

A Simple Question of Fairness for Bereaved Families

By Monica Briggs MNZM, Chief Executive, Child Cancer Foundation

Over many years at Child Cancer Foundation, I have had the privilege of walking alongside families during some of the most challenging moments of their lives. I've seen extraordinary courage, remarkable resilience, and acts of love that are difficult to put into words. I've also seen firsthand how our systems can either support families or add to the burden they are already carrying.

Few situations test those systems more than the death of a child.

In the days after a child dies, parents and carers are asked to make countless decisions no one ever imagines having to make. They choose a coffin. They select music. They decide what their child will wear one final time. They comfort siblings, answer questions from friends and whānau, and somehow find the strength to plan a farewell while still trying to comprehend what has happened.

For some families, financial pressures become yet another burden during an already overwhelming time. Carers may find themselves navigating employment obligations, leave arrangements and financial uncertainty while still processing the immediate reality of their loss.

It is during these moments that an uncomfortable inequality becomes apparent.

In New Zealand, the financial support available to a family following the death of a child can depend on how that child died. If a child dies because of an injury covered by ACC, their family may receive a funeral grant of up to \$8,236.40. If a child dies from cancer, a neurological condition, a heart defect, a genetic disorder or another serious illness, the family may instead qualify for a Work and Income Funeral Grant of up to \$2,697.43, subject to eligibility criteria.

To be clear, this is not an argument for reducing the support available through ACC. Families who receive that assistance deserve it, and the level of support recognises the real costs they face. The question is why families experiencing the same devastating loss receive such different levels of assistance depending on the cause of their child's death.

The reality is that very few carers ever prepare financially for a child's funeral. Throughout a child's illness, families focus on treatment, care and hope. They focus on making memories, attending appointments, advocating for their child and spending precious time together. Preparing for death is often the furthest thing from their minds.

When support is needed, it should protect a family's dignity and allow them to farewell their child in a way that reflects their values, culture and wishes. It should not create additional stress, uncertainty or barriers.

The death of a child is not only a profound bereavement. It can also be a traumatic event that affects every aspect of a person's wellbeing. At a time when carers may be least able to navigate complicated systems or advocate for themselves, our public services should be designed to make things easier, not harder.

The disparity in funeral support becomes even harder to justify when we consider what many families affected by serious illness have already experienced.

For some families, the journey to bereavement has involved months or years of hospital admissions, medical procedures, uncertainty and disruption. Carers may reduce their hours of work, take unpaid leave, put careers on hold and absorb significant additional costs while focusing on what matters most: caring for their child.

By the time some families reach bereavement, they are emotionally exhausted and financially depleted.

At the same time, funeral costs continue to rise. Based on indicative figures published by the Funeral Directors Association of New Zealand, funeral costs can range from around \$6,500 to more than \$20,000. Even a modest funeral can quickly exceed the maximum support available through Work and Income. The Association itself has highlighted the need for funeral assistance that more accurately reflects the costs families face and supports dignity at death.

This concern is shared more broadly across the child health sector. The Children and Young People's Health Collective has called for funeral assistance for children who die from illness to be increased so that it matches the grant available following an accidental injury. While our organisations come at this issue from different perspectives, we have reached the same conclusion: every child has equal worth, and every grieving family deserves equitable support.

For many Māori and Pacific families, the death of a child is experienced not just by parents, but collectively across whānau, hapū, aiga and community. A compassionate and culturally responsive approach must recognise the importance of these relationships and enable families to farewell their child in ways that uphold their culture, identity and dignity.

We also need to recognise that parents and carers of young children are often among those least financially prepared to absorb an unexpected funeral cost. They are frequently managing mortgages or rent, childcare costs and the day-to-day expenses of raising a family. They are planning school enrolments and family holidays, not funerals.

Ultimately, this is about more than funding. It is about fairness.

If we genuinely believe that every child has equal value, then the support available to a grieving family should not depend on whether their child died from illness or injury.

Bringing funeral assistance for children who die from illness into line with the assistance available following a covered injury would be a practical, achievable and compassionate

change. It would help ensure that families receive equitable support at one of the most difficult times in their lives. The process should also be simple, timely and compassionate, allowing families to focus on their child and their whānau rather than navigating bureaucracy.

Whatever the outcome of the election, the next Government has an opportunity to address this inequity. Aligning funeral assistance for children who die from illness with that available following accidental injury would send a clear message that fairness, compassion and dignity remain at the heart of our public services.

No family should have to wonder why the support they receive depends on the cause of their child's death. When a child dies, our response should be guided by the family's loss, not by administrative boundaries.