



LET MY BABY LIVE

Everyone understood Debbie Wyatt's feelings.
But not everyone accepted her argument

Once they would have been called miracle workers. They separate conjoined twins, transplant hearts and cure the incurable. Only gods used to have those kind of powers. Yet now you can find them inside your local hospital.

Every day doctors perform medical wonders at which we marvel. But are there times when they should stop? That's the question people are now daring to ask.

For instance, we're not surprised that specialists can now keep very premature babies alive — they have a high degree of technical skill. But should they always use it? And what if the doctors and parents disagree?

Charlotte Wyatt was born three months premature. She weighed

one pound and was five inches long. She was deaf and blind and

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Take a Break, June 2004

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WOULD YOU HAVE DONE JUDGES?

her kidneys, lungs, heart and brain were damaged.

Naturally her parents Debbie and Darren loved their baby girl and her fighting spirit. Three times she stopped breathing and was resuscitated. Then the doctors said that was enough.

But the parents disagreed and the case went to the High Court in London.

Darren Wyatt told the judge: 'When you grow to love someone, you can't just throw them away like a bad egg.'

But a doctor testified that Charlotte had no quality of life.

He said: 'She is permanently sedated, living in a plastic box with a tube up her nose and blasted with gas. Intermittently she is stabbed

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We face a new dilemma

with needles.'

The judge Mr Justice Hedley backed the doctors, saying: 'I do not believe any further aggressive treatment, even if necessary to prolong life, is in her best interests.'

As *Take a Break* went to press, Charlotte was still fighting for life and her parents were insisting that she had started to see and hear. If the doctors did not reconsider, Debbie and Darren planned to appeal against the judge's decision.

The case of Charlotte showed that medical advances may have saved countless lives but they have also created a new dilemma.

We can keep very premature babies alive. But should we?

In the Netherlands, the Dutch Paediatric Association's policy is that, in principle, no treatment should be offered to a baby born at or before 23-24 weeks, since the chances of survival are so small.

And what kind of a life would a baby have if it did beat the odds?

The largest study of its kind, known as EPICure, set out to answer that question. The results showed that of the 4004 babies born between 20 and 25 weeks in Britain in 1995:

**1200 were born alive
811 received intensive care
314 went home**

Researchers tested the surviving children at the ages of two-and-a-half and six years. They found that four out of 10 had 'moderate to severe' problems, including cerebral palsy, blindness, deafness and arrested development.

Kate Costeloe, professor of paediatrics at Queen Mary's Hospital, Sidcup, Greater London, said: 'I would hope people would understand that being born early is a very, very serious business, that survival is not high, and that should the children survive, their likelihood of having lifelong problems — particularly in respect of learning — is high.'

But there is another side to the debate. There are exceptions, such as Layla-Jane. Her mother Tina gave

birth to her at 23 weeks and five days. She is now nine years old, has an IQ of 104 and has no physical or learning disabilities.

It can be very hard for doctors to predict which babies will live but have disabilities, which ones will die, and which ones will — like Layla-Jane — develop normally.

If, as the EPICure study shows, almost half of very premature babies have disabilities, that still leaves more than half who do not. And a baby with a disability is still someone's daughter or son.

In June 2004 *Take a Break* told the story of Carol Glass. Her son David cannot walk, talk or see. He suffers from spastic quadriplegia and epilepsy and has severe learning difficulties.

When David was 12 he went into hospital with a serious respiratory infection. Doctors decided he should be allowed to die and gave him the drug diamorphine.

Carol pulled the drug tube out of David's body and took him home. He is now 17.

'Yes, David does have a different quality of life, but so does everyone,' she told the press. 'As a disabled person, he is not a second-class citizen. He has rights of his own.'

The eminent doctors, lawyers and academics who make up the independent Nuffield Council on Bioethics will shortly begin to investigate the dilemmas faced by those involved in the care of very premature babies.

Who should live? And who should die?

Must medical advances mean that there will be more disabled people, not fewer?

If there are more, how much money do people wish to devote to them, at the expense of other medical and social demands?

Are we saving some babies only for a lifetime of pain, suffering and neglect when they grow older? How much do we accommodate parental wishes?

These are extremely hard questions with no easy answers.



Mr Justice Hedley



There are no easy answers