Cambridgeshire Community Services NHS Trust

TRUST BOARD

Title:	**A successful transition story to Adult Services from Children's Continuing Care Team in Luton**
Action:	**FOR DISCUSSION**
Meeting:	**9th May 2018**

Purpose:

The purpose of bringing patient stories to Board members is:

- To set a patient-focused context for the meeting.
- For Board members to understand the impact of the lived experience for the patient, family and friends.
- For Board members to reflect on what this experience reveals about our staff, morale and organisational culture, quality of care and the context in which our clinicians work.
- To review and recognise any shared learning and recommendations relevant to this story.

Recommendation:

To receive the patient story and note the context from which it was generated.

	Name	Title
Author:	Lisa Milner Lucinda Kilby	Patient Experience and Engagement Lead Complex Needs Nurse, Children's Continuing Care Team, Luton
Executive sponsor:	Julia Sirett	Chief Nurse

Trust Objectives

Objective	How the report supports achievement of the Trust objectives:
Provide outstanding care	Services worked together to provide a highly detailed plan alongside the patient and family to ensure the transition into Adult Services had as little impact on their care as possible
Collaborate with other organisations	Continuous communication and planning between Children's Health Services, Adult Health Services, Social Services, Care Agency and the CCG.
Be an excellent employer	Providing additional training to Nursery Nurses from the Children's Continuing Care Team to assist the Complex Need's Nurses in the delivery of a care package.
Be a sustainable organisation	Not covered in this paper.

Trust risk register
N/A

Legal and Regulatory requirements:
N/A

Equality and Diversity implications:

Objective	How the report supports achievement of objectives:
Achieve an improvement in the percentage of service users who report that they are able to access the Trust services that they require	This paper is an example of how services are working jointly to provide patient centred care and to enable service users to continue to access the services they require.
Enhance our approach to involving and capturing the experience of hard to reach / seldom heard / varied community groups	This paper provides an example of excellent care and support provided to a non-verbal service user to ensure that their opinion was taken into account.
Using the national 'A Call to Action on Bullying and Aggression', internally take action to promote our Zero tolerance policy and address bullying and aggression when it occurs.	Not covered in this paper
Ensure that the Workforce Race Equality Standard is embedded and undertake proactive work around any areas of under-representation identified. In particular, we will seek innovative methods to have co-opted representation on the Trust Board from more diverse backgrounds.	Not covered in this paper

Are any of the following protected characteristics impacted by items covered in the paper – YES

Age	Disability	Gender Reassignment	Marriage and Civil Partnership	Pregnancy and Maternity	Race	Religion and Belief	Sex	Sexual Orientation
☐	☒	☐	☐	☐	☐	☐	☐	☐

1. Introduction

1.1 The patient story focuses on the successful transition of a patient from the Children's Continuing Care Team to Adult Services within Luton. Due to the complexity of the patient's needs the transition between the two services required a robust and individualised approach to the care plan handover. This story celebrates that the transition process succeeded due to the level of detailed work and planning from Jo Benge, patient's Nursery Nurse, Lucinda Kilby, Complex Need's Nurse, Children's Continuing Care Team Team (CCN) and Sam Shujah supported by Sally Child from the Adult Continuing Care Team (ACCT).

1.2 The mother of the patient will be attending the Board in person to discuss how anxious they were at the prospect of transitioning into the Adult Services after having such fantastic service from the Children's Services. With detailed planning the services have allowed her child to transition into Adult Services with as little impact on their care as possible.

1.3 This story also celebrates the success of the service, as this patient is the first patient that the Children's Continuing Care Team in Luton provided care for and is also the first patient to transfer to the Adult Services Team in Luton.

2. Journey with the Children's Continuing Care Team in Luton

2.1 The patient, herein known as RR had received care from the Children's Continuing Care Team in Luton for approximately ten years due to complex medical health needs.

2.2 RR was diagnosed with late infantile variant Battens Disease which is a life limiting progressive neurodegenerative disease. The disease includes visual impairment resulting in RR being blind, complex epilepsy with severe seizures that are difficult to control, rapid involuntary muscle spasms and jerking of limbs, difficulty sleeping, decline in speech, language and swallow skills and a deterioration of fine and gross motor skills that has resulted in loss of mobility. RR is now totally dependent on family and carers for all of their needs.

2.3 To meet RR's medical needs a team of Nursery Nurses from the Children's Continuing Care Team were trained to assist the Complex Need's Nurses in the delivery of a care package to support RR's medical interventions. RR also had a direct payment carer to support with social needs.

2.4 The Mother was anxious about going into Adult Services at a time when the family were planning a celebration of RR entering adulthood and these anxieties were recognised and discussed with the Children's Continuing Care Team.

3. Transition into Adult Services

3.1 Eligibility for NHS Continuing Healthcare should be determined in principle by the relevant CCG when a young person is in their 17th year, so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday. In order to do this staff from Adult Services need to be involved in both the assessment and care planning to ensure smooth transition to Adult Services.

3.2 In RR's case the Children's Transition Nurse met the family to discuss transition when RR was approximately 16 and half years old and provided them with knowledge of the services that would be involved with the transition process.

3.3 The first multi professional meeting took place between the family and relevant services when RR turned 17 years old. The Services and Nurses involved were as follows:

- The Adult Continuing Care Team
- The Transition Nurse
- The Complex Needs Nurse
- The Nursery Nurse

3.4 As part of the first multi professional meeting the parents were asked to complete a Ready, Steady, Go questionnaire. The answers were reviewed by the multi professional team alongside the parents at this meeting and the responses to the questions highlighted the limited knowledge the parents had around the transition process and what Adult Continuing Care looked like.

3.5 The Adult Services reviewed what 24 hour care would be needed and required an All About Me Care plan to be completed. This plan was written by Lucinda with detailed information and evidence provided by Jo who worked as an excellent advocate for RR. Evidence required by Adult Services is listed below:

- All About Me Care Plan including 24 hour care needed.
- Health Assessments
- Moving and Handling Plans
- Decision Support Tool
- A tabbed journal including parent knowledge and skills.

Once all evidence had been submitted, the Care Agency provided feedback that RR's care plan was the most detailed and comprehensive care plan they had ever received. This preparation and support was also recognised by RR's mother who gave Jo some chocolates as a thank you for all her help and support in preparing RR for Adult Services.

3.6 There were several subsequent joint meetings with key staff to set timeframes for the year to ensure a smooth transition. Arrangements were made for the same package of care for four nights a week and the same direct payment carer to continue for RR into Adult Services.

In the final month of her transition, the carer identified to care for RR worked alongside our staff gaining knowledge and skills to competently and confidently care for RR.

3.7 RR successfully transitioned to adult services on their 18th birthday, meeting timeframes set within the CCG and Department of Health. To celebrate this RR's Mother organised an 18th Birthday party for RR. The Children's Continuing Care Team and the adult carer came to celebrate.

4. Patient Experience

4.1 The Mother will be attending in person, RR will be attending school however the Mother has provided photographs which they would like to be part of this story and will be shown during the Trust Board via powerpoint.

6. Learning for Wider Trust

6.1 It should be recognised that early planning and a clear care plan from the Children's Continuing Care Team ensured the success of this transition for the patient and their family. This story and the learning from this should be recognised and shared across the trust to highlight how clear assessment at an early stage gave the team time to ensure a robust and detailed transition.

7. Recommendations

7.1 The Children's Continuing Care Team continue to reflect on and review how our transition processes can be developed further and have put forward the following recommendations: :

- They will continue to work with the Local Hospital to further embed a more joined up and seamless approach to the transition planning process and work with and involve all staff, Consultants, service users and carers in this process from both Trusts.

- They will continue to work with all families to ensure they are informed about the transition process at the earliest stage possible. Currently this is done around 15/16 years old. The team continue to reflect on and review previous recommendations that were laid out in the Department of Health (2008) '**Transition: moving on well'** document which suggested that this should start at around 14 years old.

- The team in Luton will continue to share learning and develop best practice with their colleagues and teams from Children's Community Nursing Services in Cambridgeshire and the new Bedfordshire Services.

Lead Author
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