

A Day in the Life of a Paediatric Palliative Care Specialist

The day marked the beginning of a new week at the end of a long year. Off to the local supermarket to pick-up the kai for the hākari for the whānau hui being held on the hospital marae. The infant at the centre of the hui had been in hospital for a little over two months after unexpectedly surviving a one-way extubation. Listening to the whānau kōrero on marae strengthened the planned transition home and allowed airing of outstanding distress in the company of their ancestors.

Why have the meeting on marae when weekly whānau meetings had been held on the ward? The answer was clear when the words, “We have come home”, were spoken. The change in communication dynamic reinforced this was the right place and indicated an opportunity for future working.

The case also highlighted the fraught nature of prognostication for children with life-limiting conditions especially non-cancer conditions. More often than not the time-frames are incorrect which, on reflection, has more to do with the intangible of the individual’s wairua and the strength of whānau aroha for our pēpi, tamariki and rangitahi.

Morning has given way to afternoon by the time I arrive at the office to phone the parents of a boy for symptom management follow-up. The boy has a neurometabolic condition that presented as a loss of motor skills two years earlier and has progressed relentlessly despite heroic interventions. He has been troubled by a variety of primarily neurological problems which has required interdisciplinary, integrated and collaborative care, the ethos promoted by the children’s palliative care service, to ensure timely and appropriate management by all involved.

It was pleasing to hear that his symptoms had settled with manipulation of his anti-epileptic medication and, after checking in with his father, being reassured both parent’s were coping and his older sister was benefiting from time with the teams child psychotherapist.

The final scheduled appointment for the day was a complex pain telehealth consultation. The consult runs for a little longer than anticipated but a plan reached that may allay parental concerns as to a potential cause for this young women’s pain complex before a treatment pathway can be determined.

Just as I look to respond to clinical emails, let alone get amongst the increasing paperwork, I receive a call from a paediatrician in another part of the country dealing with an extremely difficult end-of-life situation. This has required careful management across the four domains; mind (taha hinengaro), body (taha tinana), spirit (taha wairua) and family (taha whānau). The hour long phone consult supports a plan for the current situation and options for the inevitable changes. It also reinforces to me the totally inadequate funding being provided by Health NZ to care for children requiring palliative care. This despite a sector supported Ministry blueprint that has gathered dust for ten years!

One email before I head home.