

OpenVoiceNews Australia

Transparent. Unbiased. Yours.

Melbourne Mum, 29, Battles Rare Alzheimer's

August 1, 2025

– Categories: General News



Erin Kelly, a 29-year-old single mother in Melbourne, has received a confirmed diagnosis of early-onset familial Alzheimer's disease linked to a PSEN1 gene mutation. This rare, inherited form of Alzheimer's accounts for less than one percent of all cases worldwide and typically leads to symptoms appearing in a person's 30s or 40s.

Genetic testing conducted in May 2024 confirmed that Erin carries the PSEN1 mutation, which is known to guarantee the development of Alzheimer's at an early age. Symptoms such as word confusion and memory lapses began about a year earlier, and her diagnosis

was officially confirmed in July 2025 after a series of medical consultations and diagnostic tests.

Erin is raising her eight-year-old daughter, Evie, alone. She lost her mother to Alzheimer's when she was just 17. A review of her family history revealed that at least eight relatives have been affected by the same condition, indicating an aggressive hereditary pattern.

Doctors estimate that individuals with this type of genetic Alzheimer's typically live between eight and fifteen years after symptoms first appear. However, due to her age and the rarity of the condition, Erin has found that she does not qualify for many subsidised treatments or clinical trials currently available in Australia.

One potential option being explored is an experimental treatment known as Leqembi. The drug, a monoclonal antibody, targets amyloid plaque buildup in the brain and has shown promise in slowing cognitive decline in early-stage Alzheimer's. However, it is currently only approved for patients aged 50 to 90, placing Erin outside the eligible criteria. In addition, the treatment is not subsidised in Australia and costs around \$90,000 per year.

Beyond the medication itself, Erin has already spent thousands of dollars on specialist consultations and brain imaging. Other recommended support services, including neuropsychological care, speech therapy, and nutritional treatments, remain financially out of reach.

To help cover costs and secure access to care, Erin has launched a public fundraising campaign. Donations will go toward both treatment and creating lasting memories with her daughter while she is still able to do so. If treatment remains inaccessible, the funds will instead support quality time and memory-building experiences between mother and daughter.

"I want her to remember who I was," Erin said. "And who her grandmother was, too. I'm the only one who can tell her those stories."

Despite the emotional and financial challenges ahead, Erin remains focused on her health, her daughter's future, and making the most of the time they have together.