

Co-designing a reflective experience-based resource with voices of informal carers engaging in storytelling.

Research Summary

A program of research exploring informal carers' experiences of supporting older adults living with mental health conditions in home aged care settings

Informal carers play a vital role in supporting older adults living with mental health conditions to remain living safely at home. They often **provide emotional, practical and day-to-day support** alongside formal aged care services.

As the number of older adults living with mental health needs increases, so too does the number of informal carers supporting them. Despite their essential contribution, carers often receive little recognition and **may also experience stigma**. This includes negative assumptions and stereotypes about carers that can lead to unfair treatment, discrimination and social exclusion.

The **Carer Voices project** was developed to **ensure carers' experiences are heard** and better understood. Through digital storytelling, the project provides a platform to **share real stories from carers** to raise awareness and promote greater support.



Method

Using a **co-design approach**, we worked alongside carers throughout the project to ensure their voices shaped every stage of the research.

We invited carers to **share their experiences of stigma encountered during their caregiving journeys** and reflect on the moments that have shaped the carers they are today. Between January and April 2026, 69 carers from Australia, the United States, and the United Kingdom completed **surveys**, and a further 10 Australian carers participated in in-depth interviews.

After collecting these stories, we **sought feedback** from 30 carers and the research team through a survey to help select which content to feature in the digital storytelling gallery. These stories and themes **reflect what carers felt was most important** for the public to see, hear and understand about the realities of caregiving.

This project was funded by a Melbourne Ageing Research Collaboration (MARC) grant.

The Research Team thanks all carers involved and acknowledges the support of Carers Victoria. This digital storytelling gallery reflects the collaborative efforts of multiple teams at Silverchain, united by a shared commitment to amplifying the voices and experiences of informal carers.

Results

Findings from the interviews and surveys revealed that many carers feel **judged, misunderstood or unfairly treated**.

"I had a colleague make a really rude comment about how I received special treatment at work because I looked after somebody..."

P17, Carer supporting their grandparent living with anxiety.

Despite encountering stigma, many carers found **meaning and a sense of pride** in their caregiving journey.

"I have always received nothing but positive feedback from friends and family who all are appreciative that I am there for my friend and my role as her carer gives me immense joy."

P15, Carer supporting their friend living with depression.

"Others make assumptions or judgments, sometimes treating me as overly burdened, incapable of managing other aspects of my life, or even avoiding me because they don't understand the challenges of caring for someone with a mental health condition."

P11, Carer supporting their parent living with bipolar disorder

Negative public perceptions of caregiving often contributed to carers **feeling devalued** and **facing additional challenges** in providing care.

"When I can advocate for myself and make sure the necessary resources are in place, I feel proud. I feel good knowing that what I do helps the person stay independent and have a good quality of life."

P10, Carer supporting their parent-in-law living with anxiety.

Feeling understood and supported by the community **strengthened carers' confidence** and **affirmed the positive impact** of their caregiving.

Carer Voices digital storytelling gallery

With participants' consent¹, **carers' stories have been transformed into videos** featured in our digital storytelling gallery. We hope these **stories challenge common assumptions** about what it means to care for an older adult living with a mental health condition at home.

The gallery shares **carers' experiences in their own words**, providing a deeper **understanding of perspectives that are often underrepresented** in public discussions about caregiving and mental health. Every story in this gallery has been **thoughtfully developed** to raise awareness, foster understanding and inspire action to better support informal carers of older adults living with mental health conditions who receive aged care services at home.

Next steps

The **Carer Voices project** is just the **beginning of an ongoing conversation** about challenging stigmas associated with caregiving, ageing and mental health. We hope to keep working closely with carers and communities to **build on what we learn**—what's working well, where the gaps are and what new solutions might help.

The goal is to **turn carers' insights into practical improvements** including better support services, more targeted policies and greater public awareness of the vital role carers play.

¹ To protect participants' privacy, no personal identifying information is included. Representative images, actors and AI-generated voices have been used to bring these stories to life.