the muir maxwell trust

HELPING UNCOVER EPILEPSY

Oliver's story

5-year-old Oliver Joy was born with cerebral palsy, the result of a hypoxic brain injury suffered during pregnancy. "They couldn't tell us the extent of his disabilities when he was born other than that he would be severely disabled," says Oliver's mum, Francesca. "One doctor said that anybody who didn't know him would think he has no quality of life."

To add to the trauma of those first few days, Oliver also suffered several seizures, which isn't uncommon with hypoxic brain injury, but these were particularly frequent and hard to control. Three weeks later the seizures stopped and Oliver was discharged. For a year though he remained extremely irritable, crying all day and all night except for maybe ten minutes' sleep. "It was like colic," says Francesca, "but colic that lasted a year."

Oliver's next major milestone was at 18 months. On the very day that Francesca had been called for a part-time job interview, to put some "normality" back in her life, Oliver suffered a particularly bad seizure that lasted for a full hour. Distressing though this was, Oliver didn't have any more seizures for six months. "We were all convinced that was it – he wasn't going to have any more," says Francesca. But that was only wishful thinking.

From the age of two, Oliver started having seizures much more frequently – around three times a week. And nothing was stopping them. At least not until Ann Maxwell suggested a different kind of medication, one that hospitals said Francesca couldn't be administered at home but everyone else Ann knew had it at home on prescription from their consultant. Taking a leaf out of Ann's book, Francesca pushed and pushed until doctors agreed she could have it at home. "It's the only thing that ever stopped his seizures."

When Francesca first contacted the Muir Maxwell Trust, she was at a particularly low point. Not only was she just coming to terms with Oliver's epilepsy but she was watching over him every night, petrified that if he had a seizure and was sick, Oliver might choke in his sleep. She remembers leaving a message on the Trust's answer machine, Ann calling her back late in the evening and the long conversation that followed. Within a week Oliver had an epilepsy alarm and things weren't looking quite so bleak.

Next, the Health Authority advised Francesca that Oliver needed a specialist bed with pressure-relieving mattress. “Oliver’s cerebral palsy means he can’t turn from side to side,” explains Francesca “and despite the feeding problems, he’s quite a big child for his age.” Having approached other charities unsuccessfully, Francesca once again contacted the MMT. Within a month of the Board approving the funding, Oliver had his new bed. “It has just been amazing,” says Francesca. “Oliver can sleep in it comfortably. It has got guards on the side and it looks like a child’s sleigh bed rather than a hospital bed.”

In what’s proving to be a constant uphill struggle, not only with Oliver’s condition but the Health, Education and Social Services agencies that are supposed to help, Francesca is finding Ann Maxwell and the Muir Maxwell Trust a constant source of support.