Committee Secretary

House of Representatives Standing Committee on Social Policy and Legal Affairs
Attention: Carer Support Inquiry
PO Box 6021
Canberra ACT 2601, Australia

Subject: **Recognition and Support for Australia's Unpaid Carers**

I am writing to provide my personal story in the hope it sheds light on the countless hurdles faced by unpaid carers in Australia. My intention is to urge the Australian Government to take decisive action to alleviate the difficulties faced by carers, through the provision of necessary resources and funding. I implore you to ensure that this inquiry goes beyond mere recognition, and results in tangible changes that address the practical needs of unpaid carers – including funding and resources.

As detailed in my account below, my experience caring for my mother diagnosed with Stage 4 brain cancer was marred by systemic inefficiencies, lack of adequate support, and bureaucratic red tape. Despite my privileged background, education and medical family, I found it nearly impossible to get help as a carer. The emotional, physical, and financial toll of caregiving was immense.

Based on my experience, I urge the Australian Government to consider the following recommendations:

1. **Streamlined Navigation of Healthcare Systems**: Implement a unified, streamlined system that makes it easier for carers to understand and access the care options available. Work in partnership between federal and state agencies and the private sector to ensure a balanced, navigable approach.

2. **Single Point of Medical Contact:** Establish a designated medical point of contact and/or case manager who is knowledgeable about the healthcare system to help families navigate the care process. They should facilitate communication among various specialists and keep track of the patient’s overall medical condition and care, including medications.

3. **Improved Respite Care Services:** Expand and make respite care services easily accessible. Ensure that eligibility for respite is not solely based on physical incapacity of the carer, but also takes into consideration the mental and emotional strain of caregiving.

4. **Timely Access to Care:** Expedite the My Aged Care assessment process and reduce waiting times for care services. Families should not have to wait months for an assessment, only to be told that they have to wait even longer for actual services, sometimes totalling over a year of waiting even for high care needs.

5. **Palliative Care Facilities:** Develop palliative care facilities especially in areas where they are lacking, ensuring that individuals at the end of life receive the care they need in a dignified setting.

8. **Simplification of Paperwork:** Streamline the paperwork required of carers and provide clear guidance on what is required for different aspects of care and what the likely outcomes will be. This could include frequently asked questions on specific conditions, and pathway options for care.

In conclusion, despite education and a medical family background, my experience as an unpaid carer was an arduous journey, and I believe it is essential that the Australian Government addresses the pressing issues faced by carers nationwide. The lives of our loved ones and the well-being of their carers should be of utmost priority. I urge the Australian Government to translate the outcomes of this inquiry into meaningful actions, funding, and resources that make a tangible difference in the lives of unpaid carers and those they care for.

Thank you for your time and consideration.

Sincerely,

Anonymous, Sydney

My carer experience

My mother was diagnosed with Stage 4 brain cancer (glioblastoma) in June 2021 and died 11 months later. She was a retired doctor, who had spent her whole life caring for others. Now she was diagnosed with a deadly and unpredictable cancer she suddenly needed a lot of care.

Firstly, emergency care, which was excellent and swift. Within 24 hours of diagnosis she'd had surgery, and within a week she was home. Then came the rounds of chemotherapy. The cancer centre was excellent – high quality and good care. Her GP was as helpful as could be expected. So I can conclude that the medical care was first class, however the carer help was the polar opposite.

Once the medical emergency was over, things started to get very confusing. I have a friend going through exactly the same situation with his mother, and he is equally as confused about processes, who to turn to, and what might happen next.

Although my mother was assigned a social worker who could book appointments, that person didn't have much knowledge of what would happen and who to turn to for help.

My mother never regained the ability to speak beyond mono-syllabic answers. She was extremely aware of what was happening, yet she couldn't plan ahead or articulate. I had to become her voice, advocate, carer, assistant and driver to medical appointments, cook, cleaner and grieving child all at once. And stay focused on my new job, care for my kids, and care for myself.

My mother progressively got worse. She took to wiping faeces on the walls, ate raw meat from the fridge, and couldn't figure out how to pour milk on her Weetbix. But I couldn't get her into a care facility, nor get respite, nor get into a palliative care facility (none exist in my area in the Eastern Suburbs of Sydney, apparently). I moved my desk into her spare bedroom to be available 24 hours a day.

When she was first diagnosed, I lodged a request for My Aged Care. A couple of months later, they said she qualified for home help – but all 21 providers said their books were filled. Six months passed, and we received advice that my mother qualified for top-level care. But only for an aged care facility as home care wouldn't kick in for 9 months! I then rang all the aged care providers in the eastern suburbs to find a bed for her, but only one facility was available to take her, and that was in a shared room. My mother still cognisant and extremely anxious and frustrated. She'd lost the ability to moderate her feelings, and anger would kick in constantly. I didn't think it appropriate or fair to put her in a shared room.

The cancer centre said my only option was to take her into emergency for respite – but she'd be out again a few days later and cost the tax payer tens of thousands in care. It seemed utterly ridiculous.

I then turned to private care for home help. At a cost of up to $65 per hour, I could get someone in to help for three hours a day. Even then, I had to call on a favour from a friend who worked for the company as they didn't have the capacity to take on new patients.

Finally, I sought palliative care. After many phone calls and enquiries, and assistance from my assigned social worker, I was able to get a call into a provider through one of the hospitals. The first question they asked was "can you guarantee your mum will die in the next three months?" No doctor would give this advice. I, a non-medical person, had to make a call that she'd be dead soon.

Through that I received one hour of assistance a day, from a non-skilled worker who could make a meal or clean, but not administer medical assistance. They would turn up at completely unpredictable times of the day. It helped, but not much.

I also managed to convince the endocrinologist to send a nurse once a day to administer my mother's diabetes medication. Because I often had to go into work, I couldn't guarantee to be available to administer the medication at the same time every day.

At one time, I was completely beside myself and not coping. My GP prescribed anti-depressants and time off for a weekend. I called the Carer Gateway, which promises ‘practical supports like planned respite and transport services to help you in your caring role.’ The person on the phone asked if I was physically incapacitated, like hurting an ankle so I couldn’t walk. I replied no, to which they responded, ‘we can’t help you. You must be physically incapable to get respite help.’ I said my GP had prescribed medication to cope and I had a letter. About two hours later Carer Gateway rang to say they would send someone to help for 24 hours only.

At this point, it was clear that my mother was close to dying. I eventually started receiving help from a home palliative care team. They were fantastic and came every day. However, even at this point I faced hurdles.

At my mother’s request, I asked all of her medical team to stop prescribing her medication – the cancer specialist, GP, endocrinologist, heart specialist and palliative doctor. None of them was willing to make the call – they would only stop medications they’d prescribed. I supplied my mother’s health care plan, her end of life statement (written soon after diagnosis, in which she said she wanted all medication stopped, she was a doctor and knew the implications), an email from my brothers who lived overseas saying they supported the decision, and a letter from my medical father (divorced) setting out all the reasons why this was the right choice. Even then I had to keep fighting to have her medications stopped.

I have given this story to highlight just how incredibly difficult it is for carers to:

- Navigate systems that are completely disjointed, with no one able to provide a pathway or clear advice
- Have no single medical point of contact
- Have a very limited system (if at all) for respite
- Being given unhelpful advice – such as taking the patient to emergency in order to get respite
- Being asked to fill out mountains of paperwork, often to no avail. I found myself questioning anyone who asked me to complete paperwork what the likely outcome would be as it was often a complete waste of time
- No palliative care facility
- My Aged Care having ridiculous waiting times – taking 6 months to prepare a response that said we needed to wait another 9 months to qualify for home care

My privilege is that I come from an English speaking background; my family is full of trained doctors (parents and siblings) so I know the right terminology and who to ask; I am highly educated; have a good income and a supportive workplace; a supportive family and partner; and live in the eastern suburbs of Sydney. Yet the 11 months I spent as a carer was harrowing and full of unnecessary hurdles.

I strongly urge that this inquiry results in action, resources and funding from the Australian Government, working in partnership with state governments and the carer industry. Not simply ‘recognition’ or ‘understanding the value’ because that will not solve any of these issues I’ve outlined above.