What happens when I can no longer care?

Initial findings of the Future Planning Project

MICA
Mental Illness
Caregivers Association

ARAFMI
you are not alone

About the project

During March 2025 to March 2026, the Policy and Advocacy team at Arafmi (based in Queensland, Australia) set out to discover how to best help families and carers of people experiencing mental health challenges[1] to plan for the future.

We didn't do it alone. Caregivers in Canada face similar concerns about what will happen to the person or people they support when they can no longer care[2]. Arafmi and the Mental Illness Caregivers Association (MICA) (based in Ontario, Canada) formed a collaboration to better understand the issues and develop practical solutions.

Together we consulted with carers/caregivers, researched models of support that already exist, sought expertise from professionals in areas related to planning concerns and identified potential ways forward.

1 Note that we use the term 'carer' throughout this report to represent family members and friends who provide significant unpaid support to someone experiencing mental health challenges.

2 In Canada, the term 'caregiver' is used to describe families and other unpaid carers.

What we found

Carers currently provide high levels of emotional and practical support, regardless of where they live

In both Queensland and Canada, carers told us that they spend at the median (middle range):

- 11-15 hours a week providing their person or people with **emotional support**, such as helping them deal with challenges, de-escalating emotional or risky situations, monitoring and managing crises, and creating opportunities for social interaction
- 6-10 hours a week providing **practical support**, such as helping their person with cleaning, cooking, managing finances or legal issues, planning and decision-making, accessing and maintaining employment or housing
- 1-5 hours a week providing **health support**, such as assisting with medications, managing appointments, providing transport or attending appointments.

However, many families and carers spend many more hours than this (see Figures 1 and 2).

Figure 1: Estimated Hours of Support per Week (Queensland)

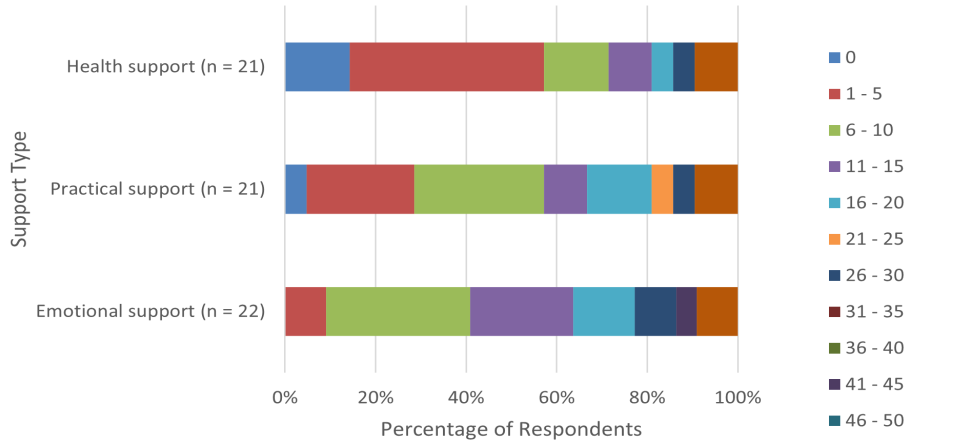
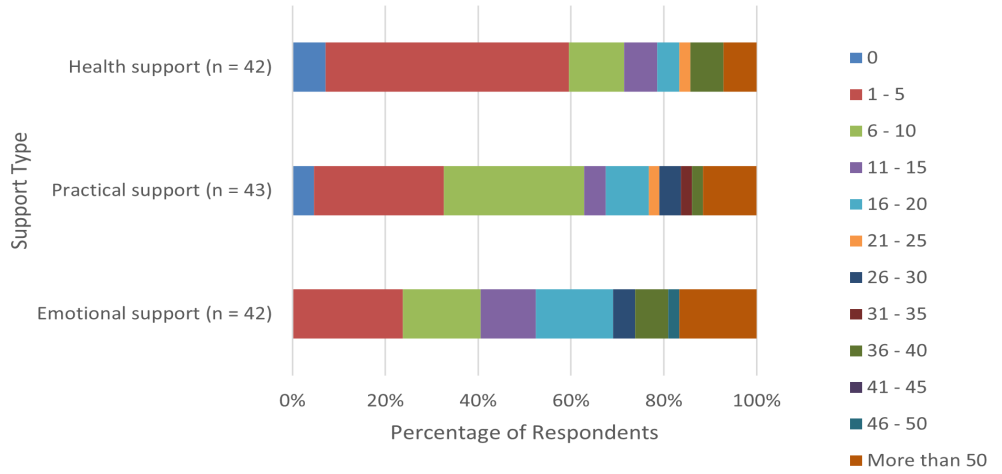


Figure 2: Estimated Hours of Support per Week (Canada)



n = number of survey respondents providing this type of support

Carers are covering significant essential living costs for the person they care for

Many carers who participated in the research provide significant financial support to cover essential living costs that enable the person/people they care for to have a safe and secure place to live (see Table 1).

Table 1: Respondents who Provide Financial Support for Essential Living Costs

Financial Support Type	Number of respondents who provide this support		% of respondents who provide this support	
	Queensland	Canada	Queensland	Canada
Rent or mortgage payments	7	23	39%	62%
Utilities and other services	12	28	67%	76%
Property management and maintenance	9	14	53%	41%
Food	17	35	89%	88%
Cleaning services	11	14	65%	44%

For some carers, support for housing and other essential living costs remains one of their biggest concerns for the future.

> **How do I provide for safe and secure housing? My kids could live in my house, but how do we support property management, taxes, financial commitments etc. when I am gone?**

> **There is a housing crisis at the moment. My person currently lives at home with us. I would like to know that there is a place for my person to be able to live in the future, with the disappearance of facilities and housing. I feel like I'm at the start of a monopoly board.**

Carers also provide financial support for a range of other costs

Carers in both Queensland and Canada also help fund critical supports such as **mental health care** (e.g. psychologist, psychiatrist, other mental health services, medications), **physical health care** (e.g. doctors, medical insurance, health aids), **financial and legal costs** and range of important **miscellaneous costs** for their person.

Carers are ill-prepared for the future and want help to put plans in place

Most carers do not have plans in place to support the person they care for when they can no longer care. For example, despite carers providing very high levels of **emotional and practical support**, less than half of Queensland carers have even somewhat of a plan in place to replace this care in the future. In Canada, the situation is similar.

Most Queensland carers do not have plans in place for continued coverage of **essential living costs** for their person. However, Canadian caregivers are more likely to have started planning for these costs or already have these plans in place.

While help to plan for all types of support was seen as important, almost 90 percent of Queensland respondents said they needed help to plan for ongoing **practical support** for their person, and 75 percent want help to plan for ongoing **emotional support**. In Canada these figures were around 70 percent.

By contrast, only 50 to 60 percent of respondents from each country would like help with planning for **essential living costs**.

In consultations, carers spoke about a range of other types of support needed to plan for the future, including:

- Estate planning
- Financial safeguarding and legal planning
- A plan for when things go wrong
- Planning for ongoing health and mental health support and continuity of care
- Help to get started with planning (including respite to create the time and headspace for planning).

Carers also want support to implement plans into the future

While having a plan is important, carers also said they and the people they care for would need help to *carry out* the plan. For example:

- A facilitation/co-ordination team to oversee implementation, including someone on the end of the phone who understands (and is available) to help with information, advice, decision-making and problem-solving
- Individual advocates who have mental health expertise
- Someone to hold the person's history

- Someone to hold the plan
- Early implementation of the plan to allow time and support for transition of care where possible.

Carers also told us that – regardless of what any future planning solution looks like – it must:

- Have an underpinning focus on supporting and upholding the autonomy, wishes, strengths and rights of the person being supported
- Foster trust and encourage long-term relationships and continuity of care
- Be grounded in a strong understanding of mental health
- Be accountable, kind and compassionate.

> **[It's] hard to know where to start the process of planning for the future. You have to find the way yourself. There is an administrative side which can be taken care of to some extent through existing services, and a personal side – what do you do to support social and emotional health?**

> **What if we do nothing? What's at risk? Doing nothing puts the most vulnerable in our community at risk and our community at risk. Carers need to share these stories.**

> **As carers we hold the story of what has happened to our person – if we are not around, who or what can hold that knowledge?**

Implications for Future Planning

The findings highlight a range of issues to address so that families and carers can have some confidence that the people they care about will continue to be well-supported into the future.

ISSUE 1.

The large majority of families and carers do not have a plan in place and are seeking support to both develop and implement a plan

The planning process could be supported through both planning tools and professionally facilitated planning sessions (individual, family, or group-based) to navigate difficult discussions about future roles, expectations, and inheritance before crisis or conflict occurs. Consideration of ongoing, secure, maintained accommodation should be a central element of such tools and discussions.

ISSUE 2.

Everyday emotional and practical supports are the hardest to replace

There is a critical gap in available practical and relational supports outside of what families and carers provide. Public mental health and specialist services provide support for acute episodes of mental ill-health, but rarely address necessary day-to-day, non-clinical supports (often referred to as psychosocial supports). Carers also identified a lack of services that can do practical things with or for their person — such as coordinating appointments, supporting daily routines or accompanying people to services.

What's needed are proactive, psychosocial supports (e.g. recovery/life coaching, care coordination, system navigation) that actively encourage a person's ongoing connection to services and supports rather than waiting for crisis periods or relapse. There is a need for support not only related to mental health, but also to other essential 'social determinants of health' such as housing, food, income, employment and social inclusion.

ISSUE 3.

Continuity and trust matter more than service type

Carers want to plan ahead but cannot do so with confidence when they do not have trusted, ongoing supports for their person. Long-standing relationships with trusted clinicians were consistently described as a stabilising factor for a person's mental health. Frequent staff turnover and short-term interventions, however, were shown to undermine engagement and safety of the person needing support. Carers suggested that team-based approaches to service delivery can assist with this continuity, as well as having key trusted relationships in place.

ISSUE 4.

Advocacy is essential for people with complex mental health needs and cannot be assumed or replaced by generic supports

In the absence of formal systems and services that fully meet the needs of people with mental health challenges, individuals and/or services that can advocate for a person when their family or carer can no longer do so become essential. Having a trusted person or a place to hold the person's story and health history when the carer is no longer able to do so is an important aspect of this type of support.

ISSUE 5.

Planning for the future support of someone experiencing serious mental illness can be expensive, complicated and resource intensive

The circumstances surrounding future planning are often unique and complex, requiring tailored planning solutions – which can be expensive. Reducing some of this inequity will require accessible future planning and financial guidance and affordable, mental-health-informed advice on wills, trusts, and financial management that balances protection, autonomy, and family relationships.

Possible models for future planning and supports

Our research identified a wide range of examples from Australia and overseas that offer possible models for solving future planning needs. Examples include:

Future Planning Tools and Information Services

These examples involve structured information, planning tools and guidance to help families prepare for the long-term future of the person they care for. They emphasise person-centred planning across legal, financial, housing and support domains, but rely on the availability of third-party services to implement plans.

Circles of Support

Circles of Support build a sustainable network of trusted individuals around a "person at the centre" to provide ongoing practical, social and decision-making support. They strengthen community connection and shared responsibility, but can be challenging to establish and maintain, particularly where social isolation exists.

Microboards

These are small, person-centred groups of people in unpaid, trusted relationships with a person with disability, who formally incorporate a not-for-profit association to help the person make decisions, pursue goals, stay connected, and live the life they choose. By combining enduring relationships with a formal governance structure, Microboards provide long-term continuity, safeguards, and support across the person's lifespan.

Care Coordination and Recovery Support

These approaches provide coordinated, recovery-oriented support to people with severe mental illness through dedicated facilitators or recovery coaches. They help individuals and carers navigate complex systems and build capacity. However, continuity and long-term sustainability can be affected by workforce turnover and funding limitations.

System Navigators

System Navigators provide short-to-medium term assistance to help individuals and families understand and access health, social and community services. They improve service linkage and system access, but evidence of direct long-term benefits for carers remains mixed.

Housing-Based Support

Examples of this model combine stable housing with personalised, community-based support as an alternative to institutional care. The model offers strong reassurance regarding long-term accommodation stability, though availability, eligibility and matching processes can limit access.

Neighbourhood-Based Support

These examples deliver holistic, relationship-focused care through small, self-managing local teams embedded within communities. They promote continuity, prevention and community integration, potentially offering carers confidence that relational support exists beyond their own caregiving role.

Social Prescribing via a Community Link Worker

Social prescribing connects individuals to non-clinical community resources to improve wellbeing, reduce isolation and ease pressure on health systems. The model has been shown to be effective as an early intervention and navigation support, but outcomes depend heavily on the strength of the local service ecosystem.

Next steps

Arafmi and MICA will continue to work together as we use the research findings to implement solutions in our respective countries.

You can read the full research report here →

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