



Lethal Paternalism: The Case of ST

A young woman’s right to make decisions about her own medical treatment is being denied in a recent court ruling. A nineteen-year-old woman, ST, has been deemed by Mrs Justice Roberts to be ‘unable to make a decision for herself in relation to her future medical treatment ... because she does not believe the information she has been given by her doctors.’ At the heart of this issue is that ST’s disagreement with her doctors is itself taken to mean that she lacks the mental capacity to make decisions for herself.

ST’s preparations for her A-Levels were interrupted last year when she was admitted to hospital due to a respiratory arrest, whilst also testing positive for COVID-19. Since then she has been unable to leave the intensive care unit, being completely reliant on a ventilator to breathe, a tube to receive nutrition, and a haemodialysis machine. The Hospital Trust has argued that ST’s progressive mitochondrial illness has damaged her organs to such an extent that she does not have long left to live and has proposed moving her to “a treatment plan of palliative care”¹, which would involve giving ventilation but withdrawing haemodialysis. Needless to say, without regular dialysis, her death will be hastened greatly. In this respect, ST has similarities to other tragic cases that have been in the public eye, such as Charlie Gard,² Alfie Evans,³ Pippa Knight,⁴ and Alta Fixsler.⁵ In many of these cases, judges ruled against the parents’ wishes and permitted doctors to withdraw life-sustaining treatment.

What is different about the case of ST is that she is not an unconscious child. She is an “alert and conscious”⁶ adult and able to communicate her wish to continue receiving dialysis and other forms of intensive care, while exploring whether she would be eligible to be included in clinical trials for experimental nucleoside treatment in Canada or the US. The disturbing nature of the case is that ST’s disagreement with her doctors about the future of her treatment is itself being treated as a sign that her mental capacity to weigh up her options is impaired. None of the

¹ [2023] EWCOP 40, para 2. <https://caselaw.nationalarchives.gov.uk/ewcop/2023/40>

² *Press Statement – Charlie Gard: Doing the Right Thing for the Right Reasons*, Anscombe Bioethics Centre (5 July 2017): <https://bioethics.org.uk/press-room/press-statements/press-statement-charlie-gard-doing-the-right-thing-for-the-right-reasons/>

³ *Press Statement – Alfie Evans: A Brief Statement of the Fundamental Ethical Principles*, Anscombe Bioethics Centre (2 February 2018): <https://bioethics.org.uk/press-room/press-statements/press-statement-alfie-evans-a-brief-statement-of-the-fundamental-ethical-principles/>

⁴ *Press Statement – Pippa Knight: The Benefit of Being Cared for Unawares*, Anscombe Bioethics Centre (4 February 2021): <https://bioethics.org.uk/press-room/press-statements/press-statement-pippa-knight-the-benefit-of-being-cared-for-unawares/>

⁵ *Press Statement – Alta Fixsler: Subsidiarity and the Importance of Circumstances*, The Anscombe Bioethics Centre (4 August 2021): <https://bioethics.org.uk/press-room/press-statements/press-statement-alta-fixsler-subsidiarity-and-the-importance-of-circumstances/>

⁶ [2023] EWCOP 40, para. 8.

doctors who interacted with or treated her claimed that her condition had affected her brain, and the judge “accepted that ST does not suffer from any recognised psychiatric or psychological illness.” And yet, because the wording of s.2(1) of the Mental Capacity Act 2005 does not require a formal diagnosis of an impaired mind or brain, “it is sufficient if the court finds some form of psychological or other impairment which impacts on ST’s ability to take a decision.”⁷ The judge therefore has taken ST’s belief in the possibility of her surviving her illness and in receiving experimental treatment to be signs that ST refuses to believe the information given to her by her doctors. As she does not accept their prognosis, her ability to make decisions is taken to be impaired.

However, the fact that people believe different things is not enough to show that they do not have capacity to decide things for themselves. Someone can make a mistaken decision, or one that is objectively unreasonable, or unwise, or even perverse or a decision that is harmful to themselves or unfair to others, and yet have capacity to make that decision. This is why we can hold people responsible for the decisions they make. To make decisions for people when they could make decisions for themselves is paternalism. It is treating adults as if they were children. This ethical truth is also reflected in the Mental Capacity Act which emphasises that someone must not “be treated as unable to make a decision merely because he makes an unwise decision.” The judge has taken a perilous step in interpreting ST’s disagreement with her doctors as tantamount to an inability to use the information she has been given about her condition. She can use it. She just disagrees with it. We may well consider her decision unwise and doctors are not required, given limited resources, to provide any and all treatments that patients may request.

In this case, a vulnerable patient’s disagreement with her doctors is being used against her as a means not only to take away her voice but further to deny her the right to litigate against the decision to take away her voice. Most disturbingly of all, her wish to continue to receive life-sustaining treatment, such as dialysis, is not only being ignored, but that very wish is being seen as a reason to deny her dignity as a mentally capable adult. This is a lethal form of paternalism.

END

Notes to Editors:

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- For interviews or comment, contact: media@bioethics.org.uk or 07900925708.

⁷ *Ibid.*, para. 101.



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