



The BMJ

Cite this as: *BMJ* 2020;370:m3019<http://dx.doi.org/10.1136/bmj.m3019>

Published: 29 July 2020

Trust was wrong to exclude parents from meeting about care of disabled child, says judge

Clare Dyer

The NHS trust that runs Great Ormond Street Hospital in London failed to take sufficient account of a severely disabled child's quality of life in concluding that she should have only palliative care if her condition deteriorated, a High Court judge has ruled.¹

Ms Justice Russell said that it was "essential" to involve parents where the quality of life of a disabled child was a central issue at a clinical ethics committee meeting. A decision by Great Ormond Street Hospital for Children NHS Foundation Trust not to involve the parents in a meeting, but to explain the outcome to them later that day, "had the effect of both raising their anxiety and contributing to their feelings of alienation and exclusion," said the judge.

She added, "The absence of any prior consultation or participation cannot be good practice and should generally be unacceptable. Even at hastily assembled meetings there should be notice taken of the views of the patient and/or close relatives which could take the form of some written notes or letter submitted on their behalf."

Russell was ruling on the trust's application for a declaration that it would be in the best interests of a 9 year old girl, referred to as X, not to be readmitted to the paediatric intensive care unit (PICU) or to have non-invasive ventilation with Optiflow if her condition deteriorated. Her parents wanted both options left open, as did the guardian appointed by the Children and Family Court Advisory and Support Service to represent the girl in the court case.

Ability to interact

The girl had been born healthy, but while still a baby she had haemolytic uraemic syndrome diagnosed. Before a kidney transplant in 2013 she had a cardiac arrest, leading to hypoxic ischaemic brain damage. She had renal disease, chronic lung disease, and intestinal failure and was blind, unable to communicate verbally, and dependent on total parenteral nutrition.

A report by an independent paediatric care specialist said that the girl was still able to interact with her family, enjoyed music, and would giggle or smile, but she had spent only 16 days at home in the previous seven years.

"The issue for the PICU team is the balance between these few episodes (where she is able to interact with her family) and the far more frequent periods she is being instrumented and subjected to painful procedures," said the report.

Independent experts for both the trust and the parents told the court that Optiflow would not be unduly burdensome and that, if the girl deteriorated, it could be stopped and she would be made comfortable. The trust said that she would have to be admitted to the PICU to have Optiflow, but Russell said that there was no evidence that the girl was particularly disturbed by the PICU.

"Given the fluctuations and unpredictability of X's condition overall and mindful of the complexities of her condition, it cannot be in her best interests to make the declaration sought by the applicant trust and I decline to do so," said Russell.

She declared that it would be in X's best interests to be provided with Optiflow if, in the opinion of the treating doctor after consultation with her parents, there was a reasonable prospect that it would improve her respiratory function enough to return to her pre-deterioration baseline. It would be discontinued if, in the doctor's opinion after consultation with the parents, she was showing signs of distress, her respiratory function continued to deteriorate, or she had not shown signs of improvement after treatment for a week.

Anonymity orders

The girl has since died. Russell granted anonymity orders for the girl, her parents, and the treating doctors but refused to allow the trust to remain anonymous. She said that there was no public campaign over X's treatment and no evidence that naming the trust would be likely to affect the clinicians caring for X or other children.

A spokesperson for Great Ormond Street said, "We understand how devastated the family must be at losing their beloved child. Every patient is to us a unique and special child and for the large multi-disciplinary team involved in the treatment of this patient, their wellbeing and quality of life was at the heart of all decision making and the team provided the very best care they could."

“We always try to involve families in the ethics committee, and we recognise the family’s frustration at not being invited to this meeting which was convened urgently due to the child’s rapidly changing clinical condition. We are sorry they were not invited. They should have been. Immediately after the meeting there was dialogue with the family about what was discussed.”

¹ Great Ormond Street Hospital for Children NHS Foundation Trust v MX, FX, and X (a child) (by her Cafcass guardian). [2020] EWHC 1958 (Fam).