**Sudiksha’s case and confusion over capacity, transparency, and palliative care: nails in the coffin for trust in doctors?**

In the majority of cases patients and their families trust their doctors. However, there is a growing number of high-profile cases hitting the media where patients, and especially the parents of very young and very poorly infants, simply do not agree with their doctors. Significantly, these cases are where the life of the patient is at stake and doctors believe that it is better to withdraw or withhold treatment and allow the patient to die ‘with dignity.’ The recent case of ST, a young woman who was keen to try to preserve her life in the face of devastating mitochondrial disease, was a development with a twist. Unlike previous cases involving infants who clearly did not have capacity to make decisions, ST was conscious and, according to two psychiatrists, she had no brain impairment and had capacity to make decisions about her future medical treatment. ST was well aware of the nature of her illness, but she hoped to be able to take advantage of possible treatments abroad. Moreover, she thought that the recent deterioration in her condition was in part due to having contracted covid. Her doctors argued that her deterioration was due to mitochondrial disease and that she had days or weeks to live. Having determined that she was ‘actively dying’ the doctors decided that the way forward was withdrawal of dialysis, no attempts at resuscitation and ‘only’ palliative care. In response, ST said that she had confounded the expectations of the doctors before and might do so again. ST wanted to live. She wanted hope.

The hospital trust took the case to the Court of Protection where they argued that ST did not have capacity to make decisions. Moreover, it was agreed that a gagging order could be put in place so that the patient, family and the trust would not be identified, though this also meant that the family could not draw attention to their case, discuss the issues publicly, and could not crowd fund for alternative treatment. Sadly, ST died in September. She can now have her name back: Sudiksha Thirumalesh.

Sudiksha’s case has raised significant questions. The focus of concern has to date been on the issue of capacity: how to trust a system where a person with capacity can be said not to have capacity for her own treatment decisions or even to litigate, that is to carry on proceedings, on her own behalf. The second consideration revolved around how to trust a system that lacks transparency: Sudiksha’s family have repeatedly argued that they were unfairly gagged by reporting restrictions, and this also meant that any commentary on the case was reliant solely on the court reports. However, Sudiksha’s case raises perhaps an equally significant issue: what do we understand by and how can we trust palliative care, given that Sudiksha was adamant that she wanted ‘to die trying to live’ while her doctors said that she was ‘actively dying’ and so planned a pathway of ‘only’ palliative care. The reason why this is significant is that it seems incorrectly to position palliative care as a pathway to death. This is not only to do a disservice to the practice of palliative care, it also buys into a level of distrust in medical professionals who seem to think that death, outsourced to palliative care, can be in a person’s best interests.

The question of capacity remains controversial. The court decision that Sudiksha did not have capacity appears to suggest that a patient can be said to lack capacity if the patient does not believe her doctors. In fact, the judge sought to give her decision within the confines of the Mental Capacity Act and she decided that Sudiksha was simply unable to weigh up the alternative argument as presented by the doctors because she was so traumatised by the presence of death all around her during her hospital stays. Trauma meant that Sudiksha could not accept that she was dying, and this amounted to an impairment or disturbance in the functioning of her brain. Notably, whether anyone can really comprehend the prospect of their own death has always been a perplexing philosophical question rather than an issue of capacity.

While Sudiksha’s refusal to believe the assertion of her doctors that she was ‘actively dying’ was based on a lack of trust, this perhaps blurs into the significant issue of what the doctors and Sudiksha understood by palliative care. This question remains opaque because the family’s view has not been heard and this lack of transparency in turn creates distrust. The notion that a person is ‘actively dying’ is imprecise and if anything refers to the last few hours of life, not life before various treatments are withdrawn. The doctors and the court acknowledged this imprecision yet accepted ‘actively dying’ as the reality for Sudiksha. The position of the doctors that Sudiksha’s treatment plan of palliative care would involve the withdrawal of dialysis with no attempts at resuscitation inevitably seems to indicate a pathway to death when what Sudiksha wanted was a ray of hope and ‘a light in the tunnel’. The view of one clinician that the ‘kindest’ course of action was to de-escalate intensive care and make Sudiksha ‘comfortable’ led Sudiksha to believe that she would simply be left to die. From the court transcript it is difficult to see whether palliative care specialists were involved in the discussions with the doctors, Sudiksha and her family. Indeed, it looks as if hospital care is curative and when everything fails palliative care comes in to manage dying and death. These perceptions do not do justice to palliative care. Palliative care is for people who are living with serious conditions and not simply for those who are ‘actively dying.’ Palliative care gives patients the medical care they need for their symptoms as well as treatments to cure or alleviate their illness. Palliative care is concerned with improving the patient’s quality of life and is based on the patient’s actual needs not on a prognosis. Palliative care does not preclude appropriate life-saving or life prolonging treatment. Good palliative care does not hide difficult truths but it also fosters hope. As the founder of the modern hospice movement, Dame Cicely Saunders said, ‘You matter because you are. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.’ This is the kind of attitude that leads to trust.