

'Doctors told us our daughter had to die, that no hospital would treat her. Two years on, she's still here'

By Olga Craig

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Jeremy Howat's recollection of the prognosis was both blunt and bleak. Doctors told him that his baby would die. They thought it was wrong to continue to resuscitate her if she stopped breathing. They wanted a court order that would allow her to die should it happen again.

Mr Howat and his wife Dionne were devastated. They knew they could face a bitter legal battle to save the life of Cariad, their six-month-old, who suffered spinal muscular atrophy (SMA). Seriously ill with a lung infection, she had already stopped breathing twice. Determined their baby should be given every chance to live, the couple hired a lawyer, were offered £40,000 in Legal Aid and prepared to fight for their child's right to survive.

"Shocked, desperate, angry... we felt all those emotions," said Mr Howat, 35. "Our baby was a fighter, she wasn't giving up. How could we not want her to have every chance?"

It was a scenario chillingly reminiscent of last week's High Court case in which another SMA baby, MB (he cannot be named for legal reasons), was granted the right to life when Mr Justice Holman ruled that he should be kept on life support against the wishes of his doctors.

The emotive ruling, which made headline news and fuelled heated debate on the right to life, was a triumph for 17-month-old baby MB's parents. But it was a decision that also struck a chord with the Howats. They faced a similar situation two years ago. It was only a referral from their local hospital in Southampton to the Royal Brompton Hospital in London, where doctors took a different view, that prevented the court action.

Today, Cariad is two-and-a-half and although she has little movement other than in her shoulders, arms and head, she is a cheerful child who has defied medical opinion simply by still being here.

Last week's case, however, was a shocking reminder for the Howats of just how easily they could have lost their only child. "It is frightening to think that we could have been deprived of Cariad, and she of our love for her for the past two years, if we had ended up in court and we had lost," said Mr Howat.

"In all, we had about 15 meetings with doctors in which they tried to persuade us that Cariad had no quality of life and should not be kept alive. Each time we said 'No'." As she stroked her daughter's face, Mrs Howat shuddered and said: "I don't think I will ever forget being told that no other hospital in the UK would agree with us. . . that the hospital had sought the opinions of 10 other hospitals and all thought Cariad should not be kept alive."

No one denies that Cariad is a seriously ill little girl whose lifespan will be short. Like baby MB, she suffers the Type One form of SMA, an inherited condition caused by a defective gene carried by one person in 40 which damages nerves in the spinal cord, breaking the link between the brain and the muscles. Lack of use causes the muscles to atrophy and the condition affects the muscles used to crawl and swallow. Type One affects one child in 25,000 and 80 per cent of babies diagnosed with it die before their first birthday.

Cariad was diagnosed at around four months and, within two months, her parents were preparing to fight what seemed like an inevitable court battle. It was only when they contacted the Jennifer Trust, a charity for SMA families, that they were offered a

referral to the Royal Brompton. "They were absolutely wonderful," Mr Howat said. "From the moment Cariad arrived she was treated as a child, not an illness."

Cariad was given a BiPAP (bilevel positive airway pressure) mask, which pumps a higher volume of air into her lungs when she inhales and inflates them. Within two weeks she was deemed well enough to go home and has not been readmitted for the past year.

Her daily routine, however, is demanding for her parents. Mr Howat, a salesman, works partly at home and so can help with her care, and his wife teaches only one day a week so that she, too, can spend as much time as possible with Cariad. Every night, she must be connected to her BiPAP and during the day her airways need to be cleared constantly.

Although Cariad's speech is indistinct, she can communicate with her parents. She adores DVDs and music and can lift pieces of Lego. Her movement in her lower body, however, is extremely limited and she cannot sit up unaided. As she smiled up at her father last week, Mr Howat cradled his daughter's head and said: "I asked the doctor to be straight. I asked how long did she have and he said she wouldn't reach two. Yet each of these children is individual."

The couple are aware they have a one in four chance of having another SMA baby, and have been offered genetic counselling. "We don't think too much about Cariad's future, we just enjoy the now," they say. Both said they doubt they could cope emotionally and physically with another SMA child, but, as Christians, would never condone aborting a baby with the condition. Last week they prayed that Mr Justice Holman would reach the right verdict: both wept when he did.

"We haven't met MB's family but they are in our thoughts. If we did talk to them we know exactly what our message would be - 'keep going because it is worth it. Be positive, don't listen to the negative. Have hope and take joy in the love of your son and his love for you'."