Statement of the Respondent

Dr Amir Khan

Statement Number 1

Dated 08/06/2023

Case:HC24001

IN THE HIGH COURTS OF JUSTICE

FAMILY DIVISION

IN THE MATTER OF THE CHILDREN ACT 1989

BETWEEN

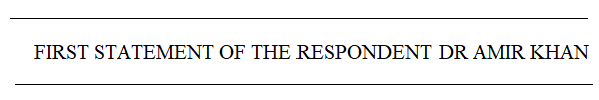
MARYAM BEGUM

Applicant

-and-

CARDIFF & VALE UNIVERSITY HEALTH BOARD

Respondent



1. I, Dr Amir Khan, am a consultant neurologist at Health Hospital, which is run by the Cardiff and Vale University Health Board. I specialise in pediatric neurology. Additionally, I have specialist training on preparation of individuals for transplantation. I have been working in this role for 20 years. As Amara Begum’s treating doctor, I am acting as a representative of the Cardiff and Value University Health Board.
2. Beyond my clinical duties, I also work as part of a clinical research team which specializes in novel organ donation for children. My specific expertise is in donation of nerves and parts of the spine, as a way to treat paralysis.
3. Recently the Welsh Parliament brought in legislation which allows doctors to presume the consent of children who have reached the age of 16 and 17 years of age. This allows the preparation of children, and harvesting of organs without their specific consent. This is in line with the Human Transplantation (Wales) Act 2013, which brought deemed consent into force in Wales for adults in 2015.
4. It is the policy of the hospital to take the organs of 16 and 17 year old as they have presumed to have consented, even if they have not signed the organ donation register. Since the passing of the Act, it has been the policy of the hospital to keep all children, on ventilator support until a decision has been made about organ donation by the treating doctor.
5. Additionally, it is the view of the trust that Principle 4 also extends the ability to ‘imply consent’ for those patient’s under the age of 16 years of age. This is because the Principle is not specific about the age of ‘Patients.’ Consent can be implied if the child has demonstrated an ‘intention’ to donate whilst they were living. Additionally, that the child whilst living was Gillick competent i.e. that they had the capacity to understand the nature of organ donation.
6. Since the passing of the Organ Donation (Informed Consent)(Wales) Bill 2023, I have harvested the organs of 10 children under the age of 16, where there has been evidence that there has been ‘implied’ consent. In these cases, all of the parents were in agreement that donation should take place.
7. In usual practice, I inform the parents that the organs of children will be harvested. I view that this is a good ethical practice, but not a legal requirement. I seldom allow parents to veto either a positive consent or a presumed consent. I have only once allowed a parent to veto a presumed consent of a 17 year. In this case the child had created a written refusal which was evidenced by the parents, witnessed and signed by them.
8. On 5th June at around 9.45am, I was working on call at the A&E department of Health Hospital. We a call that two ambulances were on their way from a care crash. The first contained Mrs. Marayam Begum and second was Asmara Begum.
9. Mrs. Begum was unconscious on arrival. She had a concussion from the impact. She also had several cuts and two broken fingers. She was treated and sent to the ward for observation until she regained consciousness.
10. At 10.30am the second ambulance arrived with Asmara, she was in a much more serious condition. She was also unconscious on arrival, had a large cut on her head, and had severe bruising to the head and face. She also had several broken bones, and injuries to her internal organs. She was rushed for a CT scan which found that she had swelling and bleeding on the brain. She was taken for urgent brain surgery. The bleeding was stopped, and part of her skull was removed to relive pressure. However, the prognosis was not good, it was likely that she had suffered severe brain damage. Amara was placed on a ventilator, however it was doubtful that Amara would regain consciousness.
11. At 2.00pm, whilst operating, I was told that Mrs Begum was awake, and wanted to see Amara. Surgery finished at 3.30pm, and Amara was transferred to Intensive Care, where I allowed her mother to visit. At 5.00pm, I talked to Mrs Begum and told her the poor prognosis. At this point I usually talk about the option of organ donation. Talking about organ donation early, allows time for the families to think about their options. However, as Mrs Begum had just been in a car accident, and she was very upset, I thought it best not to raise the option at this time.
12. I continued to monitor Amara over the following days. As predicated Amara did not regain consciousness.
13. On Wednesday 7th June I informed Mrs. Begum, that it was now extremely unlikely that Amara would regain consciousness. She had suffered severe brain damage, and if she did wake up she would suffer significant disabilities and need full time care for the rest of her life. Whilst brain stem death could not be confirmed due the nature of Amara’s injuries, it would therefore be best to turn off the ventilator. Mrs. Begum agreed that it would be best to let Amara pass away peacefully.
14. It was at this point that I told Mrs. Begum about the opportunity of donation. Amara’s primary organs were damaged and could not be donated, however, she could donate other organs and tissues. I particularly emphasised the chance of donating Amara’s lower spine. This would be used as part of a novel procedure that would allow another child to use their legs again. I informed Mrs. Begum that I could do this without the permission of the parents for those over 16, but as Amara was 15, I needed to know whether she would want to donate her organs.
15. Mrs. Begum informed me that on several occasions Amara had indicated a willingness to donate. Although, the family had pushed back on this wish, Amara had persevered as she wanted to help people and informed Mrs. Begum of this intention some weeks later (after their initial conversation). Mrs. Begum also told me that Amara was fully informed about the nature of organ donation and the law, from lessons that she had had in school. It was clear from the description Mrs. Begum, that Amara had thought about this deeply over a prolonged period of time, and come to a careful decision that attempted to balance the religious wishes of her parents, and her own wish to help people. On this basis, I was of the opinion that Amara was Gillick competent, and I could rely on the ‘implied’ nature of her consent.
16. When I informed Mrs. Begum of this, she said that she was not happy and wanted to veto. I told her that there was no opportunity to veto in the law, unless there was written evidence that Amara did not want the donation to proceed.
17. Mrs. Begum said that Amara was a Muslim, and that this was against her religion. I drew attention to the recent fatwa issued by the Muslim Law Council UK, which states:

“If anyone saves a life, it is at if he saves the lives of all humankind.”

I told her that it the Council are happy for the donation of organs to proceed after the heart had stopped.

1. Mrs. Begum was still reluctant. Sometimes when families are hesitant it is useful to informed them of personal stories of children who have, or would benefit from donation. As such, I told her that Rebecca, a 14-year-old patient at the same hospital as Amara. Rebecca is on the waiting list for an experimental spinal transplant. She has been completely paralysed since she was 11 after an accident at school. She suffers with pain everyday and requires assistance breathing. Rebecca has type AB negative blood, which makes matching for organs extremely rare. Doctors at Cardiff Hospital have designed an experimental transplantation procedure to replace part of Rebecca’s spine, which could be done with Amara’s spine. Rebecca has been given 4 months to live if she does not have a transplant and Amara is a perfect match for this experimental procedure.
2. Mrs. Begum became angry at this information and said that I was trying to emotionally blackmail her. Due to this accusation, I ended the conversation. I gave Mrs Begum a few more days to come around to the idea of donation. More time usually helps families come to term with the death of loved ones. However, yesterday afternoon, I received notice of this emergency application.
3. I believe that the facts stated in this witness statement are true.

Signed: Dr Amir Khan Dated: 8th June 2023