Beating the odds: how families deal with an uncertain prognosis

Parents whose premature babies have serious health complications often want detailed information about the future – but it is not always possible to predict long-term outcomes with any certainty. Here two parents of disabled children who began life on a neonatal unit, and who were supported by *Contact a Family,* share their experiences of dealing with unknown outcomes for their children.

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Key points

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1. Parents of babies with serious health problems need information and honest answers.
2. If the prognosis is poor it is important not to destroy all hope as it is often not possible to predict long-term outcomes with any certainty.
3. Continuity of care helps parents to build a rapport with staff caring for their child.
4. The best support is from other parents who have experienced a similar situation.

There is great uncertainty and anxiety for all parents whose babies are born prematurely. For some families whose premature babies have serious and complicated health conditions, the uncertainty and anxiety are twofold because they are told their child's life might be limited or that they will never walk or talk.

However, due to advances in neonatal care many babies are surviving longer with complex health conditions and some make extraordinary progress from a very bleak prognosis. Families who are told by doctors that their baby might not see their first birthday, go on to enjoy several birthday parties together, as well as see their child go to nursery and then school.

Contact a Family, a UK charity supporting families of disabled children regardless of the disability or health condition, reports that a family's first experience of the healthcare system – good or bad – has a huge impact on them and their child's future.

Families report that the surrounding environment and the care and expertise of staff on neonatal units at the beginning of their journey, is crucial in helping them overcome feelings of fear, inadequacy and uncertainty for the future.

Two families of disabled children who began life on a neonatal unit describe how they coped with a devastating prognosis, how their time in neonatal care helped them overcome their anxieties and how their children have beaten the odds and continue to amaze their parents.

Nicholas*

Nicholas was born at 23 weeks, weighing just 493 grams and spent six months on the neonatal unit.

"Nicholas's prognosis wasn't good, but he has proved doctors wrong so far. We were given percentages of survival and development. I have always been keen to be told the truth, as I want to know what we're dealing with. But it's a bit of an awkward area. Nicholas has just turned three, which is a miracle in itself and he had his first day at school last September, which we never thought possible.

"We recently had a meeting with Nicholas's paediatrician, who says that he is progressing well since going to school so we are on a bit of a high.

"Nicholas has chronic lung disease, suspected cerebral palsy and severe global development delay. He is deaf in both ears, has severely impaired physical mobility and is still on oxygen at night.

"On the plus side, Nicholas's sight is fabulous and he laughs all the time. I've never known such a happy baby and little boy. Considering everything he is so wonderful.

"I wouldn't change anything now, I love my wonderful little boy. But I sometimes feel with hindsight that if I knew everything that he would be put through I might have thought differently, that's just my real honest opinion.

"When I was 23 weeks' pregnant, I started haemorrhaging and was rushed to hospital in an ambulance. I was in labour and everything was a bit of a blur, but I do remember lots of professionals coming into the hospital room, telling me a number of different scenarios that could happen. It's difficult enough to make crucial decisions when you're in the best of health, but when you are in horrendous pain and completely drugged up it was almost impossible. My husband and I

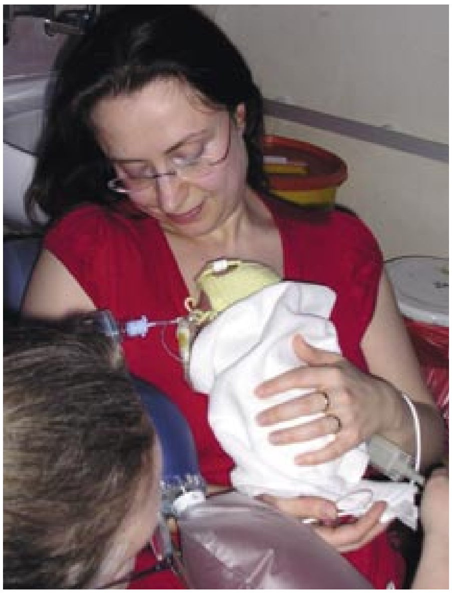

FIGURE 1 Mum holding Nicholas in the neonatal unit.

FIGURE 2 Big kisses from mum to happy Nicholas.

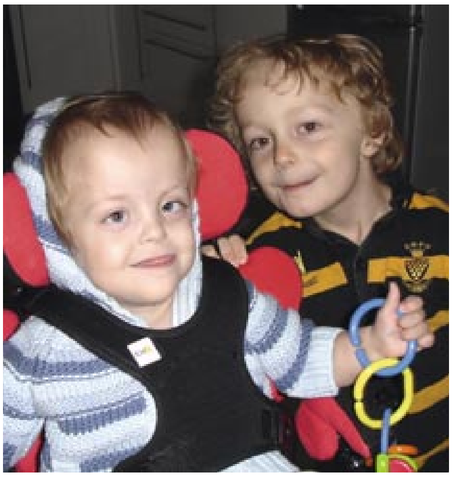

FIGURE 3 Brotherly love, Nicholas with his older brother, aged five.

managed to come to the decision that if the baby was born and his heart didn't stop and he was breathing and it wasn't cruel to keep him alive, then that's what we wanted the doctors to do.

"Miraculously he came out in good shape. I was shown a photograph of Nicholas before being taken to see him the next day. It was a very sensitive way of preparing me for how small and fragile he was. However I couldn't help myself and when I first caught sight of him in the flesh I started wailing like a banshee. It was overwhelming.

"From the very outset of our time on the neonatal unit I was treated with so much dignity and respect and that helped make a very difficult situation easier. Everyone was so understanding. After that first time, I made daily visits to the ward and the nurses were so respectful and acutely aware that they were touching my child when I couldn't, and all the emotion that brings.

"The nurses encouraged me to express milk and I did so for five and a half months. I was keen to give Nicholas something natural. Here he was in an artificial environment, being pumped full of chemicals and I wanted to provide the most natural thing in the world. It helped me because I felt like I was contributing to his care and nurturing him. This was so important particularly in the early days, when I sometimes didn't feel like a mum because I hadn't had the normal bonding experiences with Nicholas.

"It really helped that there was continuation of care on the neonatal ward. Doctors and nurses were fully involved with Nicholas and most of the time we saw the same professionals, rather than new faces everyday just passing through. They kept me informed and explained procedures and treatments. I could speak to a consultant at any time so this helped to reduce some of the anxiety. The nurses were incredible, they really showed great attention to detail in caring for him – things like checking that his positioning was comfortable – that was so important to us.

"Nicholas was ventilated on and off for four months. He had 22 blood transfusions, his blood gases needed to be regularly checked, he was screened for a myriad of things. He was constantly X-rayed and was given antibiotics and supplements.

"The day before Nicholas was due home we were taught how to use the oxygen equipment. We had to learn so much – how to calibrate the oxygen equipment, how to use the Sats machine and how to put milk down Nicholas's NG tube and check it was in the right place. Even though they showed and explained everything clearly to me, I was so frightened to the point of nausea. I actually had a panic attack just before Nicholas was sent home. With hindsight it would have been better if staff on the neonatal ward had shown us how to operate the equipment a couple of weeks before Nicholas was due home and given me a leaflet to read at home, so I had time to take in all the information.

"However the continuation of care from the neonatal ward was amazing and really helped us get over the anxieties we were feeling. A nurse from the neonatal ward did a stint in the community and visited us once a week for a whole year. I got on really well with her and the visits boosted our confidence and helped us to feel settled at home.

"Nicholas has complex needs but is a little wonder. He surprises and amazes us every day."

Abigail*

Abigail's mum had pre-eclampsia and was admitted to hospital at 25 weeks, where she stayed until she gave birth to her little girl at 34 weeks.

Her dad explains: "Abigail was born with congenital laryngeal atresia, severe airway malacia, recurrent right lower lobe collapse, congenital absence of abdominal muscles, exomphalos, requirement for long-term ventilation by tracheotomy and urinary tract infections, due to having one kidney working at 16% and one working at 84%.

"We were told Abigail would only live six to 12 months. She was so fragile when she was born because she had no airways. Doctors said that because of the damage that the ventilator would do to her, Abigail's life would be severely limited. It was devastating news and we were determined to stay by her side and provide all the love and care she deserved.

"Abigail is now six-years-old and enjoying school. She has overcome so many challenges and is a real survivor. We never dreamt that Abigail would make such miraculous improvements, because the prognosis was so bad. We were told that she'd never walk, but she's a bright young girl, who loves playing in the playground with her friends. She has no speech, but uses sign language and a computer to communicate. She's on a mobile ventilator and uses a wheelchair

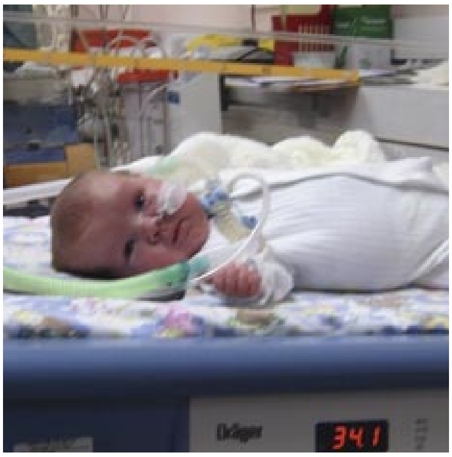

FIGURE 4 Little survivor, Abigail in the neonatal unit.

for long distances. She has made extraordinary progress.

"During the 12-week scan doctors told us that they couldn't see any organs. We asked for a second opinion and were sent to another hospital because they had more advanced equipment. We were then told that the baby had all her organs but there were some problems with compression of her airways. They couldn't give us a clear indication of how these problems would affect the baby, but my wife and I were determined to go ahead with the pregnancy.

"Abigail was born by EXIT procedure, a complex caesarean section, and had a tracheotomy fitted while still attached to the placenta. She spent the first four weeks of her life on the neonatal unit and the first two weeks in an incubator.

"Due to the major operation my wife had been through she was really poorly for a few days and it was difficult for us to deal with anything in Abigail's care. We weren't married at the time and my wife was the only one allowed to give permission for any procedures or treatments to be carried out. There was the added complication that the staff didn't know what they were dealing with because they had never seen a case like Abigail before.

"We couldn't hold Abigail for the first couple of weeks we could only hold her hand, due to all the equipment being used. After two weeks she was moved into a heated cot and then we were able to hold her for short periods. The staff on the neonatal unit were very helpful and explained everything that was happening. We were able to talk to the doctors every day and that was reassuring. Abigail had to be tube fed and was started on a special mix made in the unit then was moved onto normal baby milk when she started to take good amounts and gain weight.

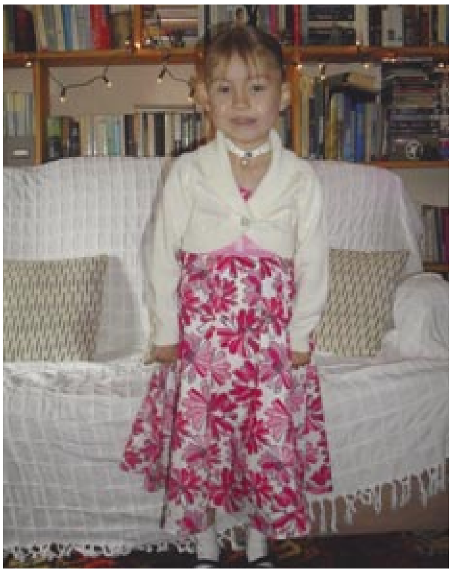

FIGURE 5 Against the odds – Abigail in pink, aged six.

"Abigail is such a rare case that doctors and nurses had never seen anything like it before. Abigail has a type of Prune Belly syndrome characterised by poor development of the abdominal muscles and urinary tract problems. In 97% of cases it is boys who are affected by the condition and incredibly rare for girls to have it. The staff on the neonatal unit were learning and we were learning too.

"Soon after she was born, Abigail's doctor was contacting doctors all over the world to try to find out more. Still to this day we have been told that there is no one like her. Even the specialists at Great Ormond Street Hospital who treat some of the rarest cases from across the world, have never seen anyone with all of Abigail's complications.

"Abigail spent a total of 19 months in hospital. After four weeks in neonatal care, she was transferred to the paediatric intensive care unit. When she was three months old doctors discovered that Abigail had an open heart duct. They performed an operation to close the duct and after that her breathing improved. It was as if Abigail had turned a corner.

"Every couple of weeks they tried to wean her off the ventilator and she responded well. Eventually doctors got her on to continuous positive airway pressure ventilation (CPAP), so she was finally doing some of the breathing for herself. When Abigail was eight or nine months, doctors said that cartilage was forming to make airways, it was a miracle."

Supporting parents

Although parents may want detailed information about the future, it is often not possible to predict long-term outcomes with any certainty. Even though a prognosis may be poor, it's important that all hope is not destroyed. Parents will want reassurance that support and assistance is available whatever happens. That's why the charity *Contact a Family* puts families with disabled children in touch with others whose child has the same or similar condition, so that they can share experiences and get a clearer idea of what the future holds.

Srabani Sen, Chief Executive of *Contact a Family,* said: "Families with children who have a health condition or disability tell us that they feel isolated and alone because they don't know anyone else facing the same difficulties and issues. They tell us that the best advice and support is from other parents who have gone through the same experience."

"*Contact a Family* brings families together across the UK at our many family events and parent workshops, so that they can get support from others caring for a disabled child. We link parents whose children have the same disability – either by putting them in touch with an already established support group or if there isn't one, we link individual parents willing to share experiences and offer support."

Abigail's mum added: "Through the portage service (a home-visiting educational service for pre-school children with additional support needs) we've met a family who live just round the corner from us. Their son is extremely disabled and his life expectancy is very uncertain. It's been great to spend time with them and we get a lot of support from each other. It's hard to talk with people who haven't been through this kind of thing because they can never fully understand. Talking to someone who is in a similar situation makes us feel less isolated and more normal."

*Names have been changed in this article to protect the identity of the children concerned.

Resource for healthcare professionals

Contact a Family – A support pack for health professionals. Working with families affected by a disability or health condition from pregnancy to pre-school.

For further information visit www.cafamily.org.uk or telephone 0808 808 3555.