

This morning in the kitchen, Tamsin and I had a conversation about Grandad Dog. It's probably not that unusual for parents of preschoolers.

Grandad Dog is in the ensemble background of Peppa Pig, but he has his moments, including a slanging match with his best friend, Grandpa Pig ("You Old Warthog!") and owning the car wash that Daddy Pig fixes by turning it off and on. ("Hooray!")

I was relaying a conversation with our son. "I just asked Jack what Grandad Dog does, and he said, 'Fix ... car'." Tam also has a Jack update. "I think he said a proper sentence before: 'I ... want ... Peppa ... Pig'."

If it's true, it's a speech breakthrough: over six months Jack has progressed from "Peeg" to "Peppa ... Peeg" to "I ... want ... Peppa ... Pig". Jack is two years old, three in May, and has cerebral palsy, an umbrella term covering physical impairment caused by damage to the developing brain during pregnancy, or just after birth.

We found out on Tam's birthday in 2011, a devastating "can you come in please" call on the eve of Jack's discharge from the Mercy Special Care nursery.

"We'll have to wait and see" became the medical mantra of our lives. Jack's brain scan was terrible, black spots fanning out like a peacock's tail, each one representing precious cells that had received too little oxygen for too long.

But some children with terrible scans can be relatively unaffected. We had our grain of hope, and we clung to it. Maybe it would just be a little limp? Maybe confined to one limb? At three months the doctor was impressed that his legs were not scissoring. "It's a good sign, but it's too early," he said. "We'll have to wait and see."

Nothing was more important than the signs. An ophthalmologist told us Jack's optic nerve was sound, and that she was confident he would have normal vision.

Tam and I cried with relief. Within months, it emerged that Jack's irises rolled as he tried to focus, and we now know he has cortical vision impairment, a condition that causes "visual confusion" and prevents him seeing more than a couple of metres.

We learnt the hard way why there is so much diagnostic prevarication. Everyone is terrified of false hope.

We now know Jack has muscle spasticity in all four limbs and weakness in his torso and neck. Every movement has to be broken down and learnt in its component parts. He can sit for short periods, but crawling and walking are a long way off. We did not get our medical miracle, but our sudden immersion in the cerebral palsy community taught us it could be worse.

We met one boy who is never out of pain. His brain cannot produce the analgesia needed to numb the sensation of blood pumping around the body. I never knew that condition existed. Sometimes this world is so lousy.

Last week I took a video of my boy, my beautiful boy, dragging himself three metres on his stomach to reach his precious "Tin". Tin is a cake tin, and Jack mouths and drums it for as

long as we let him. The occupational therapists don't like Tin, because his obsession comes as a result of sensory needs not being met. But they don't have to listen to, "Tin! Tin! Big ... Tin!" being screeched in hysterical two-year-old staccato. Tam and I secretly love these tantrums, just as we love every sign of age-appropriate development.

Jack completed his elbow-drawn "creep" for the camera. At the one-metre mark, he bent his knees and lifted his bottom, causing arms to splay and face to plunge to the carpet.

"Flat hands," I shouted. "Push up with your hands!" He could not quite manage it, succumbing to the spasticity, legs stiffening behind him. Nevertheless, the physios would go berserk when they saw that raised bottom. Half a push-up from crawl position. This is a game of small victories.

Jack is adored by us and reflects our love with equal force. He is often strapped into sitting or standing apparatus, and chirps: "Hi, mummy ... Hi, daddy ... Good day."

His favourite things are Tin, Bounce [trampoline], schvim [swim], Gyes [Paul Simon's *Under African Skies*] and Barf [Bath]. He laughs when people stub their toes or swear. He sells his cuddle requests by calling for a "quick ... cuddle". Nobody says 'please' more or with a cuter upward inflection – 'Pweeeayze'. It earns him a lot of ice cream.

We have had so many good signs, particularly with communication and intellectual development, but overall, his condition has been such a sad thing, such a draining thing.

I probably don't ask "why him?" quite as much as I did two years ago, but the question is still wedged somewhere, rising to choke me whenever I see kids 18 months his junior toddling across the park.

I even feel it when I see photos of our other two when they were Jack's age. And there is some "why me?" wedged there too. Why us? Why did Tam and I get sentenced to the endless medical appointments, the unrelenting, abnormal worry? Will he have friends, a job, a family of his own? Will he be able to read? Live independently?

Why did we have to be dropped into a world in which listening comprehension updates on Grandad Dog's place of work are family news? I don't wish it happened to your child, I promise, but I'd do anything for it not to have happened to ours.

Of course, ultimately, it's not about us. Tam and I feel the pain so acutely, because we possess the curse of foresight and the double-edged sword that is pure, boundless, parental love. But in the end, it's Jack's life, Jack's struggle to the Tin, and one day he is going to ask: "Why me, dad? Why did I have to have this?" And that's going to be a difficult day. Because I won't know what to say.

Read more: <http://www.smh.com.au/national/love-pain-and-the-whole-damn-thing-20140125-31fp9.html#ixzz2rqsKOBW1>