

## Embracing Equilibrium

The past 10 years have challenged me to move against my body's wishes every single day, the reason why is only just coming into focus. I've been gifted a body, birthed on a tropical island, connected with nature and cared for by incredible matriarchs. This same body that has sustained life for over 27 years, is home to a rare genetic disorder, progressing, with limited management options. From simple fatigue when brushing my hair, to daily debilitating episodes of complete muscle paralysis and pain that spreads throughout my entire body. Expending energy can leave me completely locked in for hours at a time, hearing and feeling everything but unable to move. One thing I quickly learnt, your independence can change in an instant and choosing how to spend your precious time is vital.

Meeting a friend, once as simple as stealing a moment away from study or work, jumping into my tiny white Toyota, singing along driving to a little cafe then inhaling a delicious chai latte or banana bread, has now become a massive planned operation. Reality check, it involves wheelchairs and timetables, a neck brace, my mother (plus or minus one of my cavalier puppies) and hours of a paralysed or weak body thrown in there for good measure. Simple joys, are no longer quite so simple. I'm beginning to realise that life may not unfold quite as planned. Entering adulthood in the trenches of my nursing degree and attending births every other weekend, life seemed busy, but purposeful. It was fulfilling and I was drawn to the whole experience, finding that beautiful sense of flow each day. Young Tayla was exploring her power, learning to live independently, enjoying her passion for dance and navigating her way through a long term relationship. She felt she had certain traits to offer the world and had found her place, amongst friends, family and helping others. Occasionally, I still crave that certainty.

Now, this profound shift has forced an alternate reality. The transition of being able-bodied during childhood, with the privilege and freedoms that entails, to redefining my sense of self and belonging, has been rocky. Regaining autonomy over my body, feeling safe, comfortable and at home within myself has been lengthy, enlightening and continuous. This is magnified in times of extreme physical and emotional vulnerability, when out in the community or in medical surroundings. Pacing myself, not fighting against the dysfunction but surrendering to a passing moment filled with ambiguity, is a challenge I still battle some days. A single interaction can start with me standing up and greeting you with a hug, then losing balance, drooping face, trouble breathing and 'rag doll' minutes later. This can be understandably unsettling and curious to those around me. Filling a desire to feel less alone, I've searched for others with similar experience, to share and create a community. Sometimes being rare can be confronting and isolating, however those small moments of connectivity and understanding can have even greater meaning. Hearing of other's experiences or personally connecting, has in return encouraged my vulnerability with others.

My journey has completely transformed my vision of the world we inhabit. It has challenged my relationships, my philosophical views and enhanced my ability to empathise and 'walk alongside others' with compassion. It has demanded a new creativity, as I aim to make the most of each available moment, challenging my adaptability, commitment, humility and humour. Each year I develop a word to centre my intentions, as we emerge from a turbulent 2020, my word for this year is equilibrium. Merriam-Webster defines this as 'a state of balance between opposing forces or actions'. Between my dreams and memories that evoke excitement and the pain of grieving lost expectations and desires. Between a mind and soul desiring to be involved in our world, and a vessel requiring much rest and stillness.

Each day brings us new opportunities to embrace. I have begun to cherish each joyful moment and learn from the loss and challenges. I've sort wisdom to distinguish what is within my control and strived for equanimity within those limits. I search for purposeful moments in each day, whether that be strengthening connections with family over a board game or cuddling my dogs a little tighter in bed. I lean on others and appreciate how crucial curating a supportive, loving community of empowered women can be. No one exemplifies this more than my mother, who has been my voice, eyes and thoughts in times of need. My disability does not define me, but informs my choices and creates opportunity to form a unique path, currently unknown to me, but guided by a refined consciousness, clarity and intuition. I'm just now realising what this is, a new hope.