



A LIFE CUT SHORT

By Shannon Clough

OUR FIRST SON **ETHAN** WAS BORN ON EASTER SUNDAY 2005. MY HUSBAND AND I WERE DRIVING UP TO THE CENTRAL COAST ON HOLIDAY.

Just before we turned onto the highway, I felt that something wasn't right. I'd only been pregnant for 26 weeks, I didn't expect to be going into labour.

Even though the signs were there, Ethan wasn't diagnosed with cerebral palsy until he was 14 months old. We started therapy, but had no idea what we could hope for.

Nobody did.

As Ethan grew up, we saw the difficulties increase. He couldn't hold his head up, he couldn't eat, he couldn't walk, he couldn't breathe properly, he couldn't hear and he couldn't speak.

If I had one wish, it would have been for Ethan to be able to hold his head up by himself, because just having that little bit more control over his own body would have changed his life completely.

Ethan required oxygen 24 hours a day. He needed a special moulded bed to hold him in place because he would spasm. He needed a sleep system so he wouldn't roll

around the bed. He needed change tables because he was in nappies his whole life and he needed a special walker just to stand up. To eat, he needed a special insert and special chair to sit in. He needed special spoons, special straws – everything.

Every part of his life he 'needed' – there wasn't anything that he could do on his own, except smile.

He was a smart boy; we knew that the first time he encountered eye-gaze technology. He was the youngest person in Australia to test it and started using it immediately. He looked so happy. It was going to change his life. His system arrived on a Wednesday. He passed away in his sleep two days before.



"Ethan's tragic loss has made me even more determined to support the research that we know holds the key to vastly improving - even saving - the lives of children like him."

NAME:
ETHAN

AGE:
PASSED AWAY
6 YEARS

PREMATURE:
BORN 26 WEEKS

PASSION:
SMILING

HEARING:
PROFOUNDLY
DEAF

CP SEVERITY:
GMFCS 5

LIFETIME EQUIPMENT COST:
\$250,000 UNABLE
TO MOVE
INDEPENDENTLY

COMMUNICATION:
NON VERBAL. The youngest Australian
to trial eye-gaze technology