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Looking skyward 🌳

Making sense of the week where we lost so much

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My daughter has a special tree that she has always been drawn to. She walks around the giant Pine, carefully stepping over the exposed roots, running her hand along the bark, giggling like she is sharing a joke with an old friend.

She looks skyward and reaches out her hands like they are extensions of the branches. Her fingers are splayed so perfectly I think leaves might sprout out of each digit. She talks to her tree, we call him pāpā rākau. It's a strange thing, to watch a 'non-speaking' child (now a teenager) connect and communicate freely with a tree, but I have seen the calm influence pāpā rākau has on her, so I dare not question it.

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It's been a rough week, for many reasons. Monday was disbelief. Tuesday was raw emotion. Wednesday I was grieving for many lost things. On Thursday I went searching for understanding and support, the kind of support where I didn't have to explain disability budgets or feel apprehensive about being judged for daring to use respite funding to find my own version of peace.

Just before school pick up time I found myself at the base of pāpā rākau. I walked around its base and made an effort to notice all the things I have seen my daughter take notice of, in her own way. The exposed roots, the rough bark, the grooves and insets where she has rested over many years. I looked up and watched the branches sway in the breeze, I leaned back and rested against its trunk.

I was hoping for a connection, something unseen and inexplicable to make sense of this horrible week. I waited, but all I felt with my unmanicured hands was bark.



Please note my non-manicured nails

I'll never see the world from her unique perspective, I'll never experience the world like she does. That's ok. I am at peace with that. The natural world is hers to embrace, and happily, it is a reciprocal connection.

But how do I explain to her these cruel decisions from people meant to be supporting us? How do I tell my sweet girl that everything is going to be alright when I don't know this to be true myself?

I turn to my constant, my written words to hopefully weave a warm and reassuring cloak of protection around us all.

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To my daughter,

This week you have seen māmā cry many times. Big loud wails, jittery, anxious tears, silently weeping while watching the news. Aroha mai, my grief was very raw at times and as much as I tried, I couldn't hide it.

The news broke on Monday while I was in a council hui, we were actually talking about an amazing accessible space being launched in the community next week. It includes a sensory footpath that you, my darling girl, inspired completely. I had talked to council staff a while ago about creating a space in nature that was both welcoming and interesting - and I'm so excited for you to see it. So, we were all talking excitedly about this new space, when my phone started bleeping. Once, twice, three times it flashed up with friends asking the same question.

“Have you heard?”

The news was swirling on social media that Whaikaha, Ministry of Disabled People had made changes to the purchasing guidelines for Individualised funding, Enabling Good Lives and Carer Support users, effective immediately.

The flexible guidelines introduced during lockdown, which acknowledged how hard it was for us find a carer, and addressed concerns about health and safety of outside people entering the house of disabled people, sometimes with high health needs. We were able to purchase items that allowed your independence and freedom within the home and the community - like sensory toys, travel and my accommodation for respite. This is all gone now, like my trust for people in power.

I know those last two paragraphs won't mean much to you, but in real life terms, it means that you won't be able to do some of the cool things you were able to do up till now. We won't be able to buy the sensory toys, or pay for the subscriptions for services you have enjoyed using independently, and I've been so proud to watch you master. I won't be able to have a night away when I am tired, and come back the happy, rested mum you deserve.

People have made decisions that impact us both, without thinking it through. They have acted in a way that shows little regard for our mental and physical wellbeing, and thats scary for me.

There have been so many tears - for us, our whānau, for our friends, for other families we don't even know. For disabled people. For the brave parents sharing their stories with journalists, or on social media. For my friends and acquaintances who work at Whaikaha.

From the moment I wake up to another bleep on my phone, another request for help and clarification that I can not give, to the moment I lay my head, still buzzing with thoughts, on my pillow to sleep, there are tears.

My gorgeous girl, I want you to know not one of those tears are your fault. None of them originated from a place of upset at you, or Autism.

The world around us is not made for us. It values vanilla over mint chocolate chip. Linear over undulating. Ordinary over extraordinary. Usual over unexpected. We are square pegs often being jammed through round holes. The world is often inaccessible, full of bumps and turns, and therefore not always welcoming.

I fight every day to knock down the barriers so you can experience the world and fill it with as much life and love as you wish. I work hard to make sure that people around you show you the grace and respect you deserve. Its not perfect, but its a work in progress.

Some days, like today, the world feels extra cruel. When people in positions of power deny your rights to a good life, I have to fight extra hard. But I do it willingly, because watching you grow, and flourish and experience life in your own unique way, without filter or fear, is the greatest honour of my life.

So if you see me crying, don't be fearful. For every bad day there are many good ones - now and to come.

Love, Māmā 



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