Personal Testimonial: Challenges Faced as a Carer for a Mental Health Patient

Submitted by: a Carer

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My Role as a Carer

For more than two years, I have been the primary carer (assigned by myself, and I have to) for my family member, who lives with "diagnosed" severe depression. My responsibilities include managing medications, coordinating appointments, advocating for their needs, and providing daily emotional support. While rewarding, this role has exposed systemic gaps in Australia's mental health system that disproportionately affect carers like me.

Key Challenges

1. Lack of Clear Information

- **Example:** When patient was first diagnosed by a local GP, I did not know such diagnosis for months until he planned to kill himself after took those antidepressants (first, prescribe by a GP started for anxieties, then a private psychiatrist for depression) that led to a suicide event without any signs and words left. After second time admission, I have insisted to review patient's diagnosis as I could see that the antidepressants only have harmed patient, then, the diagnosis was changed to ADHD..., which could be the first diagnosis.
- **Impact:** This confusion delayed suicide prevention, accessing critical care, worsening patient's condition during a crisis.

2. Exclusion from Care Decisions

- **Example:** During a hospital admission, I was barred from care plan meetings despite being patient primary support. Doctors cited "patient confidentiality," leaving me unaware of medication changes, that should be monitored closely to present suicide.
- **Impact:** I couldn't prepare our home for patient return, and was not able to prepare to prevent suicide ideation, leading to relapse and readmission.

3. No Training or Resources

- **Example:** I received no guidance on managing suicidal ideation. When an incident occurred, I froze, unsure how to safely intervene.
- **Impact:** Both patient and I felt unsafe, eroding trust in the system.

4. Emotional Isolation

- **Example:** Carer support groups were advertised, but none existed in our rural area. Online forums were impersonal and overwhelming.
- Impact: My rural friends felt alone, battling burnout without peer support.

Systemic Barriers

- Policy Gaps: The National Agreement's promise to "embed lived experience" (Clause 20) has not translated to carer inclusion. Bilateral schedules lack enforceable carer rights.
- Cultural Insensitivity: As a CALD carer, resources were rarely tailored to our cultural or linguistic needs.

The Human Cost

Caring without support has taken a toll:

- **Financially:** I reduced work hours to provide care, losing income.
- **Physically:** Chronic stress led to health issues, including anxious, insomnia, hypertension.
- **Emotionally:** I grieve the life I once had, fearing burnout will leave my loved one without care.

A Plea for Change

My story is not unique. Carers are the invisible backbone of mental health care, yet we are sidelined. I urge the Productivity Commission to:

- 1. **Mandate carer inclusion** in all care planning and policy design.
- 2. **Fund accessible training** on crisis management and self-care.
- 3. **Create accountability mechanisms** to ensure the Agreement's promises reach carers.

Signed,

Lucy