

## A personal journey navigating psychotropic medicines and dementia care

**Bronte Parkin** is a devoted husband turned dementia advocate. His wife, **Glenda**, a respected educator, was diagnosed with dementia at the age of 56. Their lives took an unforeseen turn as together they navigated the complexities of her illness until her death at the age of 69.

"Glenda was more than just my wife; she was an amazing mother and pillar in our community—a beacon of intellect and grace. She was a high academic achiever all her life, a school teacher, university lecturer and principal of two schools in Perth," Bronte explains.

Glenda was diagnosed with younger-onset dementia, specifically a rare variant of Alzheimer's disease known as posterior cortical atrophy (also known as Benson's Syndrome) in 2010.

"Glenda's ability to perceive the world around her gradually deteriorated over time. At first, she struggled to recognise everyday objects like cups and utensils, but gradually, she could not recognise her family members. As she became functionally blind, Glenda lost her ability to read, write, walk and engage visually with her environment,"

"For more than ten years, I cared for Glenda at home. During that time, I was able to help her live in comfort and with dignity, even as her symptoms worsened. Despite Glenda's dementia, we lived a fulfilling life, enjoying travel and sharing some amazing experiences."

"About nine years after her diagnosis, she began to experience behaviours such as high levels of anxiety, agitation, restlessness, aggression and sleeplessness, as well as delusional behaviours."

At that time Glenda was prescribed two psychotropic medicines - lorazepam (a sedative) and quetiapine (an antipsychotic medicine). These were in addition to an antidepressant taken since her diagnosis. "The psychotropic medications were supposed to help her manage her behaviours, but they brought unforeseen challenges," Bronte explains.

"Not long after starting on quetiapine, Glenda began to experience unusual muscular movements in her legs and to lose her balance. Unfortunately, after several close calls she had a very serious fall fracturing her pelvis and had to be hospitalised. Although her pelvic bones eventually repaired, she never regained the ability to walk. This ultimately led to her being admitted to an Aged Care home, as it was no longer possible for me to care for her at home."

"It was only in the hospital we found out that the leg movements were caused by the medicines. Even when confined to a hospital bed, Glenda was lifting her legs into the air as if doing exercises, waving them involuntarily from side to side, unable to control her body."

"The hospital psychiatrist explained that Glenda's leg movement disorder was a side effect of the medication quetiapine. He recommended that both psychotropic medications be phased out slowly," he explained.

Glenda moved into an Aged Care home during this weaning-off period, but the leg movements continued for another six months.

"It was quite a challenge for the aged care facility. She was confined to bed 24 hours a day because putting her into a nursing chair was too risky," Bronte recalled.

Finding an alternative to psychotropic medication for managing Glenda's behaviour became a top priority to ensure the best possible care for her. "With Glenda's advanced visual impairment, music and singing became her only refuge," he explains. "We worked with the aged care facility to fill her world with music, and this became the core of her behaviour support plan."

Reflecting on their journey, Bronte realised the importance of informed consent. "Many of us tend to

overlook the potential risks and harmful side effects of medications, focusing only on their potential benefits. As caregivers and partners, we rely on the professional judgment of doctors and clinicians when it comes to prescribing medication for our loved ones.

However, in hindsight, I realise that I should have gained a better understanding of the limited benefits and potential risks of these medications," he said. "I took it at face value that it was in Glenda's best interests, and I was not really given the information necessary for providing informed consent."

### **Ensuring the appropriate care for people with cognitive impairment**

A more careful approach that ensures informed consent is a key focus of the newly launched **Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard**, which aims to reduce the inappropriate use of psychotropic medicines in people with cognitive disability or impairment and to improve patient safety when medicines are the appropriate choice. When it comes to behaviours of concern, psychotropic medicines are a last resort option when other strategies have failed and there is a significant risk of harm to the person or people around them.

**Conjoint Associate Professor Carolyn Hullick**, Chief Medical Officer at the Commission, explained, "We have known for some time that non-pharmacological interventions should be the primary method for managing behaviours. It's critical that these are integral components of care for people with dementia and other cognitive impairments."

"The Standard underscores the importance of individualised care plans and regular monitoring of adverse effects. We must move away from the one-size-fits-all approach," A/Professor Hullick continued.

Bronte Parkin champions greater transparency and informed consent as he continues to advocate for people with dementia. "Glenda's experiences weren't just hers – they're a testament to the need for better understanding of how to use psychotropic medicines safely in people with dementia," Bronte asserts. "We owe it to her and countless others to do better."

To learn more about the standard visit [safetyandquality.gov.au/psychotropics-ccs](https://safetyandquality.gov.au/psychotropics-ccs).

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