

TRUST BOARD

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| Title: | A PATIENT STORY ABOUT THE CHALLENGES OF CARING FOR AN INFANT WHO REQUIRES ACCESS TO 24 / 7 CHILDREN'S NURSING CARE |
| Action: | FOR DISCUSSION |
| Meeting: | 13 MARCH 2019 |

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 Wright | Patient Experience Manager |
| Executive sponsor: | Julia Curtis | Chief Nurse |

Trust Objectives

| Objective | How the report supports achievement of the Trust objectives: |
|--------------------------------------|---|
| Provide outstanding care | This paper demonstrates where our Children's Community Nursing team (CCN) have provided outstanding care in terms of their caring, non-judgemental attitude and excellent listening skills. |
| Collaborate with other organisations | This paper highlights a potential opportunity to further collaborate with our acute service colleagues |
| Be an excellent employer | This paper highlights how the Trust has developed a well regarded CCN team that feels empowered to work flexibly to meet individual patient needs |
| 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 the Service User within this paper and similar families are gaining the required services they require from our Trust during the week. However, we are not commissioned to run the same weekend service, so this highlights the different experience when accessing the NHS at the weekend. |
| To introduce people participation in our diversity and inclusion initiatives to capture the experience of hard to reach / seldom heard / varied community groups. | Understanding and hearing the experience of parents who are living with children who are disabled or who require 24 constant access to nursing care is an important part of our People Participation approach. As these lived experiences gained through feedback and participation form a valuable part of our understanding about what is working well and what can be improved, and how this can be used in the Co-production and improvement of the services we offer, now and in the future. |
| To introduce wider diversity on recruitment selection panels. | Not covered in this paper |
| To deliver customised training and development for staff to further improve awareness of diversity and inclusion. | 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 |
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1. Introduction

This patient story focuses on an eight-month old infant, who has a diagnosis of Beckwith-Wiedemann Syndrome, which was not identified antenatally. The main carer is the Mother and she describes her young baby as “contented and happy”. Throughout this patient story the young infant will be known as HM and the mother as DM, for confidentiality reasons.

- 1.1. HM is the youngest of 3 children within the home and is receiving additional support from our Cambridgeshire Children’s Community Nursing (CCN) Team. One of the main nurses involved with his care and who is supporting this patient’s story is Angie Curtis, a Children’s Community Nurse.
- 1.2. There are 2 older siblings also in the home who are aged 6 and 7 years. To add to the context of this story, in the past few years there have been a number of pressures, in addition to those of HM’s health needs, and the family currently receive ongoing support from Children’s Social Care.
- 1.3. Beckwith-Wiedemann Syndrome affects an estimated 1 in 15,000 newborns worldwide. The condition may actually be more common than this estimate because some people with mild symptoms are never diagnosed. The signs and symptoms of Beckwith-Wiedemann Syndrome vary among affected individuals. It is a condition that affects many parts of the body. It is classified as an overgrowth syndrome, which means that affected infants are considerably larger than normal (macrosomia) and tend to be taller than their peers during childhood. Growth begins to slow by about age 8, and adults with this condition are not unusually tall. In some children with Beckwith-Wiedemann Syndrome, specific parts of the body on one side or the other may grow abnormally large, leading to an asymmetric or uneven appearance. This unusual growth pattern usually becomes less apparent over time. Some infants with the Syndrome have an abnormally large tongue (macroglossia), which may interfere with breathing, swallowing, and speaking.

2. Background to our Service

- 2.1. HM has required nursing care since birth and since discharge from hospital this has been provided by our Children’s Community Nursing Team (CCN) in Cambridgeshire. This service aims to provide direct nursing care to children and young people from birth to 18 years of age (19 if in full time special education) in their own homes. Working hours are currently Monday to Friday, 9am – 5pm, with no service at weekends or on bank holidays with the exception of end of life care.
- 2.2. The service can include family and parental support, including teaching of specific care required to maintain the child at home wherever it is safe to do so. The team comprises Children’s Nurses, Health Care Support Worker, Play Specialist, Family Support Practitioner and Administration Staff. Services provided can include:
 - Avoidance of hospital admission.
 - Early discharge from hospital through intravenous medication.
 - Wound care / dressings, oxygen therapy, care for complex needs.
 - Palliative and terminal nursing care.
 - Chronic disease management including enteral feeding and gastrostomy, tracheostomy and assisted ventilation.
 - Specialist occupational therapy support for children with life threatening / limiting illness.
 - Specialist play input to enable children to manage their fears about their illness and provide pre- and post-bereavement support to siblings.

3. The Patient's Healthcare Journey

- 3.1 DM reports experiencing a normal pregnancy; she was induced due to reduced foetal movements and experienced a speedy, 35 minute labour. DM says she "immediately noticed HM's purple colour and enlarged tongue". A few hours later HM was admitted to the Neonatal Intensive Care Unit with hypoglycaemia and unstable blood sugars. The first 3 months of HM's life were in hospital, transferring from Addenbrooke's to Great Ormond Street and back to Addenbrooke's before being discharged home.
- 3.2 As part of HM's ongoing care, there is a requirement for twice daily blood sugar checks and an intramuscular injection 4 times a day. This was initially carried out by the CCN team and over time this has been taught to DM by our CCN team. This skill and support has meant that DM can independently and confidently undertake these tasks several times a day for HM.
- 3.3 HM also has a Naso-Gastric (NG) tube in situ, due to an unsafe swallowing function. The NG is used as a previous video fluoroscopy noted HM to aspirate silently which resulted in liquid entering the lungs. HM therefore requires the NG tube for all milk feeds. One of the common problems with young infants having a NG tube is that it can easily be removed with regular movements in the infant's sleep. HM regularly removes the NG (almost on a nightly basis) and so requires it to be regularly re-sited by our nursing staff.
- 3.4 The CCN team works flexibly in order to meet this family's needs and are able to visit in a responsive way to be able to re-fit the NG tube as required. Further to this, they try to support the family and visit at times and locations that are most convenient for them. This has included places such as Grandma's house.
- 3.5 DM is emphatic in her praise of the CCN team, particularly Angie, who she says is "like a second Mum, it's good to get to know the nurses, HM knows her." DM also explained that it is great to share HM's progress and the challenges of caring 24 / 7 for a young baby with additional needs; "Angie hears when I'm exhausted". Through the good and bad times DM feels that Angie is always "non-judgemental and caring".
- 3.6 Providing this family with 24 / 7 nursing care is difficult and our current commissioned service for the CCN team as described earlier is for a Monday to Friday, 9am-5pm, service. So when the NG tube needs to be re-sited at the weekend, the family have to attend A&E. DM describes this as a very different experience. HM is considered low priority for the procedure when triaged by the Emergency Department which usually results in a wait of at least four hours within the department. DM often has to attend with the older siblings as well, and a four hour wait with all 3 children is very difficult and long: "Waiting for long periods of time with a six-year old with additional behavioural needs can be very challenging at times." As well as the time spent waiting, there is the additional challenge of considerable parking costs. DM also states that, whilst ensuring HM's medical needs are being met, another frustration is that "other families are out doing things at the weekends; we sit in A&E".

4. Patient's Voice

- 4.1. The patient's Mum will be accompanied by Angie Curtis and will attend the Board in person to discuss their positive experience of the Community Children's Nursing service. The patient will also be present at the Board outside of the meeting with an additional carer and the hope is that he may visit the board room at the end of the session. There will also be a short video clip of the re-siting of the NG tube by a nurse to aid explanation of the story and context to the care required.

5. Learning Points for the Wider Trust Services

- 5.1. From DM's perspective, the learning for the Trust that she wants to highlight is that we are providing an excellent Monday to Friday service, for which DM and her family are very grateful, but this is limited as it does not cover out of hours care, weekends or bank holidays. She is also conscious that her family is not the only family affected by these restrictions.

6. Recommendations for Potential Improvement

- 6.1. The CCN Service needs to continue to consider how best to meet the needs of patients who require a weekend service. One area of improvement is to continue to build on the collaboration with the acute service to review and look at how direct access could be sought in a timely way at weekends.
- 6.2. The CCN team and Children's Services share this story with our local commissioners and other local health care providers to share the lived experience of those who are affected by a Monday to Friday service offer, to highlight that we need to work together to streamline the care on offer for quicker and more responsive access.
- 6.3. The Cambridgeshire Children's Community Nurses should share with their team and other CCN teams in Luton and Bedfordshire, the positive experiences of this family within the month after this story has been shared with the Board.
- 6.4. Investigate whether there are other community Trusts with similar services who work in a different way and is there any learning to be gained from their models of care.

Lead Author

Lisa Wright, Patient Experience Manager

Content and story provided by

DM – Patient's Mum

Angie Curtis – Community Children's Nurse