

UNITED KINGDOM

Indi has died: «They took her body, but they can't take her soul»

LIFE AND BIOETHICS

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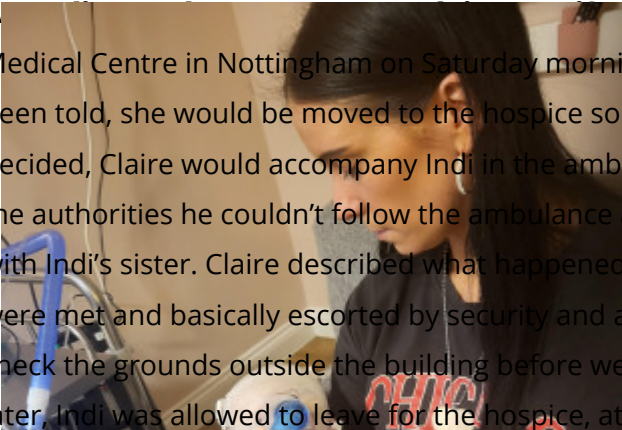
+++UPDATE, 7 am+++

**This is Dean Gregory and Claire Staniforth statement on Indi's death today:
"Indi's life ended at 01.45am. Me and Claire are angry, heartbroken and
ashamed. The NHS and the courts not only took away her chance to live, they
took away Indi's dignity to pass away in the family home where she belonged.**

They did succeed in taking Indi's body and dignity, but they can never take her soul They tried to get rid of Indi without anybody knowing, but we made sure she would be remembered forever. I knew she was special from the day she was born. Claire held her for her final breaths"

There is no difference between a hospice and a hospital when the objective is to obtain Indi's death as quickly as possible. Dean Gregory and Claire Staniforth, Indi's parents, reached this conclusion very quickly after Indi had been transferred from Queen's Medical Centre in Nottingham to an unnamed hospice on Saturday 11 November. The following is a first hand account of Indi's journey from the hospital and the ordeal they faced behind the closed doors of the hospice.

"Indi is struggling", Dean Gregory told the *Daily Compass* on Saturday at 6pm (UK time). Indi was already in the hospice, her ventilation had been removed, she was being cuddled by mum Claire, and had been fitted with an oxygen mask. Since early morning, Saturday 11 November, Dean has been sending quick WhatsApp messages to describe events as they unfold.

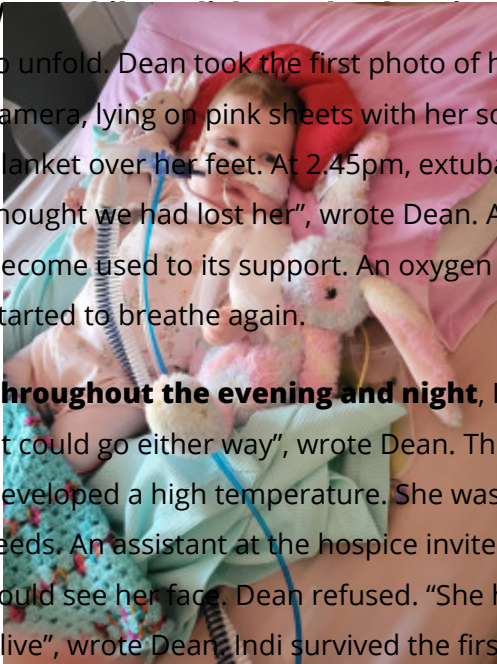
A  **th, Indi's mum** went to Queen's Medical Centre in Nottingham on Saturday morning. On Friday evening, the family had been told, she would be moved to the hospice sometime between 10 and 11am. It was decided, Claire would accompany Indi in the ambulance, while Dean, who was told by the authorities he couldn't follow the ambulance and would make his own way by car with Indi's sister. Claire described what happened when she arrived at the hospital, "we were met and basically escorted by security and a few policemen to A floor. They had to check the grounds outside the building before we went in to the ambulance". Two hours later, Indi was allowed to leave for the hospice, at 1pm.

Surprisingly, the 40 minute trip in the ambulance to the hospice was particularly uneventful for the critically ill baby whose doctors had testified in court, was "clearly distressed, agitated and in pain" because of her treatment. Dean wrote, "She didn't even notice the journey, she was just lying there chilled". "She didn't mind the travel one bit, she didn't even flinch". You see, wrote Dean, "she would have made Italy easy".

Claire and Dean are still struggling to come to terms with the UK and European courts decision to block them from accepting Italy's offer to treat Indi at the Vatican Bambin Gesù hospital in Rome. It would have fulfilled their desire to give Indi every chance at life while allowing her to live her life to its natural end. Bitterly regretting what

they perceived as a lost chance to help Indi, Dean and Claire had decided Indi should come home, a journey of 20 minutes, exactly half the distance to the hospice.

Originally, the *Compassionate Care Plan, agreed in court*, had given the family three possible locations for Indi's end of life care to choose from: hospital, hospice or home. In the first place, the family had opted for the hospice, but later changed their minds, preferring their own home, after judges had usurped the offer from Italy. At this point, Indi's doctors objected, initially claiming it was too risky to move her and then arguing the complications involved delivering palliative care at home instead of in a medical institution, could cause Indi unacceptable suffering ([see judgement here](#)). Their last request to bring her home was rejected in an acrimonious final court hearing on Friday 10 November. Dean wrote, "the hospice is a nice place, but not in these circumstances. I'm not glad to be here, we wanted Italy and if not Italy, then home".

M  **bed**, totally oblivious to the cruel destiny about to unfold. Dean took the first photo of her at the hospice. She was gazing intently at the camera, lying on pink sheets with her soft toy rabbit next to her and a hand crocheted blanket over her feet. At 2.45pm, extubation took place. Indi stopped breathing. "We thought we had lost her", wrote Dean. After 12 weeks on a ventilator, Indi's body had become used to its support. An oxygen mask was placed on her head, and Indi slowly started to breathe again.

Throughout the evening and night, Indi continued to battle between life and death. "It could go either way", wrote Dean. The monitor registered the fluctuations and Indi developed a high temperature. She was treated with ibuprofen. She was given her feeds. An assistant at the hospice invited the family to remove the oxygen mask so they could see her face. Dean refused. "She has no choice at the minute, she needs to stay alive", wrote Dean. Indi survived the first night.

But, the new day brought new problems. The next morning, Sunday 12 November, at about 10am the family was presented with forms to sign. It concerned the care Indi should receive if she needed resuscitation. There were two options, the first accepted basic care and the second to no care. A second form requested authorisation to update the hospital doctors of Indi's medical state. Dean consulted his lawyer from the Cristian Legal Centre. He didn't sign either forms. "If you sign, that form takes our rights away", wrote Dean.

Notably, Indi was better yesterday than the day before. Her body seemed to have absorbed the shock of her ventilation being aggressively removed. She was more stable,

her temperature had dropped, she was getting used to her oxygen mask. Discussions turned to Indi's future care. According to the court judgement, Dean messaged, "they can refuse to do anything for Indi". An assistant at the hospice told Dean, "the mask can stay on a couple of days then they will remove it". Dean wrote to the consultant to defend Indi's "best chance to survive" and reminded him that "the mask is for seven days and that it could be extended but if she is doing well, then maybe she would go to a nasal canula".

Yesterday evening, Indi was calm and stable. At midnight, Dean wrote before closing communication for the night, "I've been thinking", he wrote, "I feel Indi was born for this purpose, to expose what's happening to other children in the UK. I knew Indi was special from day 1".