process, particularly where the patient may not have capacity to make specific decisions.

Support to carers was also identified as an area that requires further improvement in the previous Patient Story provided to the Governing Body (Dec 17).

2. Improve knowledge and awareness of CMD

There appears to be limited awareness and understanding of CMD across health services in North Lincolnshire, A believes that patients would benefit if healthcare professionals were more informed of this condition. Please see the links provided at page 4 for further information.

3. Improve staff communication at NL&G

A and his family witnessed poor communication between some NL&G staff; these communication lapses could have led to B being harmed. A suggests that patient's would benefit if NL&G staff were fully informed of each patient's specific needs, at the time of handover.

4. Continuing Healthcare process at North Lincolnshire CCG

There appears to be some remaining challenges in the NLCCG Continuing Healthcare assessment process, which have led to delays in payment. A requests that the NLCCG Continuing Healthcare team reviews its processes in order to improve service user experience of this service.

5. Missed referral letters

A and his family have limited confidence in the local process for communicating with patients, specifically in relation to the management of referrals. Further work is required, between local primary and acute care providers to improve the level of confidence that the local population has in this process.

Useful contacts

For further information on the issues identified in this story, please follow the link below:

<http://congenitalmyotonicdystrophy.org/index.html>

<http://www.musculardystrophyuk.org/>

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