MICA
Mental Illness
Caregivers Association

ARAFMI
you are not alone

What happens when I can no longer care?

Future Planning for Mental Health Carers Project Stage One Report

March 2026

Contents

1. About the project

Many mental health carers[1] who engage with Arafmi's support services are concerned about what will happen to the person they care for when they are no longer able to provide support. This worry was echoed during Arafmi's 2023 statewide consultations, particularly among ageing carers who feel the urgency of planning for the future. However, there are currently few straightforward or accessible supports to help mental health carers prepare for these transitions.

This challenge is not unique to Australia. Caregivers in Canada face similar concerns[2]. In early 2025, Arafmi and the Mental Illness Caregivers Association (MICA) of Ontario, Canada formed a collaboration to better understand the issues and develop practical solutions.

The Future Planning for Mental Health Carers project (the project) is the outcome of that collaboration. The project aims to:

1. Understand what would assist mental health carers/caregivers in Queensland and Ontario, Canada to plan for the future support of the people they care for and give them some assurance that their people will continue to be well supported in the future
2. Identify what elements of ongoing care and support need to be in place
3. Understand what services and models of planning for ongoing support already exist in Australia and overseas
4. Gather a coalition of organisations and service providers who are interested in progressing solutions to the issue
5. Develop potential solutions
6. Advocate for the funding and implementation of those solutions.

While the project primarily focuses on carers who are stepping back permanently from their caring role, it also recognises carers may be temporarily unable to provide care due to their own physical or mental health needs, and plans are needed for both situations.

Stage One of this project was completed between March 2025 and March 2026. It included:

- A desktop review of existing Australian and international services and planning models
- A series of three focus groups with Queensland mental health carers to better understand what they need to plan for the future (see questions in Appendix A)
- Five Future Planning workshops for Queensland mental health carers, which included expert presentations from guest speakers on topics related to future planning and opportunities for carers to contribute to the research activities

1 The term 'carer' or 'mental health carer' is used throughout this report to describe families, kin, friends and community members who provide unpaid care and support to someone experiencing mental health challenges. They may be receiving a carer payment but are not employed to provide care and support.

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

- An online survey of mental health carers/caregivers in Australia (Queensland) and Canada (Ontario and British Columbia) and analysis of survey responses
- Five in-depth interviews with mental health carers, with 'carer stories' developed from these case studies (see questions in Appendix B)
- Identification of service and system gaps and potential solutions based on research findings to date.

This report contains key insights from the Stage One research and issues for further investigation.

2. The current state of caring

The survey completed by carers and caregivers in Queensland and Canada showed many similarities and some interesting differences in the patterns of care and support provided to family members or friends experiencing mental health challenges.

In total, 66 carers in Queensland and Canada provided a valid response to the survey [23 from Queensland and 43 from Canada].

The individual interviews conducted with carers in Queensland provide additional depth and practical illustration of the survey findings as described below.

Survey and interview respondents were invited to participate in this study via support groups, programs or networks facilitated by either Arafmi or MICA. As a result, the research sample is likely to include carers who support people with serious long-term mental health conditions or disorders, such as schizophrenia, rather than carers for persons with other common mental health conditions.

Regardless of these sampling considerations and the relatively small number of survey responses, the results are consistent with findings of other research conducted into the scope of mental health caring roles[3], giving confidence in the validity of these findings.

On a technical note – **'n'** in the graphs below refers to the number of people who answered that particular question.

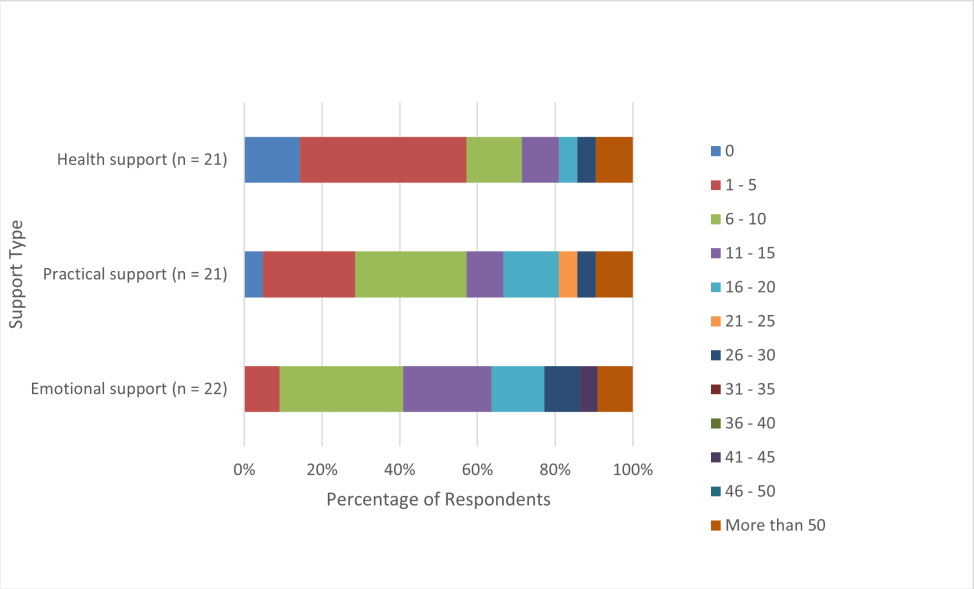
3 For example:

- https://mindaustralia.org.au/sites/default/files/2023-05/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf
- https://www.families.qld.gov.au/_media/documents/carers/qld-carers-social-return-and-investment-full-report.pdf
- https://arafmi.com.au/wp-content/uploads/2025/08/A04-Arafmi-Consultation-Report_190825.pdf

2.1 Mental health carers provide high levels of emotional and practical support for their person, regardless of where they live

Amongst the 22 Queensland carers who responded to the relevant survey question, five respondents (22 percent) told us they provide more than 20 hours of **emotional support** per week and four respondents (20 percent) provide more than 20 hours of **practical support** per week.

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

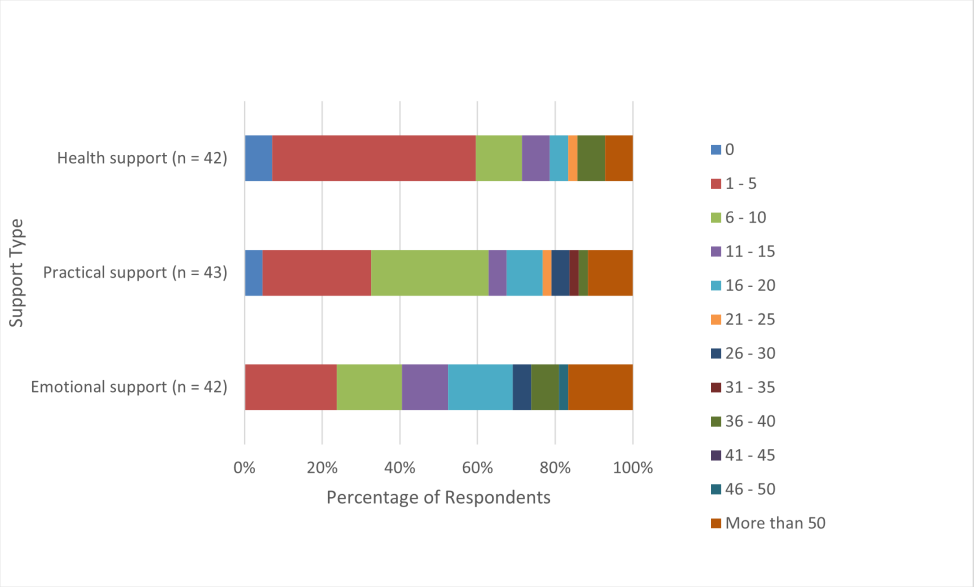


The proportions are slightly higher amongst Canadian respondents. Of the total 43 Canadian carers who responded to the survey, thirteen carers (30 percent) report that they provide more than 20 hours per week of **emotional support**. Ten respondents (23 percent) provide over 20 hours of **practical support** per week.

The survey also showed that a significant proportion of respondents in both Canada and Queensland provide *extremely* high levels of **health, practical or emotional support** for the person they care for. In Queensland, two out of 22 carers (nine percent) who responded to the Future Planning Carer Survey report that they provide more than 50 hours of support weekly in these categories.

In Canada, seven out of 42 respondents (17 percent) report spending more than 50 hours per week on **emotional support** for the person they care for. Similarly, five out of 41 Canadian carers (12 percent) spend more than 50 hours on **practical support** and three out of 42 (seven percent) report spending more than 50 hours on **health support**.

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



Respondents did note that it is difficult to separate types of care that they provide, so it is possible that the estimates of hours may overlap categories and therefore can't reliably be added together to determine a total amount of time spent caring. Regardless, the findings indicate that mental health carers provide significant unpaid support to the people they care for.

Interestingly, in both Queensland and Canada, the median (i.e. middle range) of support hours that carers provide is 11-15 hours per week **emotional support**, 6-10 hours per week **practical support**, and 1-5 hours per week **health support**. This suggests that to some extent, the day-to-day realities of mental health caring may be similar regardless of where one lives.

Table 1: Support Hours by Country - Emotional, Practical and Health Support

Support Type	Location	% of Respondents that Provide this Support	Number of Respondents that Provide this Support	Median Hours of Support per Week
Emotional support (e.g. support to deal with challenges, de-escalating emotional or risky situations, monitoring and managing crises, creating opportunities for social interaction)	Queensland	100%	n = 22	11-15 hours
	Canada	100%	n = 42	11-15 hours

Support Type	Location	% of Respondents that Provide this Support	Number of Respondents that Provide this Support	Median Hours of Support per Week
Practical support (e.g. cleaning, cooking, managing finances or legal issues, assisting with planning and decision-making, helping to access and maintain employment or housing)	Queensland	95%	n = 20	6-10 hours
	Canada	95%	n = 41	6-10 hours
Health support (e.g. assisting with medications, managing appointments, providing transport or attending appointments)	Queensland	86%	n = 18	1-5 hours
	Canada	93%	n = 39	1-5 hours

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

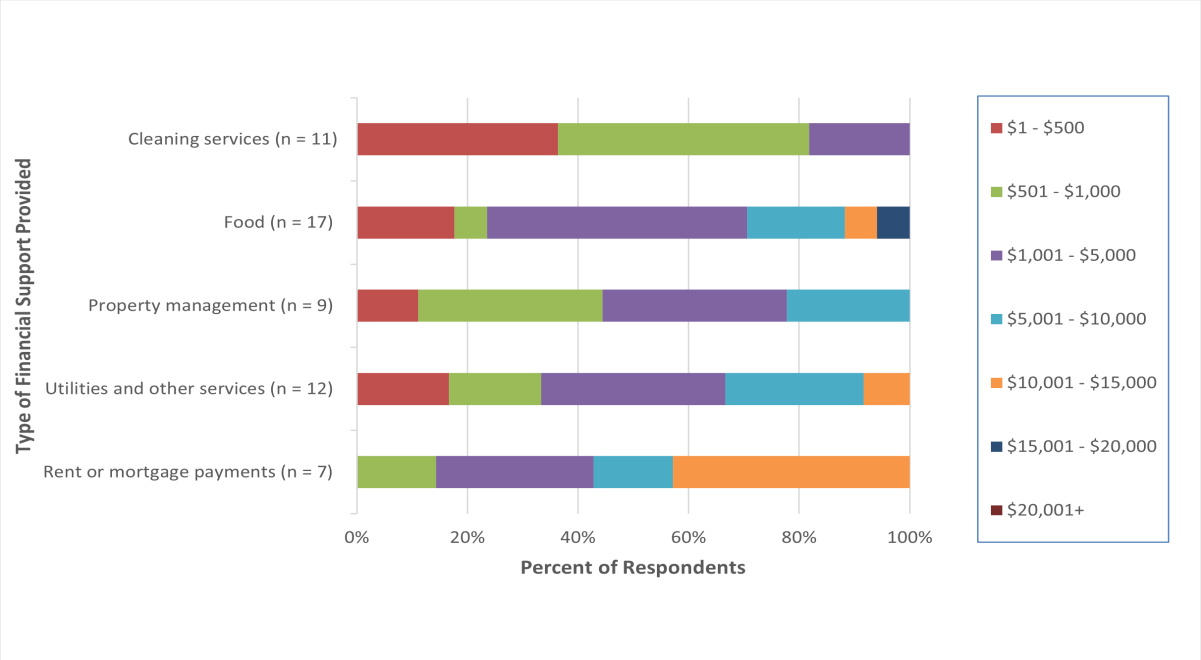
Carers told us that they provide significant financial support to help the person they care for have a safe and secure place to live. Table 2 below shows the number and percentage of carers who provide each type of support.

Table 2: Percent of Respondents who Provide Financial Support for a Safe and Secure Place to Live

Financial Support Type	Number of respondents who provide this support		Percentage of respondents who provide this support	
	Queensland	Canada	Queensland	Canada
Rent or mortgage payments	7	23	39%	62%
Utilities and other services (e.g. phone, electricity, gas, insurance)	12	28	67%	76%
Property management (e.g. maintenance costs)	9	14	53%	41%
Food	17	35	89%	88%
Cleaning services	11	14	65%	44%

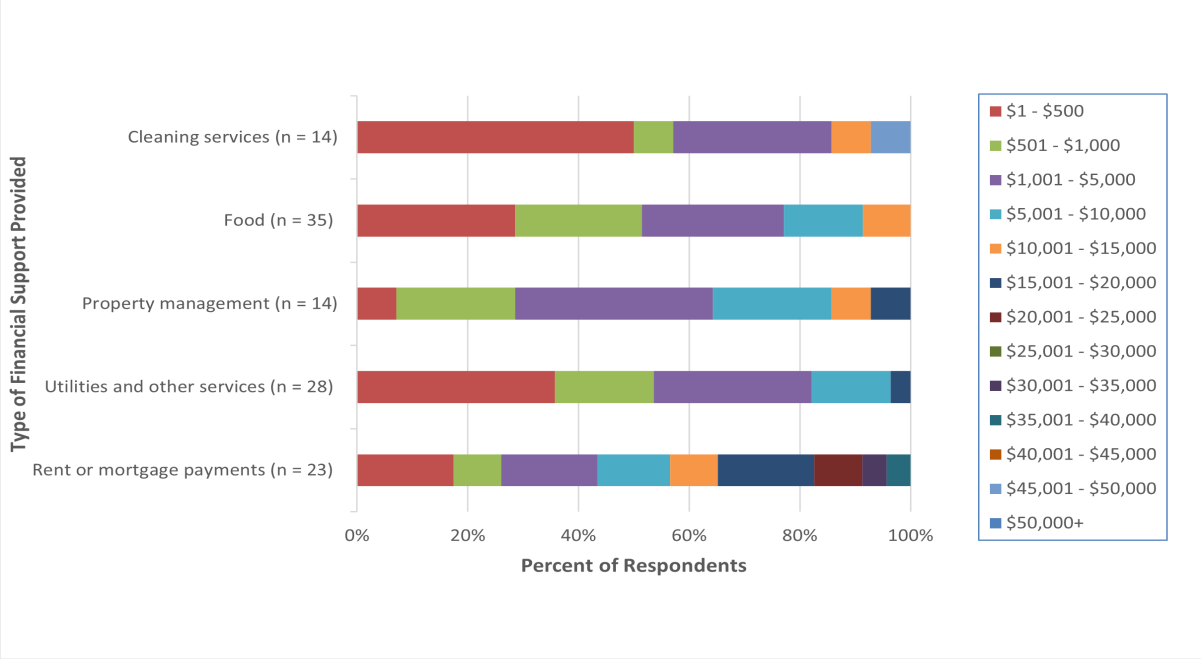
Financial support for rent or mortgage costs is often the largest expense for both Queensland and Canadian carers. Of the seven Queensland-based respondents who provide this type of support, three carers (42 percent) contribute between AUD 10,000-15,000 towards **rent or mortgage costs** for their person annually.

Figure 3: Annual Costs Covered by Mental Health Carers to Provide a Safe and Secure Place to Live (Queensland)



In Canada, a much higher proportion (62 percent) of respondents provide financial support for **mortgage or rent payments** compared to Queensland (39 percent). They also spend more, with two respondents (nine percent) spending CAD 10,000 – 15,000 annually, six respondents (26 percent) spending CAD 15,000 – 25,000 and two respondents (nine percent) spending CAD 30,000 – 40,000 on this support each year.

Figure 4: Annual Costs Covered by Mental Health Carers to Provide a Safe and Secure Place to Live (Canada)



Financial support for **food** is also significant, with almost 90 percent of respondents in both countries providing this type of support. In Queensland, one carer out of 17 (five percent) spends more than AUD 10,000 per annum on food for the person/s they support. In Canada, three out of 35 (eight percent) of carers report spending more than CAD 10,000 per annum on food for the people they support.

These costs are significant and likely reflect carers' recognition of the vital role a safe, stable and well-maintained place to live plays in mental wellbeing.

In one interview, a Queensland carer told us she had invested significant resources to put in place arrangements that would ensure her adult children were well supported in the future and reduce the potential for future conflict amongst family members. This included legal planning to:

- ensure the family home cannot be sold while either child is alive, providing them with ongoing housing
- direct remaining funds toward house maintenance and bills, recognising her children's limited capacity to manage these responsibilities independently.

For others, meeting housing and essential living costs remains one of their biggest concerns:

> ***"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?"***

> ***"We are in our late 50's. What I need in support is a vast unknown for me – location is the most pressing thing when I think of what we need, 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."***

> ***"It's ultimately about them being safe and housing is a big part of this."***

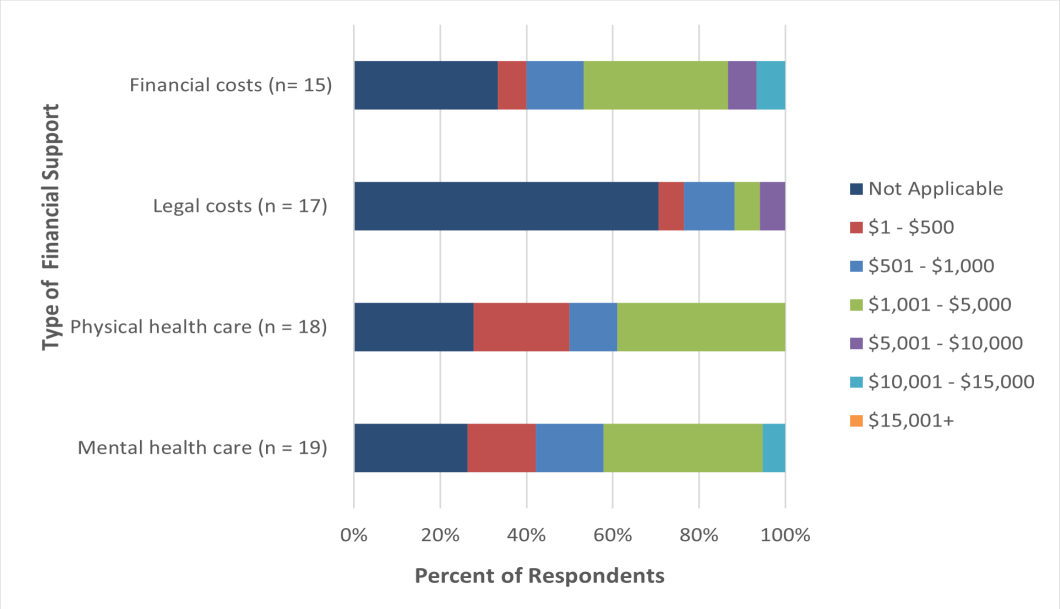
2.3 Carers also provide financial support for a range of other costs

In addition to costs directly related to having a safe, secure home, there are a wide range of other costs that carers provide important financial support for. Between 30 to 40 percent of Queensland carers who responded to the survey told us that they spend AUD 1,000 – 5,000 per support type on 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) and **financial costs** for their person.

For some these costs were even higher, with one Queensland carer reporting that they spend as much as AUD 10,000 – 15, 000 per year on **mental health care** and one carer spending AUD 10,000 – 15, 000 on **financial costs**. One carer (out of five who report providing this support) also spent AUD 5,000 – 10,000 on **legal costs** for their person.

When considered together, these figures represent a large financial burden for some carers. Yet these supports are critical to maintaining their person's wellbeing.

Figure 5: Other Costs Covered by Mental Health Carers per Annum (Queensland)

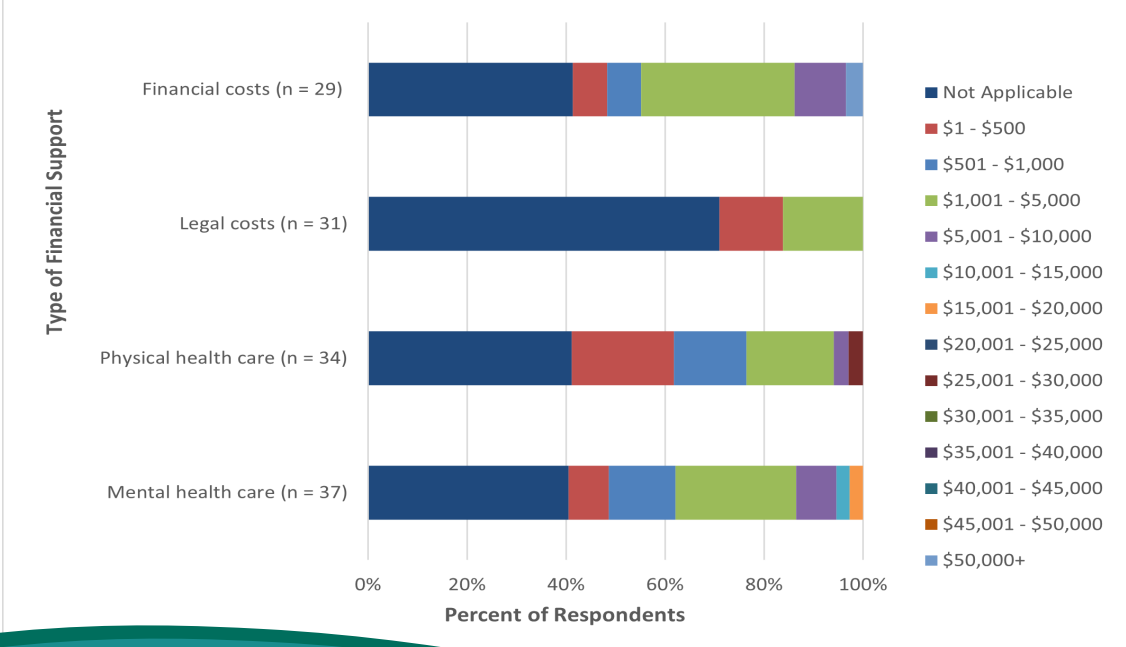


In Canada, the situation is similar. However, some carers may spend even more on these supports. Approximately 25 percent of Canadian respondents spend CAD 1,000 – 5,000 on **mental health care**, eight percent spend CAD 5,000 – 10,000 and a further five percent (two carers) report that they spend CAD 10,000 – 20,000 on this same support.

Approximately 18 percent of Canadian respondents told us that they spend CAD 1,000 – 5,000 per year on **physical health care** for their person. However, one carer reported that they spend as much as CAD 25,000 – 30,000 per annum on this support.

Thirty-one percent of Canadian carers report spending CAD 1,000 – 5,000 per annum on **financial costs** for their person, with one carer reporting that they spend more than CAD 50,000 per year on this support.

Figure 6: Other Costs Covered by Mental Health Carers per Annum (Canada)



Carers told us that they also cover **miscellaneous costs** such as clothing, entertainment, holistic health support, gym and/or social club memberships and transport costs, including vehicle maintenance and running costs, for their person. In some cases, Queensland carers report that these costs - especially for clothing and transport - are over AUD 1,000 per year.

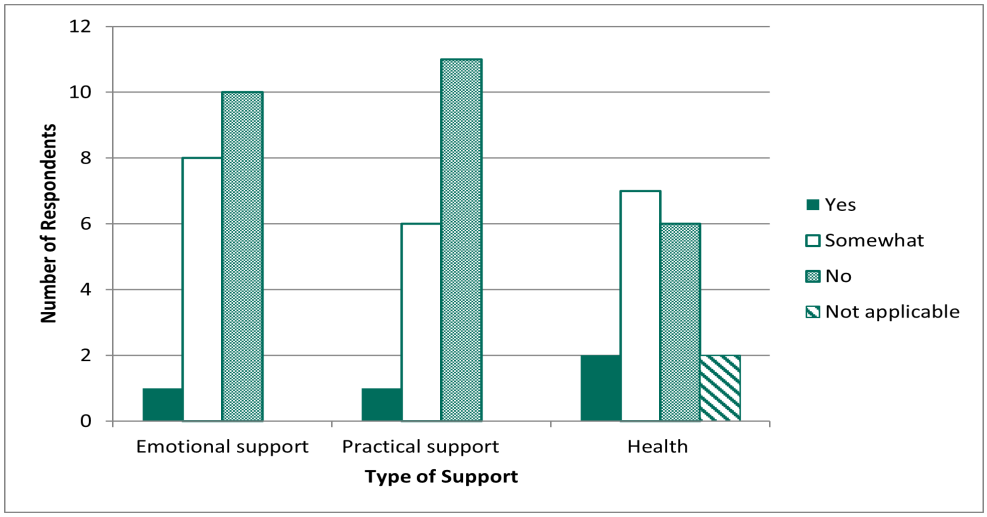
In Canada, respondents noted similar miscellaneous costs, with additions such as financial support to attend supervised day programs and support to purchase furniture and appliances.

While these items may be considered discretionary, carers noted the important role they play in the wellbeing of the person that they care for. In many cases, these items are unlikely or unable to be funded in other ways. Even where a person receives income support, such as the Disability Support Pension in Australia, this is usually only sufficient to cover essentials such as rent and bills.

2.4 Carers (and the person they care for) are ill-prepared for the future

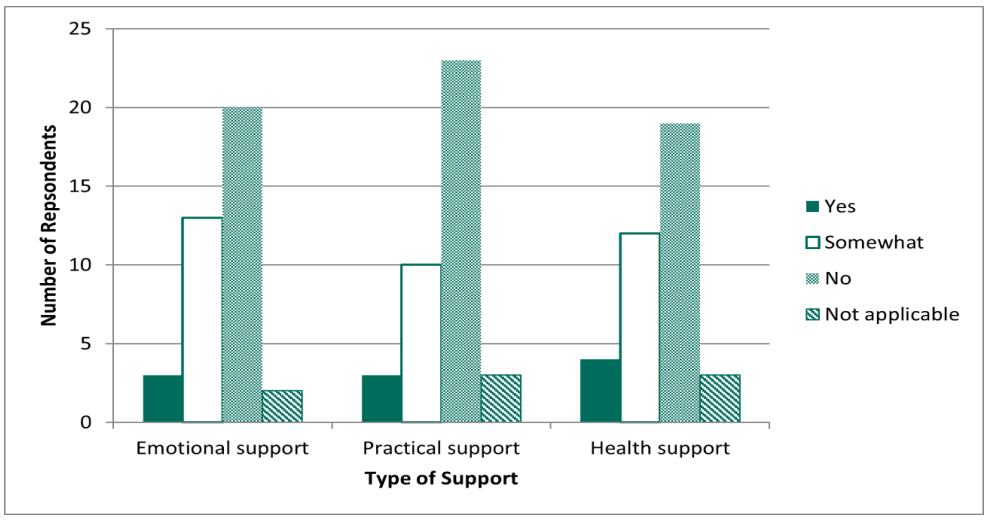
Most carers do not have plans in place to ensure continued support of the person they care for into the future. For example, the survey showed that – despite carers providing very high levels of **emotional and practical support** – less than half of Queensland carers have even somewhat of a plan in place to replace this care in the future. In Queensland, just one respondent out of 19 (five percent) confidently stated "yes" to having plans in place for emotional support, and one respondent out of 18 (six percent) has definite plans in place for practical support.

Figure 6: Number of Carers with Plans in Plans in Place for Emotional, Practical or Health Support (Queensland) (n= 22)



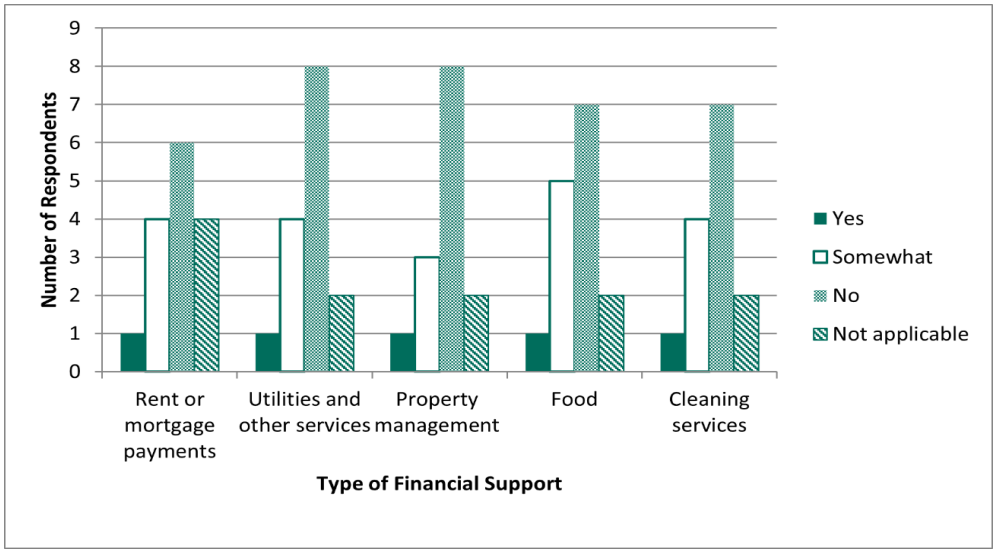
In Canada, the situation is quite similar, with just three out of 38 respondents (eight percent) stating "yes" they do have plans in place for emotional support and three out of 39 respondents (eight percent) having definite plans in place for practical support.

Figure 6: Number of Carers with Plans in Plans in Place for Emotional, Practical or Health Support (Canada) (n = 43)



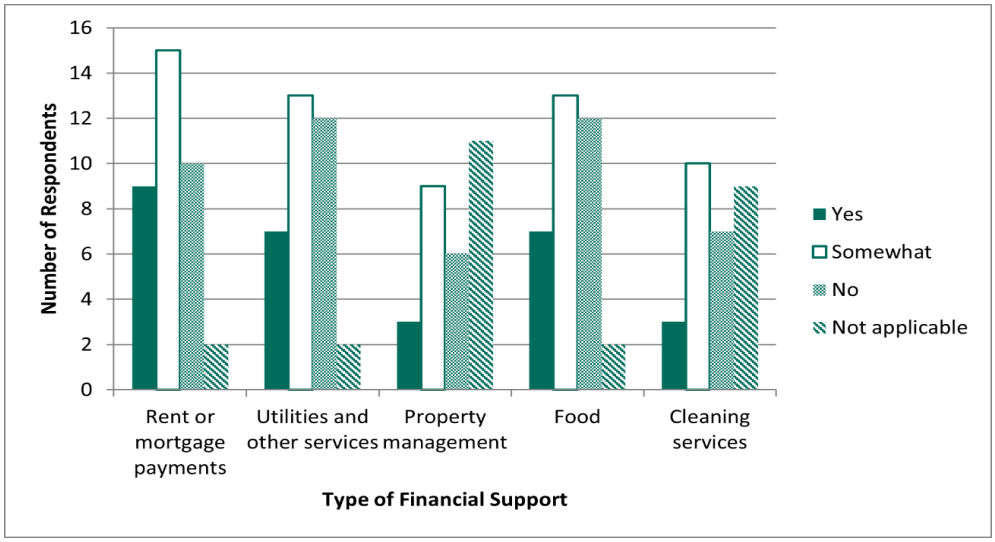
Similarly, most Queensland carers surveyed do not have plans in place for continued contributions to their person's **essential living costs**. Just one carer in each category of support indicated that they have plans in place to provide this type of financial support when they are no longer able to care.

Figure 7: Number of Carers with Plans in Plans in Place to Provide Financial Support for a Safe and Secure Place to Live (Queensland) (n=21)



Amongst the 43 Canadian carers who responded to the survey, a higher proportion of carers than in Queensland report that they have either started planning for essential living and accommodation costs or already have these plans in place. However, approximately a third of Canadian carers still report that they do not have any plans in place to continue these financial supports when they are no longer able to care.

Figure 7: Number of Carers with Plans in Plans in Place to Provide Financial Support for a Safe and Secure Place to Live (Canada) (n=41)



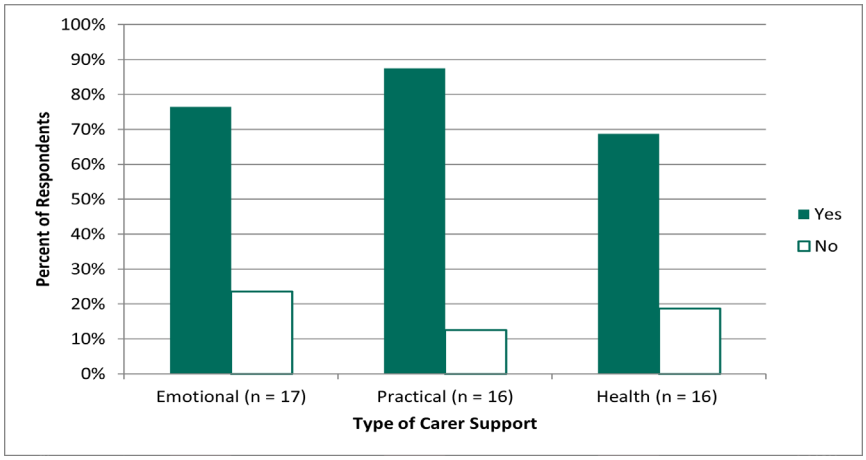
3. What mental health carers want

3.1 Carers want help to put plans in place for the future

While help to plan for all types of support is important, practical support is the thing most carers in Queensland say they need help to plan for.

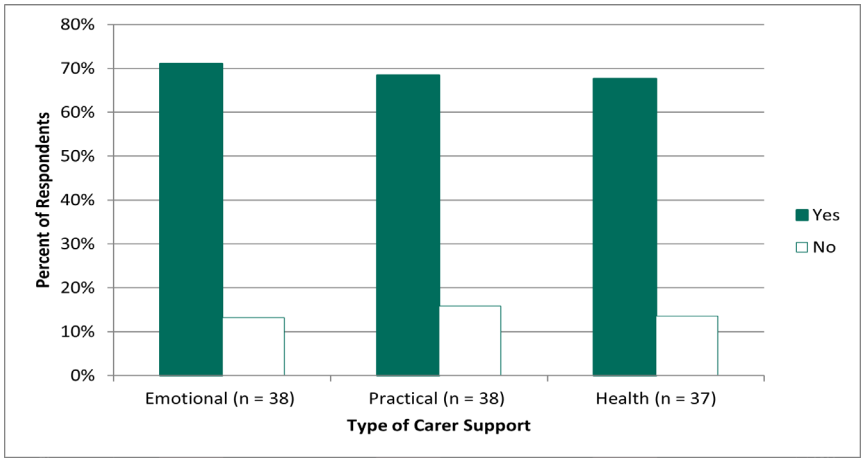
Fourteen out of the 16 Queensland carers (88 percent) who responded to this survey question told us they need help to put a plan in place for **practical support** into the future. Thirteen out of 17 respondents (76 percent) said they want help to plan **for emotional support** and 11 out of 16 respondents (nearly 70 percent) said they need help to plan for **health support**.

Figure 8: Queensland responses to "Do you need help to put a plan in place?"



The Queensland proportions are slightly higher than those of Canadians, where approximately 70 percent of carers told us that they need help to plan across each category.

Figure 9: Canadian responses to "Do you need help to put a plan in place?"



By contrast, around 50 to 60 percent of respondents from each country would like help with planning for **a safe and secure place to live**.

3.2 Carers want support for a range of planning needs

Planning for the future support of a person who experiences ongoing mental health challenges involves thinking about many different aspects of that person's life. During focus groups, Queensland mental health carers told us that they need a range of different types of support to help them and the people they care for to more easily and confidently plan for the future, including:

- Estate planning
- Financial safeguarding planning
- Other financial and legal planning (e.g. enduring power of attorney, advanced health directives, insurance)
- A plan for when things go wrong
- Planning for ongoing practical support
- Planning for ongoing social and emotional support
- Planning for safe and stable housing
- 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 space for thinking through planning)
- Planning for different kinds of caring situations and stages of life.

MICA has identified from their own conversations that they want to focus on supporting Canadian caregivers to plan for their person's ongoing personal supports, legal supports, financial supports and property management supports.

3.3 Carers want support to implement future care plans

While having a plan is important, carers also said they and the people they care for would need help to *carry out* the plan once its decided. Supports that Queensland carers felt would be useful included:

- A facilitation/co-ordination team
- Someone on the end of the phone who understands mental health challenges (and is available to speak to their person)
- Alternatives to the Public Guardian/Public Trustee to help manage finances and decision-making
- 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 (i.e. what can be implemented now to support independence and autonomy).

In Canada, MICA is interested in pursuing the establishment of a 'third party organisation' that could take on the role of ongoing implementation of the plans that caregivers and the people they care for put in place.

3.4 Carers want supports in place that foster trusting long-term relationships

In addition to having the right type of support in place, carers told us that the quality of the support provided (i.e. how it feels for their person) is also important. Queensland mental health carers 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 cared for/about
- Foster trust
- Encourage long-term relationships and continuity of care
- Use a team/partnership approach
- Be grounded in a strong understanding of mental health (e.g. peer workers)
- Be accountable
- Be kind and compassionate.

4. Future planning challenges in Queensland

The focus groups and interviews conducted with family members and other carers in Queensland highlighted a range of issues that need to be considered in developing solutions to help with planning for the future.

The Queensland context differs significantly from the Canadian one in terms of mental health and disability support systems. The findings below should therefore be considered within context.

4.1 Families and carers are providing supports that the mental health system is not equipped to provide

The carers we spoke to during interviews and focus groups described a mental health system that is fragmented and reactive. The broad lack of proactive support and continuity of support for people experiencing mental health challenges requires carers to "fill in the gaps". Carers spoke about:

- mental health services being primarily crisis driven and failing to foster long-term mental health stability
- challenges in accessing Specialist Mental Health Clinicians (e.g. psychiatrists, psychologists) with frequent clinician turnover impacting continuity of care
- lack of access to the NIDS, inconsistent NDIS services and funding packages that are underutilised due to frequent provider changes, poor worker fit and/or a lack of proactive engagement with the person being supported.

As a result, carers frequently act as de facto support coordinators, advocates and system navigators, without formal recognition or relief.

Carers also described being the ones who are left to hold the story, provide continuity across services and provide the ongoing support and check-ins that help their person maintain wellbeing and avoid crises.

> ***"In the old days the family doctor, or psychiatrist would have held the story of the patient, however these days there is such high turnover in health professionals that medical history is quite skimpy."***
>
> ***"[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."***
>
> ***"I haven't had a holiday in 20 years. My foster children are in NDIS housing but it's unclear what things are my responsibility and what are the responsibility of the coordinator – they have been quite happy to let me shoulder the responsibility."***
>
> ***"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?"***

Some interviewees did talk about highly supportive long-term relationships with health professionals, such as allied health professionals, psychiatrists and GPs, who both support their person well and work to engage and support the family. In these professional relationships, trust and consistency are the factors that make the biggest difference in mental health care. In these few cases, the carers also reported feeling highly supported themselves.

Most of the carers however were concerned about who was going to fill those gaps, hold the story, provide continuity and help navigate fragmented systems when they are no longer able to.

4.2 Legal and financial planning supports are mostly accessed by carers who have time and money to do so

Most carers we spoke to during interviews and focus groups felt that having legal and financial supports in place would help them to be more confident about the future.

> ***"I have also bequeathed my money to go via the Public Trust – this will need to be drawn out by invoice. This has eased my mind, and my other children's minds, about how this will go after I pass. It's ultimately about them being safe and housing is a big part of this."***

Queensland carers told us that they access legal and financial planning supports such as lawyers, will and trust planning and financial advice to protect housing, income security, and continuity of care. However, these supports are largely paid for privately and accessed by carers with sufficient means, time, and confidence to address future planning.

Most carers described feeling overwhelmed, burdened and confused by the process.

> ***"My son's inheritance could go down the gurgler really fast. I have tried to address this by setting up a disability trust, but this costs thousands of dollars."***

> ***"The prospect of will creation is overwhelming. We have an annual meeting with our financial planner, and every year he asks, "how are things going with our wills?" and we have to face the duality of what we present to the outside world vs what is going on in our hearts. There is a highly emotional and practical challenge in creating a will because it's not a simple process in our case."***

> ***"If you are not feeling emotionally or practically able, is this the right time to create a will?"***

> ***"You can't predict or control the future. I did go to a solicitor and paid a lot of money to have a will put in place. If you mean, how have we managed to establish harmony? It's because I decided…money wasn't important"***

> ***"I was told by a judge when seeking guardianship to do everything you can to keep them out of Public Trustee. I don't have anyone who has capacity to take on this responsibility when I am gone. It's hard to know where to start the process of planning for the future. You have to find the way yourself."***

4.3 Future planning circumstances are unique and complex, and often require tailored solutions

One of the things that stood out from the interviews was how unique caring situations and the range of planning complexities that are involved are for each family. These complexities can be related to the challenges of family dynamics, fluctuating decision-making capacity of the person being cared for, and/or consideration of the legalities and unintended consequences or implications that planning decisions may have on other aspects of a person's long-term wellbeing.

For example, one carer described how – while it may seem supportive on the surface – receiving a large inheritance from another family member would negatively impact her adult child's eligibility for the Disability Support Pension, which they had adapted to living within. However, this decision was not hers to make and required the whole family (including those separated by geography and divorce) to come together to find the best solution.

In instances like these, a deep understanding of the rules of the system is required. In most cases however, carers are not equipped to delve into these technicalities themselves and professional services are needed.

5. Possible models for future supports

The Literature Review identified a wide range of examples from Australia and overseas that provide possible models for solving future planning needs. These are briefly described below, along with some of strengths and weaknesses of each approach.

These examples are described in greater detail in a separate Literature Review report.

5.1 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.

5.2 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.

5.3 Microboards

A Microboard is a small, incorporated, not-for-profit group of trusted family, friends, and supporters. They work alongside a person with disability to help them make decisions, pursue goals, stay connected, and safeguard their wellbeing through a formal long-term support structure. It combines the relationship focus of a Circle of Support with governance capacity to coordinate supports, advocate, and provide continuity when primary carers are no longer able to do so.

5.4 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.

5.5 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 caregivers remains mixed.

5.6 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 to carers regarding long-term accommodation stability, though availability, eligibility and matching processes can limit access.

5.7 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.

5.8 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.

5.9 Mental Health Hubs

These examples provide accessible, walk-in multidisciplinary support for people experiencing distress or crisis. They improve early access and reduce emergency presentations, though their short-term, episodic nature may offer limited reassurance for long-term future planning.

5.10 Public Trustee/Public Guardian

These are government-appointed services providing financial administration, wills, trusts and substitute decision-making support for people with impaired capacity. The models offer legal and financial safeguards for future planning, but have faced criticism regarding transparency, cost and person-centred practice.

6. Implications for Future Planning

The research findings highlight a range of issues that need to be addressed if families and carers are to have confidence that the people they care about will continue to be well-supported into the future.

Addressing these issues may enable families and carers to begin to step away from some of their caring responsibilities well before the point when they can no longer care. This could have a significant impact on the sustainability of caring roles and help to avoid the long-term anxiety, stress and burn-out experienced by so many families and carers.

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.

Helping families and carers to address this issue may involve:

- Planning tools and resources
- Professionally facilitated planning sessions (individual, family, or group-based) to support difficult discussions about future roles, expectations, and inheritance before crisis or conflict occurs.
- Consideration of ongoing, secure, maintained accommodation, as this is central to sustained wellbeing for people with serious mental illness. The research shows that families and carers are covering significant financial costs to help the person they care for have a safe and secure place to live.

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 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.

These kinds of services need to incorporate:

- knowing the person well enough to recognise the signs of deterioration
- trauma-informed, non-judgemental service responses, especially following negative health system experiences
- practical "walk alongside" support that helps to rebuild confidence
- a strengths-based approach that supports identity beyond diagnosis and enables meaningful connection and contribution.

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, who can step in when needed.

Long-standing relationships with trusted clinicians (GPs, psychiatrists, dietitians) 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 person or a place to hold the person's story and health history when the family/carer is no longer able to do so is an important part of this type of support.

Issue 5.

Planning 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
- affordable, mental-health-informed advice on wills, trusts, and financial management that balances protection, autonomy, and family relationships.

7. Next steps

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

In Stage 2 of this project, we will share the findings of this Stage 1 research with carers and other stakeholders and work with them to identify possible solutions. We will then advocate for the funding and implementation of those solutions.

Appendix A: Future Planning Focus Group Questions

1. What is the most important thing that you would most like to have in place, that would give you some comfort that your person would be cared for if you're not around?
2. Is there anything stopping you from putting plans in place? Is there anything that has helped?
3. What would help you feel some confidence that your person will be well supported when you can no longer care?

Appendix B: Carer Interview Guide

What happens when I can no longer care?
Future planning for mental health carers project

Interview Guide - August 2025

Important Information

Thank you for agreeing to be interviewed as part of this important piece of work.

A few things to note:

- We will be recording the interviews for the purposes of accurately transcribing the conversation. The recording will be deleted once the transcription process is complete.
- We will use elements of the interview to write up a story in a way that is anonymous, with any identifying information removed.
- We will send the draft story to you for review.
- The story, or selected quotes from the story:
    - will be used as part of our report on the findings of this project
    - may be shared with Government or other stakeholders for the purposes of advocating for the needs of families and carers and the people they support
    - may be included in the planning tool we will develop to assist families and carers to plan for the future.
- If we would like to use the complete story in any other way, we will seek your approval first.

If you have any questions about the above, you can discuss these with the interviewer prior to the discussion. The interviewer will seek your consent to the above at the beginning of the interview.

Interview questions

The interview will take up to an hour and will be conducted online using Teams.

We would like to discuss the following:

1. Can you give a brief overview of your caring situation as a background to understanding your future planning needs?
   (For example, how long you have been supporting someone through their mental health challenges, their relationship to you, the nature of their mental health challenges, whether they live with you etc.)

2. What services and supports are already in place for the person or people you care for?

3. What support is your person or people reliant upon you or others to provide?

4. What supports do you have in place for yourself?

5. What would need to be in place for you to be able to step away from your caring role with confidence and trust?

6. What would help you to put that in place?

If the conversation raises any issues that cause distress, the Arafmi Carer Support Team can support you. The interviewer can arrange for a team member to call you, or you can call our 24-hour Carer Support Line on 1300 554 660.