

Judith Woods

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@judithwoods

Sometimes even a mother's love can't conquer all



If there is such an obscene thing as a hierarchy of grief, losing a child stands at the very pinnacle.

There can be no worse bereavement than to be robbed of the baby - whatever the age - you love most in all the world.

Nobody can say Charlie Gard's parents have been lacking in love. There was love as Connie Yates and Chris Gard cradled their precious newborn in August last year.

Then, when their infant son was found to be suffering from a life-limiting genetic disease, they met that terrible diagnosis, too, with love.

And love was their only defence against fear and despair and helplessness when, aged eight weeks, he was admitted to Great Ormond Street Hospital.

But love can be blind. Love can blur judgment. Love can put paid to all reason.

In this case, it was love that set Charlie's parents on a terrible and ultimately fruitless collision course with the medical experts who treated him.

The nurses and doctors may have cared for him day and night, but they did not love him, so how could they possibly know what was best for Charlie?

Love in all its fierce, weepy, stubborn permutations is the very reason why the General Medical Council advises doctors to avoid treating their kith or kin; emotional involvement can lead to a lack of

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objectivity in clinical decision-making.

Yet no clinician worth his or her salt would dismiss the role of a mother's instinct. Last year, an investigation by NHS Improvement led to the recommendation that medical staff should listen to parents who report that their child is deteriorating, even if tests show no cause for alarm. Why? Because we parents are hard-wired to nurture our children, to tune into their moods, their needs. It was a realisation that something was wrong with Charlie that led his parents to seek medical help in the first place.

They were devastated when they were told by Great Ormond Street that nothing could be done. But they refused to stand by and do nothing. Was that so wrong of them?

They pored over medical data online, researched cutting-edge



Love is blind: Connie Yates and Chris Gard with their beloved Charlie

treatments and focused on the future, rather than the present.

When a doctor in the US agreed that Charlie would be a candidate for his "pioneering" treatment, they pinned all their hopes on that.

But doctors at Great Ormond Street Hospital felt that Charlie would not benefit, and instead suggested that the kindest thing would be to take him off his life-support system.

Connie and Chris refused and the case went to court, as is established procedure in cases where agreement cannot be reached. And with that, an extraordinary train of events was set in motion.

A social media campaign to raise money for Charlie's treatment gained traction, and tens of thousands of pounds poured in. Lawyers agreed to represent his parents for free as they took their case to the highest courts in the land.

In their own minds, they were fighting for Charlie - a rallying cry that led to T-shirts and hashtags and demonstrations with placards.

But fighting for Charlie meant doing battle with Great Ormond Street Hospital, where intensive care specialists saw a baby unable to breathe or move, deaf and blind.

In a statement, the hospital said that if Charlie were conscious of anything, his only sensation would be one of pain. Yet his parents believed they knew best - by simple virtue of being his parents - and repeated their conviction over and over.

Perhaps they were mindful of the parents who bitterly regret not making themselves heard. Or believed.

In 2012, Joanne Hughes set up a support and campaigning group called Mothers' Instinct, after a delay in diagnosis that she believes led to the death of her daughter Jasmine, aged 20 months, from a neurological disorder.

Every few months, another poignant name is added to the dreadful litany of children who have died while their parents battled to make doctors understand the gravity of their son or daughter's condition.

But Charlie wasn't in the grip of a virus or an infection. He was breathing through a tube, needed round-the-clock-care and his health was deteriorating with every day that passed.

When the US doctor turned out to have peddled them false hope - he had never met Charlie, nor even looked at his medical notes before making his cavalier offer - Connie and Chris abandoned their campaign to keep their son alive.

But they would not - could not - give up the fight. Instead, they argued over the place and manner of Charlie's death, their courtroom pleas reducing listeners to tears.

They wanted time with Charlie, they said. They were fighting now for their right to be with their son to make fresh memories. They loved him. Wasn't that reason enough?

All parents love their children. But that doesn't give them the sole right to dictate the terms of their life or their death.

Is it moral to keep a very sick baby alive for his parents' sake? Especially when the hospital felt, as long ago as March, that it was in Charlie's best interests to let him slip away from his potentially pain-filled existence?

I don't think it is. Love is powerful. Love is primal.

But sometimes even a mother's love can't conquer all.
