

UNITED KINGDOM

"I'm ill, but I want to live." Hospital asks judge to end her life

LIFE AND BIOETHICS

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ST is a young 19-year-old girl who has spent the last year being treated in an intensive care unit in a hospital. She wants to live but her doctors have decided that her illness offers no prospect of improvement and therefore she should die immediately. Unlike

cases where the patient is an unconscious baby, child or adult supposedly on death's doorstep, ST is a young adult, completely conscious, capable of making decisions, who has expressly stated her will to live. Nonetheless, the court has taken away her right to decide for her life. This is the case today in the UK, which marks an ulterior step in the barbarism that has become a hallmark of the British National Health Service (NHS).

The story of ST (real name suppressed due to reporting restrictions) is about a young woman who is suffering from a rare form of mitochondrial disease (RRM2B). ST's condition causes chronic muscle weakness, loss of hearing, and damage to her kidneys making her dependent on regular dialysis and other intensive care but importantly has not affected the functioning of her brain. In fact, the disease did not prevent her attending mainstream schooling or obtaining good grades in her GCSE results. She was studying for her A levels when she contracted Covid 19 last August 2022, causing her severe respiratory difficulties. ST was admitted to hospital and put in an intensive care unit (ICU) where she has remained since.

Last February, her doctors reported that her condition had worsened. She later suffered two life-threatening episodes requiring emergency medical treatment in July. Her treating clinicians decided ST's medical condition was progressively degenerating and defined her medical state as "actively dying". They presented her with a palliative care plan which would stop her life-saving dialysis treatment and cause her death in a matter of days from kidney failure. ST turned the option down.

The doctors acted immediately by passing the hot potato to the courts. The NHS Foundation Trust responsible for the hospital treating the girl, brought the case forward on the grounds they believe ST does not have the mental capacity to decide her treatment.

The teen, described as "a fighter" by those who know her, wants to join clinical trials for nucleoside therapy, preferably in Canada beginning this autumn or in one of two hospitals in America. She believes this therapy offers the possibility of a 50/50 chance of improvement even if she understands, it might not be successful in her case. At the same time, she has expressed her loss of trust in her doctors. In particular, she has said she does not believe she may have "only days or weeks to live" and it's worthless keeping her alive and until arrangements can be made for her transferral to one of the hospitals abroad willing to treat her. She says she has already confounded them before when she recovered, despite their expectations to the contrary, from two recent acute life-threatening episodes. Under provocation in court, her doctors stated, "her death is necessarily imminent," but admitted giving her "weeks or even months to

live,” was a consensus made by the medical professionals who testified, although, “the exact prognosis is uncertain”.

Moreover, two psychiatric experts, referred to as Dr.D and Dr.C, instructed by the Hospital to examine ST, told the Court that she is not suffering from any mental health illness and has the mental capacity to make decisions about her own welfare or healthcare.

The doctors testified that “there is no evidence that ST is now in denial about the fact that her overall condition is progressive”. The evidence from both Dr D and her brother was that “she was aware that her condition involved the possibility of death”. Whereas, Dr C reflected ST’s expressed wish that she wanted, “to die trying to live” and that no option must be left unexplored in that endeavour (“We have to try everything”). Inexplicably, their expert medical opinion was rejected by the court.

Instead, her doctors who have no expertise in mitochondrial disease, insist her obstinacy to continue fighting to live is a “delusion” and indicates she does not have the mental capacity to decide her treatment. One of the doctors stated in court, “whilst she [ST] clings to this hope of a better outcome involving her survival, she has closed her mind to the alternative of 'greater comfort' or 'less intrusive or painful treatment' which palliative care is likely to provide.”

Last week, August 25, Mrs. Justice Roberts presiding over the hearing, sided with the NHS hospital and agreed that ST lacked the mental capacity to make her own decisions and therefore her end-of-life care could be determined by the Court of Protection. **Roberts wrote in the ruling,** “ST’s complete inability to accept the medical reality of her position, or to contemplate the possibility that her doctors may be giving her accurate information, is likely to be the result of an impairment of, or a disturbance in the functioning of, her mind or brain.” The judge argued, “she is frightened by the prospect of dying and clings to her desire to survive what her doctors have repeatedly told her is an unsurvivable condition.” Unless the family decides to appeal the decision and is successful, ST’s fate will be decided at a best interests hearing where she will be represented by the Official Solicitor – the official responsible for representing patients who lack capacity in court proceedings of this nature.

ST’s Christian family have spent all their savings to pay lawyers to stop the NHS ending their daughters life. Their last hope is experimental nucleoside therapy which is available only abroad. But, the Transparency Order imposed by the Court in March 2023, which imposes severe restrictions on reporting information which might lead to the identification of ST, family members, physicians or the hospital involved in the case,

prevents the family from speaking to the press or making appeal for funds.

In a statement published by Christian Concern and communicated via their solicitors, the family said: "This has been a year of continuous torture for the family. Not only are we anxious about our beloved daughter's fight for survival, but we have also been cruelly gagged from being able to speak about her situation. We are not allowed to ask people for prayers or for help which she desperately needs. It is a matter of life and death for our daughter to raise money for treatment in Canada, so these arbitrary reporting restrictions are literally killing her.

"We are shocked to be told by the judge that our daughter does not have capacity to make decisions for herself after all the experts have said that she does. We are very distressed by this injustice, and we hope that, by Jesus's grace, this will be corrected on appeal.