



# Parley

Parents And Relatives  
Listening and Empathising  
with You

## Christina's Story

### Worcester Drought Syndrome.

I gave birth to my 3rd child, a son on 28th July 2009, weighing 7lb 15oz, by c-section due to polyhydramnios (excess amniotic fluid).

I begged my consultant to scan my baby to check him but was told I was getting in a state over nothing. Any way he was born a flat baby, and ended up in the intensive care baby unit. There it was discovered that he had no suck or swallow reflex, he required almost constant suctioning and was NG fed but was refluxing almost everything so was drip fed. After 12 days in our local NICU he was transferred to a children's hospital 60 miles away. He was seen by nearly every department and finally his neurologist came up with Worcester Drought Syndrome (a cerebral palsy mainly affecting the bulbar muscles). Having lost so much weight it was decided he needed a fundoplication and gastrostomy asap.

He had these done when he was 4 weeks old weighing 5lb 4oz. After a week we were transferred back to our local hospital where he spent another 10 days, finally coming home at 7 1/2 weeks old.

He has weekly physio and SALT appts, and has numerous appts with other depts. He is a lot of hard work and it has been tough on my older 2 children having mummy away for so much of last year, and everything revolving around their brother.

He is still not sitting or rolling and only weighs 11lb now, we are waiting for a date to have his fundoplication re-done and hopefully he will then put on weight.

He will need ongoing input from physio and SALT for the foreseeable future, and is highly likely to have other health issues as he grows up, we are hoping his condition is not progressive and are trying to enjoy him for who he is. It is however very hard work and we do feel quite isolated which is why we are trying to connect with other parents who know what we are going through.