



# Parley

Parents And Relatives  
Listening and Empathising  
with You

## Marie's Story

My son Neil was born at 31 weeks, weighing 3 and a half pounds, and seemed quite healthy but within 24 hours everything dramatically changed.

He went into respiratory failure and his lungs collapsed. It took quite a while to get him stable and he was very poorly and not expected to live.

The next day he had a bleed on his brain but wasn't too bad, however his condition worsened and at 5 days old he was touch and go and in serious trouble, his organs were closing down but his heart was strong and he wasn't giving up.

He was transferred to Edinburgh to a more specialist unit and spent 5 weeks there, a number of times he suffered setbacks including dreadful infections, and more respiratory failure but after 5 weeks there was a light at the end of the tunnel and he came off the ventilator and improved a little.

We eventually took him home after 9 weeks but things were not right and we realised that he would suffer some long term effects.

At 6 months old he was diagnosed as having a moderate to severe hearing loss and was fitted with two hearing aids. At this point we realised that his development wasn't where it should be and he was closely monitored. After about 2 years we were told that he probably had global development delay and mild cerebral palsy. This became more apparent as he grew older.

But he is now a happy 11yr old with Global Development Delay of about 2 yrs, has problems with coordination, mild CP, wears glasses, and has learning difficulties but doing well in mainstream primary with lots of support. It is just me and him now as this probably was the cause of our marriage breakup but Neil and I are doing fine.

We have had help from outside agencies, especially the National Deaf Children's Society (which I now work for as a Family Officer helping other parents with deaf kids) and the Family Fund.

