

Childhood Dementia in Australia: a health and care crisis with a national solution ready now

Childhood dementia was a hidden crisis: affecting 1 in every 2,900 babies born and causing a similar number of deaths as childhood cancer. Half of all children die before age 10, most don't reach adulthood.

Now, due to groundbreaking work in Australia, it's a crisis we know about. An evidence base built over the last 5 years, assisted with funding by the Australian Government, spanning lived experience, data, and expert input, revealed catastrophic inequities and gaps in health and care systems. Families struggle to manage and advocate in care systems not designed for them or their children's needs; overwhelmed health professionals are without adequate guidance; Australia is losing research opportunities and millions in inefficiencies and reactive care. Children suffer. They lose their abilities, their health, and their lives with little to no hope of getting the care, treatments or cures they need.

The Australian Government funded a 2-year project to design a solution. The result: the National Childhood Dementia Unit. Conservative economic analysis reveals that a \$12.6 million investment over 5 years would deliver \$61.5 million in quantified economic returns.

1 in every 2,900 babies is born with a condition that causes childhood dementia.

Diagnosis is delayed on average by 2 years after symptom onset.

50% of children die by age 10.

Fewer than 2% of children in Australia can join a clinical trial.

Annually: childhood dementia causes 91 deaths. Childhood cancer causes 92 deaths in children aged 0-14.

1 in 3 parents give up their careers to care full-time. Anxiety, grief, social isolation and financial strain are pervasive.



Model of Care

Sets nationally consistent standards of care for children with dementia



National Reference Centre

Gives health professionals access to expertise & resources to enable the delivery of quality care



Therapy Access Hub

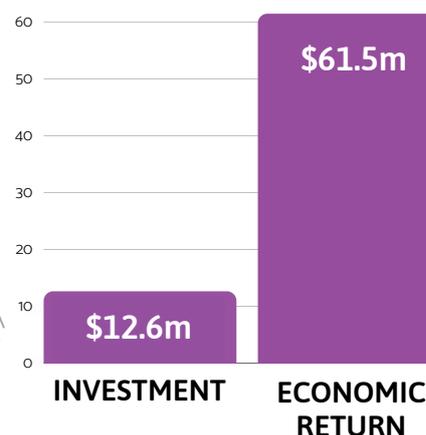
Identifies and facilitates access to potentially life-saving emerging therapies and clinical trials



Patient Data Solution

Makes children with dementia visible in our health system through national collection

4.9:1 Quantifiable Return on Investment



This was a hidden crisis, but now we know about it

Now we know about the solutions that will benefit children, families, our health system and Australia. Now we know how Australia can lead the world in childhood dementia innovation and ensure equitable, expert care, for every child, no matter where they live.

Childhood Dementia Initiative is calling on the Australian Federal Government to fund the National Childhood Dementia Unit and transform care for children with dementia.

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