Sii

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Patient safety – learning from incidents

Baby R is a 10-month-old infant diagnosed with Hyperplastic Left Heart Syndrome at birth. Following several cardiac surgery procedures at BCH since his birth and spending several months in hospital, Baby R was allowed home from UHL on 27th July 2020 at 7 months of age. Discharge planning was organised between BCH, UHL, and LPT community services as Baby R had been an inpatient at both hospitals.

Mum is a 17-year-old single mother with known previous safeguarding concerns in order to support her to care for a complex child. Support was given to mum from community HENS Nutrition and Dietetics, Healthy Together Health Visiting, SALT, Diana Nursing Service and Cardiac Liaison Nurses.

At the time of Baby R's discharge, no further safeguarding concerns had been raised.

Baby R had a nasogastric tube inserted for top up feeds to maintain a healthy weight. Mum was taught how to perform the nasogastric top ups in hospital to continue top up feeds at home with support from the community services. Mum lived with her grandparents who gave her additional support to care for Baby R.

Baby R was awaiting further cardiac surgeries and had been a very sick baby since birth with poor prognosis. Baby R would make several attempts to pull out his naso gastric tube and following his discharge home, pulled out the nasogastric tube on 2 occasions within 72 hours.

Circumstances leading up to the Incident

When baby R accidentally pulled out the nasogastric tube on Friday evening 30th July 2020, mum rang the community Diana services, who, as usual practice, were closed for the weekend. Mum left a message and was called back the following morning by the health visitor and advised she would need to go to the ED to have the tube replaced as the community service to replace the tube was closed at weekends.

Due to social circumstances, mum did not attend the ED over the weekend and rang the community HENS services on the following Monday morning explaining the situation and requesting the nasogastric tube remain out for a few days as Baby R was taking oral feeds.

Community services HENS made the decision to not replace the nasogastric tube and monitor Baby R's weight to assess if and when the nasogastric tube needed to be replaced.

Due to social circumstances and equipment issues, during this time of having no nasogastric tube reinserted, Baby R did not have an accurate weight measurement for 3 weeks where a weight loss of 700g was recorded at a routine cardiac appointment on 18th August 2022. Baby R was also noted to have poor cardiac function and was admitted to the cardiac unit.

The hospital contacted community services the following day on 19th August 2020 to ask why the nasogastric tube had not been replaced with Baby R losing weight? It was identified that although attempts to weigh Baby R had been made at the GP practice on 13th August 2020, the baby scales were broken and Baby R's weight had been recorded on adult scales with mum holding the baby and then subtracting the mother's weight. Although Baby R's weight was noted as 7.2 kg, a loss of 500g, it was not recorded in Baby R's records as it was felt to be inaccurate, nor was it highlighted as a possible weight loss. Mum reported to the HENS that this weight was unlikely to be accurate as Baby R was feeding orally well and mum felt Baby R was not losing weight.

It was agreed with HENS following the inaccurate weight that the weight would be recorded at the cardiology appointment the following week on 18th August 2020, where mum would inform HENS of the accurate weight.

By the time of this appointment Baby R had lost 700g and become unwell.

Baby R's condition deteriorated and he sadly died in hospital on 10th October 2020.

Due to the length of time taken to complete the investigation, a reflection session with staff did not take place and an internal investigation was completed to identify if and how non- attendance at ED was communicated and followed up by the Diana/HENS Team and any actions that were implemented in response. The investigation would establish how information and concerns about Baby R's condition, feeding, weight and plan of care were communicated across the different services and to explore why a review of weight was not undertaken following the report received by the mum that at the GP practice they couldn't obtain an accurate weight. The measurement given by mum was not recorded in Baby R's SystmOne record (despite potential for inaccuracy due to weighing method) and how this indicated Baby R's weight had declined over the 3-week period.

Emergent Issues

Baby R did not have the nasogastric tube replaced following its second accidental removal. An MDT meeting was not arranged to discuss the implications of the nasogastric tube not being replaced and no MDT decision was made which could have highlighted the more complex needs of Baby R. The decision was made by the community HENS dieticians to monitor Baby R's weight without discussion with MDT.

Immediate Learning

For complex cases where several services are involved with the care of an infant, continued loss of access to a tube for feeding requires an MDT meeting and decision to fully understand all complex needs of an infant to maintain adequate weight gain of an infant with underlying complex conditions. There needs to be a Lead identified within the MDT to make decisions to change existing care plans in place.

Emergent Issues

Baby R's weight was not recorded for 3 weeks following the accidental removal of the nasogastric tube. With such a significant change to the care plan with the removal of the tube, weight should have been closely monitored to ensure there was no subsequent weight loss and an appropriate feeding regime in place.

Immediate Leaning

When there is a significant change in care plan for weight gain such as accidental removal of a nasogastric tube, weight measurements should be monitored and recorded weekly to ensure there is no significant weight loss.

Emergent Issues

Baby R's weight was inaccurately measured at the GP practice. This inaccurate weight was not recorded in Baby R's SystmOne record or highlighted as a potential loss of 500g which could have indicated urgent recheck for accuracy and weight loss monitoring, as opposed to waiting an extra week to record Baby R's weight.

Immediate Learning

Baby R's weight was not monitored on a weekly basis or checked following the inaccurate measurement expressed from mum. There is a possibility that through weekly weight gain/loss monitoring it may have indicated a deterioration in Baby R's health prior to the accurate weight recording 3 weeks after accidental removal of the nasogastric tube revealing a 700g weight loss.

Emergent Issues

Mum is a 17-year-old single mother living with her grandparents. There had been previous safeguarding concerns raised in February and April 2021 about a Section 17 (Child in Need) investigation regarding support for the young mum and Early Help Support was given from BCH. It is unclear from the investigation if Early Help Support was put in place from LPT and it was declined by mum on 30th July 2021 following discharge from hospital on 27th July 2021.

Immediate Learning

Where additional support has been offered but refused by a vulnerable mum with complex infant needs, the service need to maintain close monitoring to both support and to recognise a deteriorating child.

Immediate Actions

HENS Nutrition and Dietetics to put a robust system in place to monitor progress with feeding and to involve MDT where needed. This should include safety netting information to be given to patients' carers/families regarding risk factors and warning signs of deterioration.

Where there are multiple agencies involved, teams are to identify who is taking the lead with complex needs for sick children to avoid individual decision making.

Diana and SALT to be made aware of how to utilise the task functionality in SystmOne and gaining consent to share information to support teams with sharing information. This will be done through SystmOne training and a flowchart or quick reference guide to support sharing across the Directorate/Trust.

To ensure the processes in the event of a nasogastric tube accidentally coming out are robust. This should include a documented MDT decision to remove or replace a Nasogastric tube and weight to be recorded in 1 week to ensure the infant is gaining weight and feeds are amended accordingly.

When previous safeguarding and vulnerability factors have been identified, this should be clearly communicated with all services to support with ongoing safeguarding and professional curiosity. This includes improved communication between UHL Safeguarding Team and LPT Safeguarding Team of previous and current safeguarding concerns.

Further Learning/Sharing

Patient story to be shared with UHL Safeguarding Team for wider learning and to support with improved communication on previous and current safeguarding concerns.