

## Fahima's STORY



Fahima sustained a devastating brain injury aged 1, which has left her with significant disabilities and complex needs. The family were referred to us by hospital staff. We have been supporting this family for several years and during this time our involvement has helped to minimise other potential risks for this child.

Fahima sustained a severe non-traumatic brain injury as the result of a sudden illness. She spent several weeks in a coma in Paediatric Intensive Care. Although Mum and Dad were relieved that she had survived -it was bitter - sweet because their child is now severely disabled. We supported them to not focus on what they had lost – but what they still had.

### **Hospital Meetings**

Mum and Dad asked us to support them at several MDT meetings in the hospital and including the Discharge Planning Meeting (DPM). During the DPM, we suggested that as Fahima was now visually impaired, the parents purchase some sunglasses to try to protect the eyes from any further potential UV harm as they were no longer reacting to bright light. This was also important as post brain injury people can experience increased sensitivity to light. The Consultant agreed with this recommendation.

We also asked about the appropriateness of Fahima's car seat. It was stated by a Professional that the car seat had been assessed by the Road Safety Team and had been deemed safe for the Fahima's age and weight. We expressed concern that it may no longer be safe for a brain injured child that was now severely disabled with no head control and unable to self-mobilise. Another Professional agreed to check this at the pre- discharge home visit. When the car seat was assessed for Fahima's post-injury needs – it was deemed unsuitable.

We researched potentially suitable car seats and we worked with Dad and the OT to find a suitable and safe replacement. We also ensured the OT approved the car seat before it was purchased. However, the cost meant the family could not afford to buy in at such short notice. Out of the project budget we bought the car seat for the family – without which the Fahima could not have been discharged from hospital.

### **At home**

At home, the family had to adjust to a significantly different way of life. The happy, fun loving, active, and mischievous child they had known was no longer apparent. Both parents were completely devastated and were physically and emotionally exhausted. They said they coped because we were there to help them and support them.

During the early months' we visited them four times per week to provide emotional support and practical help. Fahima now needed to regularly take a significant amount of medication that was administered both day and night. She was also NG tube fed but had problems feeding and was persistently vomiting which was really upsetting Mum and was adding to parental stress and anxiety. This continued for weeks!

### **Continuing Health Care Team**

Fahima was also at significant risk of inhaling vomit – which had happened several times in hospital – and had caused lung/chest infections. Also, when she vomited, the NG feeding tube became displaced and this needed to be reinserted by the community nurses. Each time her child's chest was not checked to ensure vomit had not been inhaled or checked for any potential infection.

Whilst all this was going on – the UK also experienced some very hot weather. We became increasingly concerned that despite a range of professionals visiting the child every day, nobody appeared to be concerned that his child was regularly vomiting his full feeds.

We realised that the level of daily vomiting meant Fahima:

- a) was not receiving the correct nutrition needed to keep her well;
- b) the lack of food being absorbed could also have significant implications for how much medication she should have been given – even though Mum was correctly following the plan given by the hospital; and
- c) was at risk of becoming dangerously dehydrated. This was further exacerbated by the unusually hot weather.

In the interim to record this we contacted the dietician to express our concerns. We also created a vomiting chart that Mum used to record the time and how much Fahima was vomiting.

Day-to-day a range of NHS community professionals were visiting Fahima at home, but this went on for months - meaning that Mum could not leave the house at all. This was also adding to her stress levels and was affecting her mental health wellbeing. Dad worked permanent nights - so he slept during the day. Mum does not drive so could not have any respite time away from the child or the house. With so much pressure on Mum, her wellbeing started to suffer. We could see that she needed a break – but with so many appointments for the child - it was impossible. Mum had become a prisoner in her own home.

We asked the professionals to also consider Mums needs and asked if they could align their visits so that Mum had the opportunity to have a break and go out into the community with us.

The GP didn't visit to see how the family were coping. Both parents knew very little about their child's brain injury and had been provided with very little information. The only information they received was what we provided them with to help them to understand.

### **Social Care - Children with Disabilities Team and MATRIX**

Fahima had been appointed a Sensory Loss Social Worker from the above team. The Social Worker also worked closely with a professional from the Continuing Healthcare Team. We learned that the role of the professionals was to assess need and make recommendations to a Panel to commission care services for the child. However, neither professional knew anything about acquired brain injury and its complex effects – so how could they make effective recommendations for this child ongoing needs?

### **MDT Meetings and MATRIX**

Regular community MDT meetings took place; however they had no terms of reference – so parents were unclear as to the purpose of the meetings and what they were all about. Shockingly every detail of this family's life was openly discussed openly with everyone present. Mum withdrew from the meetings and would not participate preferring to stay at home with her child. There were times when what was being discussed was humiliating for Dad. The professionals did not even pick up on this.

Parents were also asked to make important decisions for their child's needs with no prior-warning that this was needed. Nothing should be discussed at a meeting without the parents knowing in advance and giving their permission for this to be discussed.

Every aspect of this family's private life was discussed in front of every professional who attended - and whoever else was shadowing them that day! These meetings should have been planned so that issues were discussed only with those who needed to know. At times Dad felt very uncomfortable, became disinterested and emotionally detached from the whole process. When he was put on the spot and unable to make an informed decision, he just agreed with whatever was being suggested – whether it was right for his child or not. This was because he lacked all the information needed to make an informed decision.

Whilst we acknowledge that a vulnerable child safeguarding needs are paramount, in the community MDT meetings, consideration should also be given to the human rights of the parents and their rights to both a 'private and a family life'.

## Outcome

We made a number of recommendations to both the NHS and the local authority.

- a) Parents should be provided with the Terms of Reference, so they know the purpose of the meeting. They should also be provided with an Agenda before the meeting so they know what will be discussed about them and who will be present. Not every community professional should know everything!
- b) Parents should be informed in advance of any decision that needs to be taken – giving them time to fully discuss those issues as a family and in private. They should also be provided with enough information to make an informed decision – rather than be put on the spot and expected to make an immediate decision.
- c) Parents need to be better informed about their child’s brain injury, prior to discharge for these important reasons.
  - How can parents make informed decisions at these meetings – when they don’t understand what has happened inside their child’s head?
  - How can they keep their child safe – when they do not know what the potential risks are?

We continue to support this family with a range of different issues and will likely do so for some time to come.

