

INTERVIEW / VARSHAN THIRUMALESH

«This is how British doctors caused my sister Sudiksha's death»

LIFE AND BIOETHICS

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“The doctors denied my sister the medicines she needed.” “They refused to give her antibiotics to cure an infection she got in hospital until my parents begged them on their knees but they stopped her blood pressure medicine which caused the cardiac arrest.”

“This is what killed my sister **Sudiksha Thirumalesh**.”

Varshan Thirumalesh, speaks on the phone to the *Daily Compass* while travelling back by train to Birmingham from Kent to attend his sister’s funeral. He describes the shocking treatment Sudiksha Thirumalesh (ST) was subjected to while convalescing in a Birmingham hospital. Sudiksha (ST) is the **19-year-old school girl** who was suffering from **Mitochondrial Depletion Syndrome** (MDS) and who became embroiled in a court case against her doctors who wanted to suspend her life sustaining treatment against her will.

She died on 14 September of a cardiac arrest and before a final judgement had been reached by the courts. Her doctors claimed it was a natural death considering her health. But, Varshan tells a different story. He describes the chilling reality of what is standard practice in end of life cases in the UK. The counter part, University Hospitals Birmingham NHS Trust not only fought to end Sudiksha’s life, they had the family gagged by the courts with a **Transparency Order** to stop the family and press from revealing names or reporting critical events in real time. Recently, reporting restrictions were partially lifted enabling the family to call their daughter by her name Sudiksha Thirumalesh (not ST) in public and for Varshan to tell her story.

The Daily Compass has been following your sister’s story with dismay, can you tell us something about your family?

We are a Catholic family from northern India. My father was the first to emigrate to England in 2001. He is a skilled computer analyst and he transferred to the UK for better job prospects eventually opening his own company. My mother, my sister and I joined him in 2003. We settled happily in the Birmingham area and live by our Christian values.

How our family faced your sister's illness and the court case which ultimately denied her right to life?

From the beginning, it was clear as Christians we give a different value to life compared to the hospital doctors. We believe life always has value and dignity even if the person is very ill. The system instead gives up on life very easily in the name of the patient's best interests. Staff made fun of our beliefs and mocked Sudiksha. They tried to break her psychologically and to destroy her will to live by telling her repeatedly she was going to die. They told her they knew what was best for her. They told her there was no magic wand to wave and she had to accept death was close. They choreographed everything to bring about her death as quickly as possible. My sister told them she was under God's protection. She never let go of a little wooden cross she clutched in her hand, even when she was receiving treatment. She lost trust in the doctors completely. In the end, she said she trusted only God.

How was the family treated by the hospital?

It was very stressful and intimidating. Once the doctors had decided to end Sudiksha's life, we were taken to a meeting room. The doctor told us they wanted to withdraw her ventilator and dialysis. I replied, it was a pathway to kill my sister. The doctor said, or you retract that sentence or leave the room. At a certain point, Sudiksha was well enough to come home on a ventilator but they wouldn't let her out of the hospital. You won't leave the Intensive Therapy Unit, they told her. We were afraid to leave her on her own and a member of the family stayed by her bedside day and night. My mother even learned to monitor her day to day needs and her nasal gastric tube. Even if the nurses were very helpful, that hospital and one doctor in particular is responsible for my sister's accelerated death.

If mitochondrial disease cannot be treated in the UK why wouldn't the doctors let Sudiksha go abroad?

It's a very expensive illness to treat and the NHS does not provide the treatment. But, there is research being conducted into nucleoside treatment for the disease in Newcastle. Sudiksha supported this research by going to Newcastle several times to provide muscle biopsies for the clinical trials. One of the doctors told her she needed to go abroad for treatment or the illness would gradually kill her. The Trust doctors said they were not against my sister going abroad for treatment but in reality they did everything they could to stop her leaving. All the doctors testified against Sudiksha going to Canada for experimental treatment. If Sudiksha had been allowed to go to Canada six months earlier, I believe she would still be alive today.

In hindsight, do you still think it was the right decision to fight "the system" in the courts?

In hindsight, probably not, because it's impossible to win. The doctors know very well, the one thing the patient doesn't have is time. They know that if the patient doesn't receive the treatment they need, squandering time will prevent their survival. They know a protracted court case is in their favour and they know you are on your own. It's a David against Goliath situation. The doctors have top barristers fighting for them paid by the State. The family has to find its own lawyers and pay for them from their own pocket. Even what happened in court was shocking. The judge ordered a second opinion to decide if my sister was mentally capable of making decisions on her health care. Two psychiatrists, chosen by the court, were brought all the way from Bournemouth to Birmingham to do an in-depth assessment on my sister's mental health. When they found Sudiksha was mentally capable we thought we had a chance to save her. Then the judge ignored their specialist report and handed Sudiksha a death sentence. We felt helpless.

What are the family's plans now?

We intend to appeal the decision on Sudiksha's mental capacity and have it overturned. My sister was not only able to make decisions about her health she was fully alert and conscious until her last breath. We want to prevent other families being gagged by the courts stopping them from asking for prayers, speaking to friends and relatives, or raising funds for treatment at the risk of heavy fines or imprisonment. We don't want anyone else to have to throw themselves at the doctor's feet begging them to help their child as my father did when Sudiksha had a cardiac arrest and then watch their daughter die because the doctors refuse. Sudiksha did not die naturally of

mitochondrial disease as the Coroner wrote on her death certificate. She died of a cardiac arrest brought on by her treatment in hospital and we want the doctors involved to take their responsibility for what happened. We are devastated, but we are also a Christian family and we say to those few clinicians who seemed only to care about Sudiksha dying, we forgive you.

The Daily Mail produced a compelling [documentary of Sudiksha's fight to live](#) .

Christian Concern has started a fund raising page under the heading "make a gift to support the family". [Donations can be made here](#).