

**Case Reference: 202000558**

**Sector: Health and Social Care**

## **The care and treatment of a child in the Royal Hospital Belfast for Sick Children**

The mother of a nine-year old boy who tragically passed away following treatment for a rare form of leukaemia complained about the treatment he received in hospital.

She said that the Belfast Trust lacked the knowledge and expertise to treat her son's condition, and that it should have acknowledged this and advised her to transfer him to hospital in Bristol for specialist treatment and ongoing care. She also complained that she, rather than the Trust, was the person driving the direction of her son's treatment. She said that the Trust had no care plan and were reacting to her inputs instead of proactively setting the course of treatment.

She also said the Trust's communication with the doctors in Bristol was poor and felt that because of the rarity of her son's condition it should have devoted more time to discussing his care.

She acknowledged earlier treatment was unlikely to have changed the outcome for her son, however she questioned whether earlier treatments may have improved the quality of his life or reduced his, and her family's, stress. In particular, she claimed that the specialist based in Bristol obtained stem cells for her son, but the Trust did not administer these until seven months later. She said the Trust waited until her son was at his weakest before administering certain treatments, particularly in the weeks leading up to his death.

She also said that the Trust's communication with her family was poor, in particular that it took too long to explain the severity of his condition.

During our investigation we took advice from an Independent Professional Advisor (IPA).

The boy had an extensive and severe form of a syndrome called Graft-versus-host disease (cGvHD), which is characterized by inflammation in different organs. He was placed primarily under the Trust's Haematology Department care, with consistent input from the specialist in Bristol. He also required input from respiratory doctors, rheumatologists and orthopaedic teams, as well as from physiotherapy and occupational therapy teams and dieticians.

It was apparent from the relevant documentation that the boy's mother took an active role in the direction of her son's care and treatment.

The IPA's advice stated that 'it is not at all uncommon for parents and families to seek outside opinions and make suggestions to the medical team' in respect of a patient's care. She advised the Trust appropriately followed-up on her inputs into the treatment plan and treatment options, whilst maintaining overall responsibility for the direction of care.

Having considered the IPA's advice, while we found that Trust staff did not possess specialist expertise, we did believe they had enough knowledge and experience to provide the boy with reasonable and appropriate care. On that basis we were satisfied it was not unreasonable or inappropriate for it to have continued to treat him instead of transferring him back to Bristol.

The Trust said it worked in tandem with the specialist in Bristol to chart the direction of care for the boy. It said it discussed treatment options with his family and acknowledged his mother's role in her son's care, which it described as 'quite extraordinary'. It said many departments and disciplines were involved in the care and acknowledged some of these were involved at parental request, but said that did not imply that their opinions would not otherwise have been sought and welcomed.

It said it investigated all treatment options the boy's mother put forward. The Haematology Department made decisions about whether treatment suggestions or interventions were appropriate, in consultation with the specialist. It said it extensively and carefully researched and assessed the risks vs benefits of each intervention and proceeded accordingly.

We reviewed the medical notes and were satisfied there was an appropriate treatment plan in place. We also acknowledged that the boy's mother was under a lot of pressure in looking after her son and facilitating a demanding treatment regime. She felt she had to take on additional pressure to research treatment alternatives and seek external input, and believed that the Trust should have done this itself. We were satisfied, however, that her significant efforts to drive the treatment plan did not mean the Trust failed to take reasonable and appropriate steps to also drive that plan. We also believed that she may not always have been aware of the Trust's action in this respect.

We noted the IPA's advice that the boy's medical records demonstrate the Trust discussed the treatment plan and changes to it with his family. However, she said it was impossible to decipher from the notes whether the Trust did so at each change in direction in the plan. This hindered her ability to determine the reasonableness and appropriateness of the Trust's communication with the family about when it was changed.

Given the rarity and complexity of the boy's condition, and his significantly evolving treatment plan, we considered it was particularly important for the Trust to maintain consistent communication with his family, and to accurately record that communication. This would have ensured the Trust fully appraised them of all elements of their son's care and treatment, including all multi-disciplinary input and forward planning. The second Principle of Good Administration '*being customer focused*', requires a public body to communicate effectively with service users. In addition, the third Principle of Good Administration '*being open and accountable*', requires a public body to keep proper and appropriate records. We considered the Trust failed to adhere to these principles in this respect.

We noted the Trust has since appointed a Bone Marrow Transplant (BMT) Specialist Nurse to act as a liaison with patients' families and to improve communication. It is our expectation this will improve the Trust's communication with families, and the accurate recording of that communication, going forward. The IPA also advised it would be beneficial for patients' families if, going forward, the Trust were to copy families into internal or external letters between clinicians discussing a patient's care and treatment. We agreed that this would ensure families are fully aware of the plans and decisions made by professionals.

We also observed that the Trust does not currently have in place a formal treatment pathway for the management of patients following stem cell transplants. A formal pathway would provide greater consistency for transplant patients and their families regarding the direction of care. This would be particularly beneficial for patients who undergo transplants externally, before coming into the Trust's care.

If a formal pathway had been in place during the relevant period this is likely to have had a positive impact. We therefore strongly encouraged the Trust to consider this observation and asked it to update us with its views.

In relation to the complaint about poor communication between the Trust and the specialist in Bristol, the IPA advised that given the complexity of the boy's condition, it would have been appropriate to discuss his case on a weekly basis on these calls. We considered that the failure to do this was a failure in the care and treatment the Trust provided. This failure caused the boy to experience the loss of opportunity to have his care and treatment discussed weekly in line with the Trust's established telephone communication model. It also caused his mother to sustain the injustice of frustration and uncertainty regarding the extent of communication between the Trust and Bristol about her son's care. However, on foot of the IPA's advice, we were satisfied adhering to the established model of weekly calls was unlikely to have resulted in any change to the direction of his overall care and treatment.

The Trust said it had to give careful consideration to the balance of good versus no or harmful effect when considering treatment options and the timing for them. This was necessary to maximise the boy's quality of life.

The IPA advised earlier treatment with new drugs may have had a positive impact in the short-term, but advised it was unlikely that starting these treatments 4-6 weeks earlier would have made any significant difference to his condition.

We found that, with the benefit of hindsight, it can reasonably be determined that if the Trust had provided these treatments earlier the boy's treatment journey may have improved in the short-term, without any notable adverse effects. However, an Ombudsman's role is to assess the Trust's approach under the circumstances it is faced with at the time, and overall we were satisfied that the care and treatment it provided in this respect was reasonable and appropriate.

We looked at the Trust's decision to await the effects of one medication (ibrutinib) before administering the stem cell treatment.

We found that given the good safety profile of the stem cells, earlier administration would not have changed the outcome and may not have changed the boy's symptoms, but it may have had a positive impact on his treatment journey and experience. Earlier administration would have required him to travel to Bristol, but the Trust did not discuss this option with his mother.

Taking everything into consideration we were satisfied that, on balance, it was not unreasonable or inappropriate for the Trust to consider it was in the boy's best interests to put the stem cell treatment on hold and await the full impact of ibrutinib. Whilst the Trust liaised extensively with the specialist, it was the Trust who were ultimately responsible for the boy's care and treatment whilst he was under its jurisdiction.

However, Standard 49 of the GMC Guidance requires doctors to '*work in partnership with patients, sharing with them the information they will need to make decisions about their care*'. This includes sharing '*options for treatments*'. As the patient was a nine-year old boy, we considered this extends to a requirement to work in partnership with his parents. Standard 33 of that Guidance requires doctors to '*be considerate to those close to the patient and be sensitive and responsive in giving them information and support*'. We noted the Trust's position that it contacted Bristol to seek potential dates for the stem cell administration, and that when it received no response it assumed there were no dates available. Nonetheless, we believed that the Trust should have made further efforts to find out about potential dates, and discussed with the boy's mother that travel to Bristol for the procedure was a viable option.

In relation to the complaint about taking too long to notify the boy's mother about the severity of his condition, the Trust explained that she had told them she wanted to focus on the positive aspects of her son's prognosis, care, and treatment, rather than the negatives.

We appreciated that the doctors did not want to add to her distress by going against her wishes and giving her upsetting news. Nonetheless, we considered they had an obligation to fully explain the situation. We believed that if they had been more direct with her about the severity of her son's condition and his long-term prognosis, the specialist revealing that he had grave concerns about the boy's prognosis may not have come as such a shock. We concluded this was a service failure.

Overall, however, we found that the Trust showed it had learned from the complaint and from the experience generally. It has used that learning to improve the experience of patients and families who find themselves in a similar situation. It has created several new staff posts and identified the importance of keeping these under review to make sure it can meet the needs of patients with complex needs.

Finally, our report acknowledged the determination and perseverance of the boy's mother and her family in fighting for the boy, both while he was undergoing treatment and in the years since his sad death. We expressed hope that the report went some way to address their concerns and provide them with some reassurance.