



At what cost?

The experiences of
unpaid mental health
carers in Queensland



Acknowledgements

Arafmi wishes to thank the many mental health carers who contributed their time to this project. In doing so, Arafmi acknowledges the generosity of these mental health carers in sharing their insights and experiences.

Arafmi also wishes to acknowledge the Queensland Mental Health Commission for providing funding for this research, and to Queensland Health, Mental Health, Alcohol and Other Drug Branch for its continuing support in funding the advocacy work we do.

Arafmi extends its appreciation to [Numbers and People Synergy](#) for their assistance in designing the online survey and analysing the survey data.

© 2024 Arafmi Ltd
All rights reserved.

At what cost? The experiences of unpaid mental health carers 2023–2024

Arafmi
PO Box 248
New Farm QLD 4005
07 3254 1881
advocacy@arafmi.com.au
arafmi.com.au



Arafmi was founded in Brisbane in 1976. We are a not-for-profit organisation supporting families, kin and other unpaid carers of people experiencing mental ill-health.

As the peak body for mental health carers in Queensland, our mission is twofold:

- to provide a platform where unpaid carers can share their experiences in supporting someone with mental ill-health, and
- provide advocacy across all levels of government to address the systemic challenges faced by mental health carers.

Lived experience leadership plays a vital role in creating system change to better support mental health carers and the people they care for.

Lived experience can be described as experience "that has caused life as we knew it to change so significantly, we have to reimagine

and redefine ourselves, our place in the world and our future plans... Importantly, it's about learning how to use those experiences in a way that's useful to other people".¹

As a peak body, Arafmi ensures that the voices of lived experience inform all of its work and will continue to advocate to government, decision-makers and service providers to do the same.

Arafmi also provides free supports and programs in Queensland to those caring for someone experiencing mental ill-health, including a 24 hour Carer Support Line, workshops, groups and respite.

If you would like to provide feedback on issues raised in this report, or help to shape priorities for Arafmi's advocacy work, you can:

- contact advocacy@arafmi.com.au
- share your thoughts by scanning the QR code



For further information visit arafmi.com.au



Arafmi acknowledges Aboriginal and/or Torres Strait Islander peoples as the First Nations peoples of Australia and recognises their continuing connection to country, waters, kin, and communities. We pay our respect to Elders past, present and future and are committed to ensuring that Aboriginal and/ or Torres Strait Islander peoples voices are heard and respected across Queensland.

¹ Louise Byrne & Til Wykes (2020): A role for lived experience mental health leadership in the age of Covid-19, Journal of Mental Health, DOI: 10.1080/09638237.2020.1766002. p243

Contents

Executive summary	6
1. Introduction	9
2. Key findings from the consultations	12
2.1 Some roles, responsibilities and experiences are unique to mental health carers	14
2.2 Mental health carers support individuals with a diverse range of needs	15
2.3 Financial impacts on mental health carers are significant	15
2.4 Impacts on mental, emotional and physical health and wellbeing are also significant	19
2.5 Carers are concerned about what will happen when they can no longer care	21
2.6 Mental health system navigation and advocacy are ongoing challenges	21
2.7 Mental health carers experience stigma and social isolation	24
2.8 Carers often struggle to get a break from their caring responsibilities	25
2.9 There are differing views about use of the term 'carer'	25
2.10 Mental health carers seek support from a range of sources, but more is needed	27
3. What's needed to better support mental health carers?	28
3.1 Personal and practical support	30
3.2 Financial assistance	30
3.3 Information, education and training	32
3.4 Improvements to the mental health system	32
3.5 Recognition by the mental health system and wider community	34
3.6 Greater support for balancing work and caregiving responsibilities	34
4. Areas for action	36
Appendix A. Methodology and participation	41

Executive Summary

This report details the findings of consultations with mental health carers across Queensland. A **mental health carer** is someone who provides unpaid care and support to someone experiencing mental ill-health. They may be caring for a child, a parent, a partner or other family member, or for a friend or member of their community.



Executive Summary

Between September and December 2023, Arafmi consulted mental health carers across Queensland about their experiences and support needs.

A total of 83 carers participated in focus groups, 126 carers completed a short questionnaire, and 305 carers completed an online survey.

The consultations revealed that:

- The financial impacts on mental health carers in Queensland are significant, with almost three-quarters of respondents to the survey having experienced financial hardship due to their caring responsibilities.
- The impacts on carers' mental, emotional and physical health and wellbeing are also significant, with 46 per cent of survey respondents identifying as having mental ill-health themselves.
- Many carers are concerned about what will happen to the people they care for when they are no longer able to provide that care and are anxious about a lack of long-term sustainable support systems for the people they care for.
- Mental health system navigation and advocacy are ongoing challenges for carers and many feel excluded from important discussions and decisions regarding the people they care for.
- Mental health carers experience stigma and social isolation, which can contribute to poor mental health.
- Carers often struggle to get time away from their caring responsibilities, with respite and other support services in short supply.
- There are differing views about the use of the term carer and some people who provide support to someone with mental ill-health do not describe themselves using the term.
- Mental health carers receive support from a range of sources, but it is clear that more support is needed and carers need to be made aware of the support available.

The consultations highlighted that while carers are very clear on ways in which the mental health system needs to change to be of help to the people they care for, they sometimes struggle to ask for the support they most need for themselves. Despite this, there were some clear themes across the consultations about what was needed to support carers themselves, as well as to support the people they care for. These included:

- **Personal and practical support** – such as emotional support, practical assistance with daily tasks, respite, peer support and connection, family support, and support for carers' own physical and mental health.
- **Financial assistance** – to cover the costs of mental health caregiving, as well as to help address the financial disadvantage experienced by many carers.
- **Information, education and training** – assistance with navigating systems and services, information about mental health conditions and building skills in advocacy and self-management of health and wellbeing.
- **Improvements to the mental health system** – better access to mental health services, individualised care for those with mental health conditions, cultural sensitivity and diversity in service delivery and long-term planning to ensure the people they care for are looked after into the future.
- **Recognition by the mental health system and the wider community** – including understanding of mental health carer roles and greater communication with health professionals.
- **Greater support for balancing work and caregiving responsibilities** – such as flexible work arrangements.

Given these findings, Arafmi has identified six areas for action that will guide our advocacy work over the next two years:

1

Raise awareness of mental health carers so that they can be better recognised and supported

2

Advocate for physical, emotional, social, mental health and practical support for mental health carers

3

Facilitate access to relevant information and training for mental health carers

4

Promote carer inclusion in mental health treatment planning and implementation

5

Increase financial assistance for carers

6

Advocate for inclusion of the voices of mental health carers in mental health reform

01.

Introduction

The role of carers and families in the mental health system and the impact of caring responsibilities on unpaid carers have been the focus of several State and Commonwealth Government inquiries and reviews and numerous pieces of research in recent years.

It is clear from this work that families, kin and other carers are under-recognised, under-valued and under-supported, both within the mental health system and within our communities more broadly.

As the peak body for mental health carers in Queensland, Arafmi has set out to explore whether families, kin and others who are unpaid carers for someone with mental ill-health have had similar experiences in carrying out their carer role. We also sought to understand what mental health carers most need in terms of support and systemic changes that could help to reduce the negative impacts of caring and assist in caregiving.

Between September and December 2023, we conducted a series of consultation activities that included 10 focus groups, a brief questionnaire and an online survey. A total of 83 mental health carers participated in the focus groups, 126 carers completed

the short questionnaire, and 305 carers completed the online survey. The vast majority of those who engaged in the consultation activities were currently in caring roles.

It is important to note however, that many people providing unpaid care and support to someone with mental ill-health do not recognise themselves as carers. They may associate 'caring' with providing assistance with personal care and daily living tasks, rather than with the provision of emotional and practical support, as is often the case with mental health carers. They may also think that the care and support they provide is "just what you do" for family members, friends or members of their community. Arafmi acknowledges that the experiences and needs of those who do not recognise themselves as carers may not be fully captured in these findings and will be the subject of further research.



What do mental health carers do?

Mental health carers commonly mentioned that they:

Provide emotional support

Mental health carers provide emotional support, understanding, and comfort to the person they care for. This includes being patient, empathetic, and non-judgmental, as well as creating a safe space for open communication throughout the slow and non-linear process of recovery from mental ill-health.

Provide practical assistance

Mental health carers often engage in practical tasks such as organising appointments and supporting the person they care for to attend them, managing medications, providing transport, assisting with decision-making and planning, and assisting with daily activities like cooking, cleaning, and personal care.

Advocate for the person they care for and navigating systems

Mental health carers frequently act as advocates, navigating complex systems such as healthcare, social services, and support networks. This involves coordinating with healthcare professionals, accessing resources, and advocating for the needs of the individual they care for.

Build knowledge and combat stigma

Mental health carers often need to educate themselves about mental illness to understand the specific challenges faced by the person they care for, as well as to promote awareness and acceptance of mental illness within their communities.

Make personal sacrifices

Many mental health carers spoke about the personal sacrifices they make, including putting their own needs behind those of the person they care for. They also spoke of the demands of coping with the stress and emotional toll that arises from supporting someone with mental ill-health.

Constantly monitoring, supervising and managing crises

Caring for someone with mental ill-health often requires constant vigilance and monitoring of their wellbeing. This includes observing changes in behaviour, mood and symptoms, as well as providing crisis intervention when necessary.

Provide financial support

This includes supporting the payment of medical expenses, living expenses and other financial commitments.

Encourage professional help and social connections

Mental health carers often play a crucial role in encouraging individuals with mental health issues to seek professional help, whether that be therapy, counselling, or medical treatment. They are often also a facilitator of social interactions for the person they care for to help combat social isolation.

Create a stable environment

Providing a stable and supportive environment was highlighted by many carers as an essential component of caring for someone with mental ill-health. This includes minimising stressors, establishing routines, and ensuring the safety of the person they care for.

02.

Key findings from the consultations



Key findings from the consultations

1

Some roles, responsibilities and experiences are unique to mental health carers

2

Mental health carers are engaged with a wide range of service systems and are supporting individuals with a diverse range of needs

3

The financial impacts on mental health carers are significant

4

The impacts on carers' mental, emotional and physical health and wellbeing are also significant

5

Carers are concerned about what will happen when they can no longer care

6

Mental health system navigation and advocacy are ongoing challenges for carers

7

Mental health carers experience stigma and social isolation

8

Carers often struggle to get a break from their caring responsibilities

9

There are differing views about use of the term carer

10

Mental health carers seek support from a range of sources, but more is needed

2.1 Some roles, responsibilities and experiences are unique to mental health carers

The Productivity Commission has previously described the unique elements of mental health carer roles in terms of:

- **Nature of Support:** Mental health carers are more prone to provide emotional and psychosocial support instead of daily living assistance.
- **Relationship Strain:** Symptoms of mental illness may strain relationships, making care provision stressful.
- **Episodic Nature:** Fluctuations in mental illness intensity and duration render caregiving unpredictable.
- **Earlier Onset:** Mental illness typically manifests earlier than many physical health conditions.
- **Stigma:** Associated stigma with mental illness complicates the caring role further.²

Responses to the online survey and short questionnaire confirmed many of these points of difference.

Interestingly, many respondents to the survey and questionnaire reported providing daily living assistance in addition to emotional and psychosocial support. Carers reported that they frequently take on the responsibility of managing daily living activities and health needs of the people they care for. This includes organising medications, scheduling doctor visits and overseeing personal care and practical tasks. Carers spoke about helping with practical tasks like getting car repairs done and paying bills, as well as providing emotional support and guidance, like persuading a child not to undertake risky activities due to their mental health condition. The stress of managing these tasks can be overwhelming, particularly when carers have to act as coordinators for all aspects of the lives of the people they care for.

2.2 Mental health carers support individuals with a diverse range of needs

Respondents to the online survey support individuals with a diverse range of mental health and wellbeing needs, including caring for the mental health of children, youth and older people, and caring for those experiencing both mental health issues and disability, homelessness or alcohol and other drug disorders (see Figure 1).

Whilst the largest proportion of respondents have engaged with State Government provided mental health services, engagement with private and community services was also common (see Figure 1).

2.3 Financial impacts on mental health carers are significant

Despite two-thirds of respondents to the online survey reporting that they receive

a government support payment or allowance for their carer role, almost three-quarters of respondents reported having experienced financial hardship as a result of their caring responsibilities.

A third of the respondents work fewer hours, or not at all, due to their caring role. Unsurprisingly, those mental health carers are more likely to have experienced financial hardship (see Figure 2).

The financial impact of caregiving also emerged as a major theme in focus group consultations. Mental health carers spoke about the high costs associated with medical care, including medication, appointments and transport costs, and how these expenses often led to financial strain. Many carers spoke about the significant costs involved in getting assessments and reports done so that the person they care for could apply for the NDIS or other supports.

“

My 'carer' role fluctuates with my child's level of wellness\ functioning. He can be quite independent with lower level needs and then have periods of higher needs with constant monitoring and support.

Survey respondent

“

I am his portal to the world.

Focus group participant

“

[You play a] life logistics role - whatever is needed you do.

Focus group participant

“

Attempting to get my daughter in to see a psychiatrist to get tested for a diagnosis was stressful. I spent time on the phone researching psychiatrists and it was going to cost over \$2,000. I couldn't do this and pay rent and get the car serviced.

Focus group participant

“

It cost \$5,000 to get reports done to support the NDIS application. You get some money back through Medicare, but there's also the cost of medication, doctor's appointments, psychiatrist appointments.

Focus group participant

² Productivity Commission (2020). Mental Health Inquiry Report (No. 95). Commonwealth of Australia. p873-875

Figure 1. Numbers and percentages of survey respondents engaging with different types of services and supporting different types of health and wellbeing needs

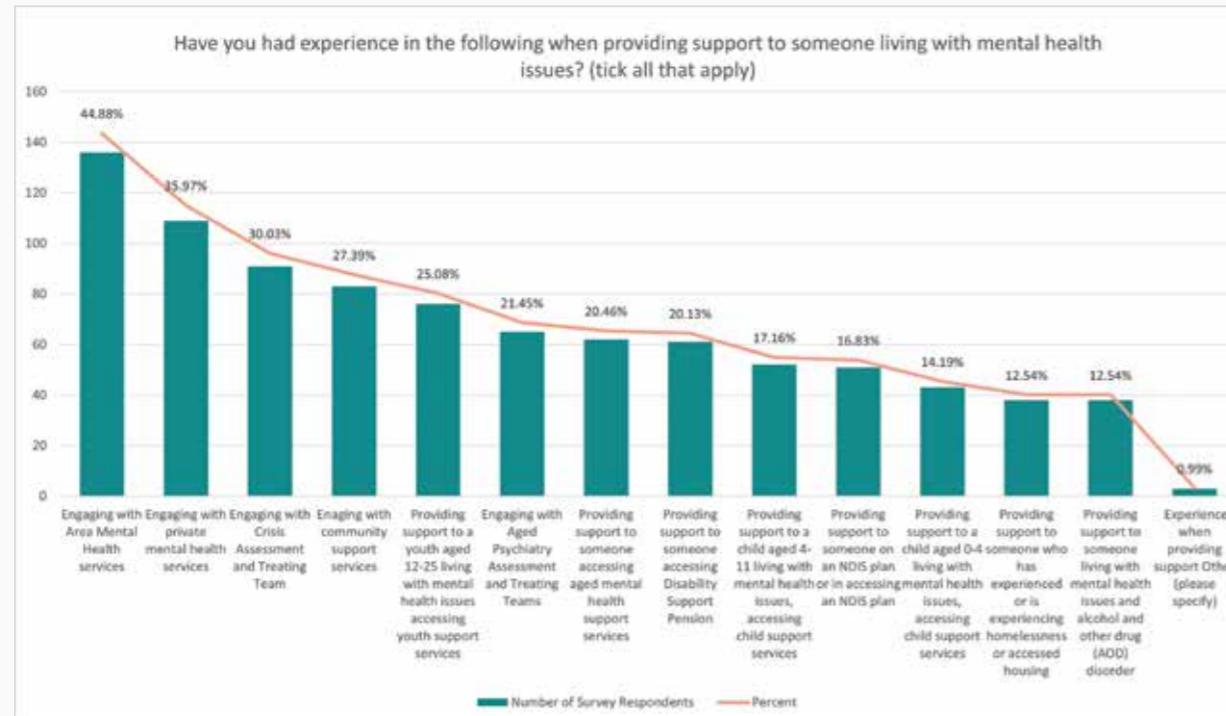


Figure 2. Relationship between participation in paid employment and experience of financial hardship

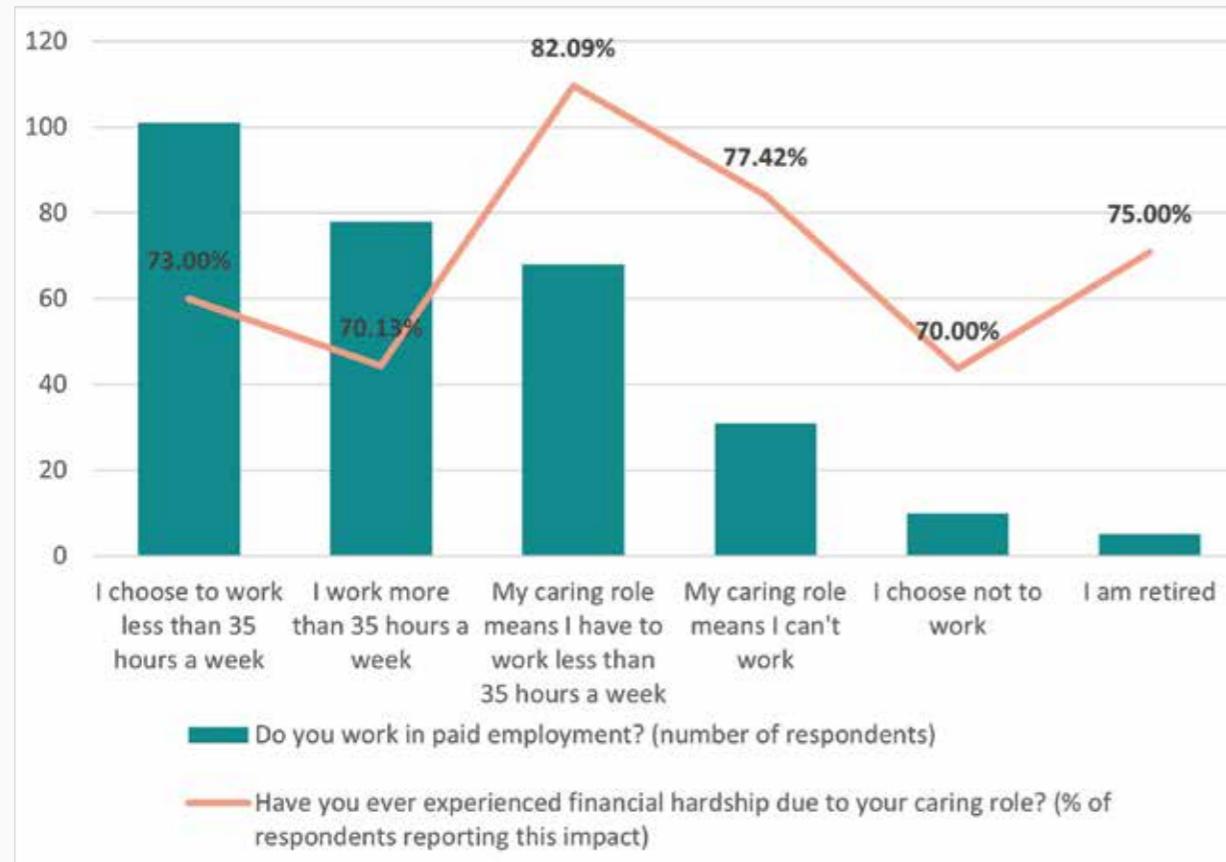


Figure 3. Number and percentage of survey respondents reporting particular impacts of caring

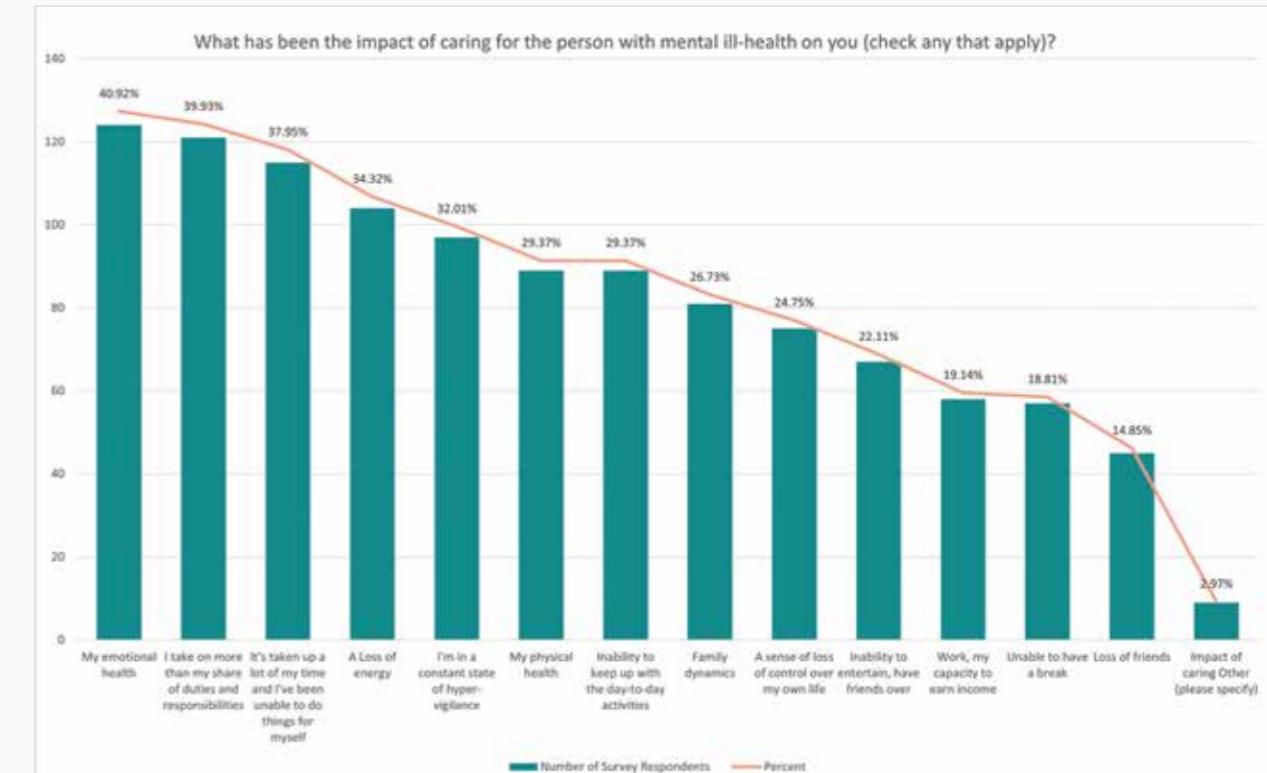
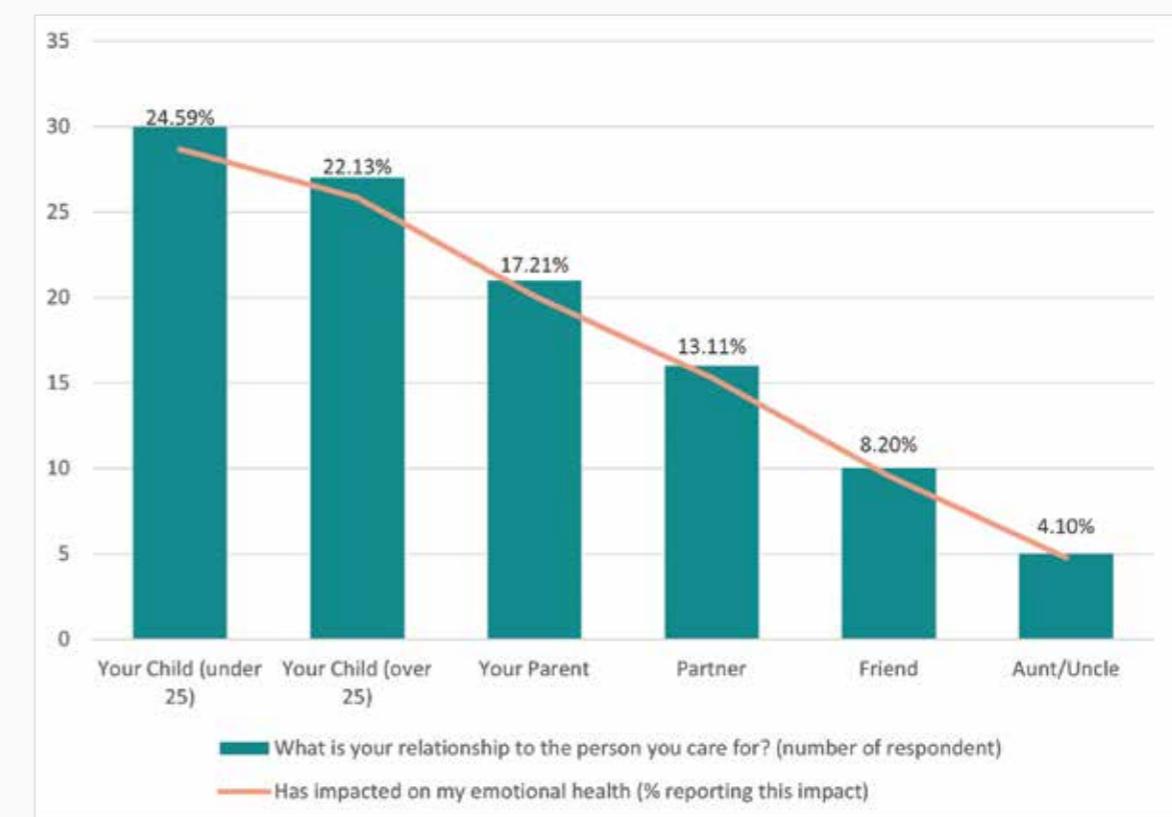


Figure 4. Relationship between impact on emotional health and carers' relationship to the primary person cared for



Balancing work and caregiving duties is a common struggle for mental health carers. Many find it challenging to maintain a full-time job while ensuring the needs of the person they care for are met. This balancing act often results in carers making sacrifices in their professional lives, leading to additional stress and financial insecurity.

The consultations also revealed stories of carers having to choose between paying for their person's care needs or covering basic expenses like rent and food as government allowances are insufficient to cover both.

Others spoke about the gap between their ability to work due to their caregiving responsibilities and eligibility for government support.

These findings echo those of many recent reports on the impacts of caring. The 2023 Report of the Senate Select Committee on

Work and Care highlighted the effect that caring has on financial wellbeing, particularly for women, who continue to carry the majority of caring responsibilities.

It explains the very wide gaps in lifetime earnings for workers with caring responsibilities and it casts a long shadow into retirement for many working carers and women who, after a lifetime of work and care, enter a retirement of poverty.³

Research conducted by Carers Australia also found that Australian carers lose a considerable amount in lifetime earnings and superannuation and that the age at which a person becomes a carer has significant impact on the financial impact.⁴ Given that mental ill-health typically manifests earlier than many physical health conditions,⁵ mental health carers are more likely to experience significant financial impacts over time.

2.4 Impacts on mental, emotional and physical health and wellbeing are also significant

46 per cent of respondents to the online survey reported that they also live with mental ill-health.

Mental health carers participating in the consultations spoke about the immense stress, anxiety, and often depression they face due to their caregiving responsibilities. One carer mentioned the need to "protect yourself, as you can go down if you do too much," reflecting the emotional toll of caregiving. Others shared feelings of guilt and self-blame - common emotional experiences amongst carers who are deeply involved in the lives of those they care for. Many spoke about the impact of constant vigilance and the episodic nature of mental ill-health.

Other common experiences amongst mental health carers who responded to the survey were:

- impacts on emotional health and physical health, including loss of energy and being in a constant state of hyper-vigilance
- impacts on life balance, including having to take on more than their share of duties and responsibilities, being unable to do things for themselves, being unable to keep up with daily activities, feeling a loss of control over their lives, loss of capacity to earn income and being unable to take a break
- impacts on family and social relationships, including impacts on family dynamics, inability to entertain/have friends over, loss of friends, relationship breakdowns and social isolation (See Figure 3).

“

I receive a carers allowance and pension of \$1200 a fortnight. My rent is \$590 a week, so it just covers it. I have to drive my daughter to the mental health service every 2 days and fuel is expensive and I cook for my daughter so that she eats well. So I have to choose whether I'm going to spend money on my daughter, or on food, or rent or bills.

Focus group participant

“

We had a great GP at the time who referred our son to a psychiatrist. They were a great psychiatrist and prescribed the right medications. However getting the funding for that was a challenge. We remortgaged the house to pay for the bills. It wasn't until my husband could no longer work that the government would help.

Focus group participant

“

I can't work very much, but I can't get a carers payment.

Focus group participant

“

I am a capable person in a caring role unable to work & money is a big problem.

Survey respondent

“

Supporting people who have intermittent periods of poor health (i.e. months of unwellness, inpatient admission, treatment and then experience recovery/ remission) are difficult to describe in terms of caring responsibilities... I suppose the impact of the constant "vigilance" and "low grade worrying" is hard to define as a carer and even more impossible to quantify to others (to have any kind of acknowledgement of the "mental load" this places upon me). I also have other carer responsibilities for my children, so it feels like someone is always experiencing some kind of distress. This worry gathers inside me and just generally makes me feel uncertain and anxious.

Survey respondent

³ The Senate Select Committee on Work and Care (2023). *Final Report*. Commonwealth of Australia. pxxv

⁴ Carers Australia (2022) *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers – a report for Carers Australia: Summary of Findings*.

⁵ Productivity Commission (2020). *Mental Health Inquiry Report (No. 95)*. Commonwealth of Australia. p873-875

Analysis of different variables in relation to emotional health (which was the most common impact reported by survey respondents), has highlighted some interesting patterns:

- Those who were caring for a child were more likely to report that their responsibilities had impacted on their emotional health (see Figure 4)
- Those caring for someone under the age of 15 were most likely to report an impact on their emotional health. Those caring for someone between 55 and 74 were also more likely than not to experience impacts on their emotional health – although the low number of responses here requires caution in interpretation (see Figure 5)
- Those in the first 12 months of their caring journey were more likely to have experienced impacts on their emotional health than those who had been caring

for between 1 and 5 years. After that point however, the likelihood of impact grows significantly, with more than 80 per cent of those who have been caring for 10 years or more reporting impacts on their emotional health (see Figure 6)

- The likelihood of caring responsibilities impacting on the carer's emotional health also increased significantly as carers aged (see Figure 7).

These findings regarding the differential impacts of caring on the carer's emotional health and wellbeing may suggest that further support is needed for:

- mental health carers who are at the beginning of their caring journey and those who have been caring for a long time
- those caring for children – especially when caring for children with mental ill-health who are under the age of 15
- older carers (from age 55 onwards).

“
It feels like you are constantly walking behind, waiting for them to drop, to then pick them up.
Focus group participant

“
I'm at breaking point trying to keep everyone afloat. But we [carers] don't have the option to break, otherwise who will support our loved ones?
Focus group participant

“
I have my eldest son to take over from me when I pass and that's a lot to take on, but he's got no choice. I've seen people in care without family and it's horrendous and I can't let my son go through that.
Focus group participant

“
I needed to go to the mental health tribunal to get him treatment.
Focus group participant

2.5 Carers are concerned about what will happen when they can no longer care

Concerns about the future were raised by mental health carers, particularly in relation to what will happen to the people they care for when they are no longer able to provide care themselves.

The consultations revealed anxieties about long-term care and the lack of sustainable support systems. For example, one carer shared her worries about her son living independently and the realistic challenges of achieving this goal, highlighting the need for long-term planning in caregiving.

2.6 Mental health system navigation and advocacy are ongoing challenges

The consultations revealed many instances where carers had to navigate complex health systems, sometimes struggling to secure

necessary medical appointments or procedures and experiencing long wait times and difficulties with transportation and funding.

Carers must often advocate for the people they care for, in situations such as interacting with health professionals and dealing with social services. Carers shared experiences of advocating at appointments to ensure the needs of the person they cared for were understood and met, and sometimes having to provide additional information to medical professionals when the person they care for is unable to recognise the realities of their own situation.

This dual role of supporter and advocate is both challenging and essential to the care process. However, the emotional toll of these responsibilities on carers is significant.

Mental health carers frequently face challenges in navigating health and support systems.

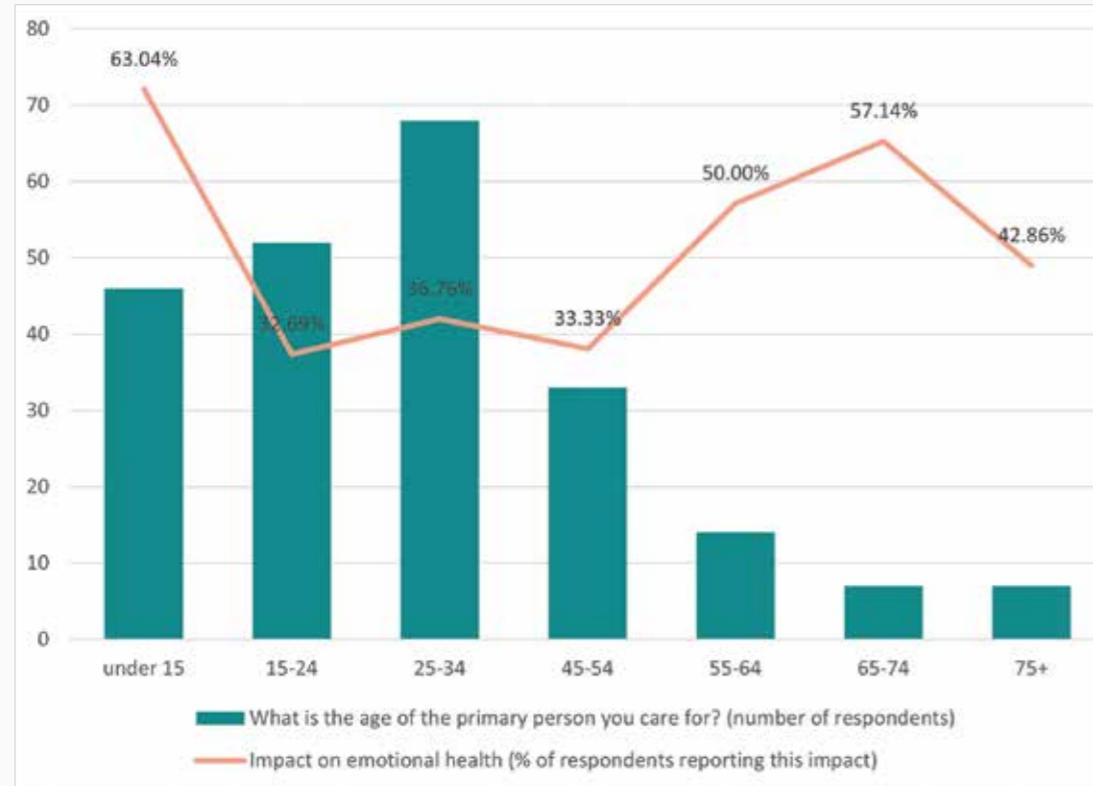
“
It's very hard to find a supportive GP and psychiatrist. It takes time to build a relationship with professionals and very expensive too.
Focus group participant

“
You often find out the hard way what's available and what would've helped in the early stages. It would be good to have someone support you from the beginning and throughout the journey to help connect to services.
Focus group participant

“
I am a holder of the whole story.
Focus group participant

“
In the past I've had a breakdown due to the pressures. I was in hospital for five months due to doing it alone.
Focus group participant

Figure 5. Relationship between impact on emotional health and age of primary person cared for



N.B. As there were fewer than 5 respondents who were caring for someone in the 35-44 age bracket, these responses have been omitted from the analysis.

Figure 6. Relationship between impact on emotional health and length of time caring

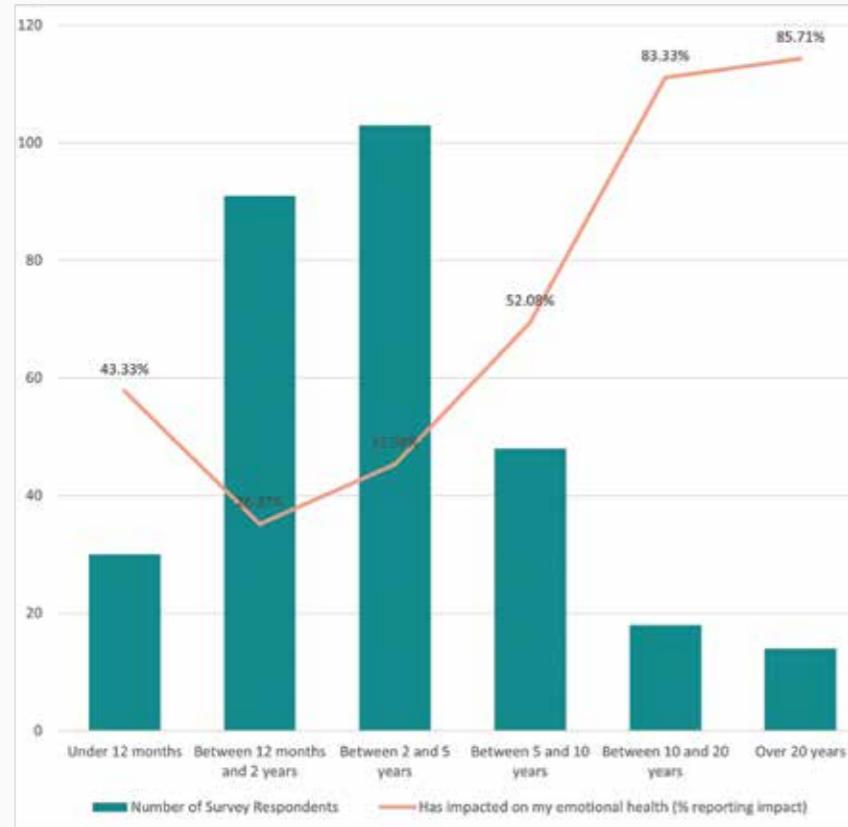


Figure 7. Relationship between impact on emotional health and age of carer

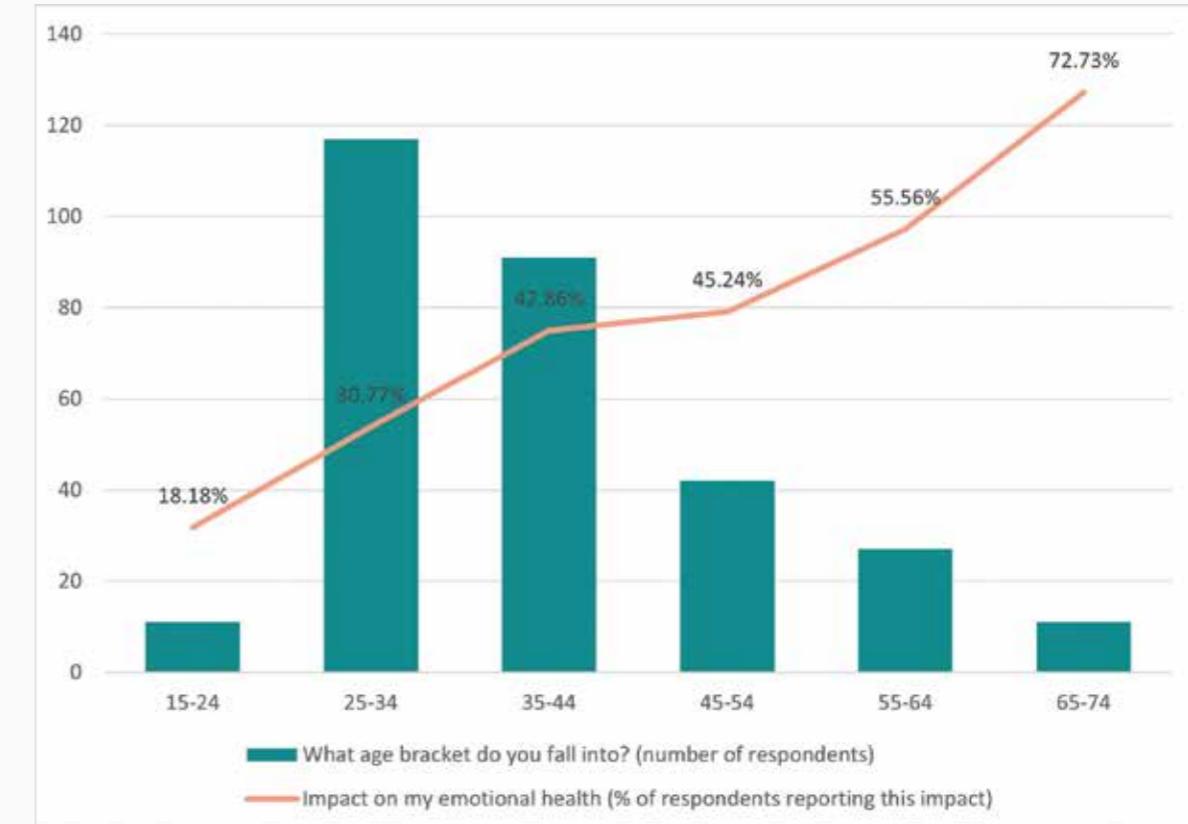
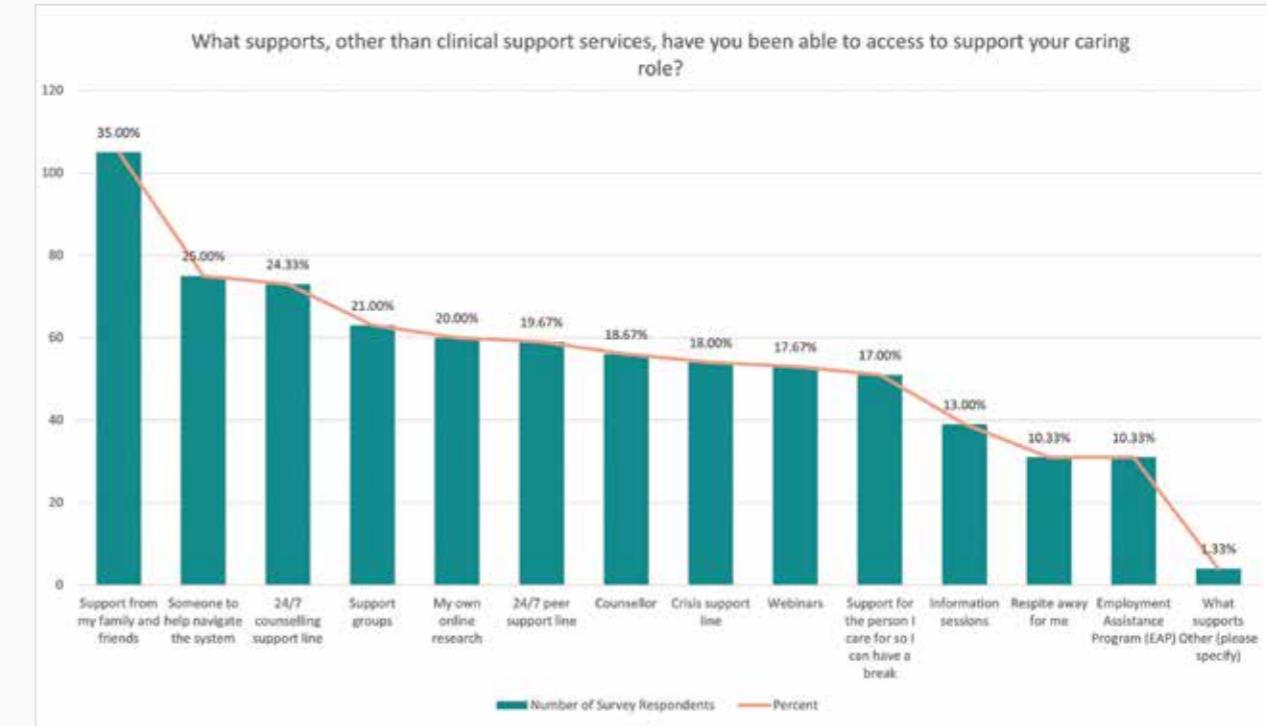


Figure 8. Number and percentage of survey respondents accessing different types of support



The consultations revealed stories of carers struggling to understand and access services like the NDIS. For example, one carer described the process of securing NDIS support as overwhelming and confusing, noting the extensive paperwork and bureaucratic hurdles involved. Another shared frustration about the lack of coordination between health services, which can lead to gaps in care and support for their loved ones.

Difficulties in accessing services are often compounded by the complexity of the systems themselves. Carers spoke about the need for more streamlined processes and better information to help them navigate these systems effectively.

2.7 Mental health carers experience stigma and social isolation

Stigma surrounding mental health and caregiving is another significant issue faced by carers. The focus groups revealed that carers often feel judged and misunderstood

by others, leading to social isolation. One carer's experience of being treated differently by medical professionals after disclosing her caring role exemplifies the stigma associated with mental health caregiving. This stigma can make carers reluctant to seek help or share their experiences, exacerbating feelings of isolation.

Social isolation is a recurring theme among carers, as their responsibilities can limit opportunities for social interaction and personal time. The consultations showed that carers often have little time for social activities outside their caregiving duties. This lack of social engagement not only contributes to feelings of loneliness, but can also impact carers' own mental health. A lack of understanding of what it is like to be a mental health carer can also contribute to feelings of isolation, suggesting that interaction with peers with similar experiences can provide valuable support for carers.

2.8 Carers often struggle to get a break from their caring responsibilities

Respite and personal time are crucial for carers, yet often hard to come by. The focus group discussions highlighted the constant nature of caregiving, with carers expressing a need for breaks to manage their own health and wellbeing. The lack of respite opportunities can lead to burnout among carers. One carer mentioned the importance of "turning off the phone" to take a break from her responsibilities. Another shared the value of engaging in personal hobbies, like gardening, as a form of respite.

In their 2023 report, the Senate Select Committee on Work and Care noted that:

The committee was informed of the complexities for carers in seeking and securing respite care or substitute care for those they care for. It was also made aware of the importance of quality respite care for working carers as a means of managing their own

wellbeing and employment obligations as well as ensuring that those they care for receive the best quality care and support. To this end, the committee is convinced of the need for accessible, affordable and flexible respite care for the benefit of both working carers and those they care for.⁶

Our consultation findings suggest that this is also an issue for mental health carers more broadly, not just those who are working.

2.9 There are differing views about use of the term 'carer'

The consultations highlighted that while many mental health carers are comfortable with the term, others struggle with the label 'carer' and feel that it does not adequately capture the deep personal connections they have with the people they care for or the complexity of their roles. They seek acknowledgment of their unique contributions that go beyond professional care, as they

“

Having connections with other carer peers who had walked in a similar situation would have helped. I would have been able to learn from them and it would help me not to feel so alone or ashamed. I started to pathologise my 'caring too much' and feel crazy when the rest of my friends and community wished for me to have it easier. I was often encouraged to give up my caring duties, pushed to accept it as 'never going to get better', and judgements around my unwillingness to give up. This further isolated me and led me to fear that my caring was somehow shameful. Friends supported as much as they could but without a closer living experience of this, what was being offered as support actually was deeply disempowering to me at times.

Focus group participant

“

Being a carer is such a dignified thing, but people judge you being on a carer pension. The opportunity for full-time work is low. People judge you based on income.

Focus group participant

“

Some of the stories I have to tell, a lay person may not be able to reciprocate, hear comfortably, nor understand and appreciate in the ways I dearly need to feel seen heard and safe.

Survey respondent

“

My loved ones were resistant to accepting myself as a carer under carer payment applications. Being a support to my loved ones has impacted my life hugely, it has deepened me, grown me, however it has also had significant impact on my own mental health and physical health at which I was left without the same level of support I had given.

Survey respondent

⁶ The Senate Select Committee on Work and Care (2023). *Final Report*. Commonwealth of Australia. p178

encompass emotional, physical, and often financial support. The term 'carer' can also feel inadequate for individuals who view their role as a natural extension of their relationship, be it as a parent, partner, or friend. Similarly, there can be resistance to the use of the term carer by the person being cared for.

Interestingly, when asked about their preferences for language used to describe the role they play in supporting someone with mental ill-health, the large majority of survey respondents (79 per cent) agreed that the term 'carer' fits with their situation. Only 11 per cent disagreed with the term, while 9 per cent said that they don't know. This, however, may simply be a reflection of self-selection to participate in the survey by those who already identify with the term.

Suggestions for alternative terminology were

Support Person, Companion, Care Provider, Helper, Assistant, Guardian, Advocate, Loved One, Listener and Mentor.

The issue of whether people identify with the term carer is a significant one as it has implications for decision making and the provision and access of services. The recent Inquiry into the recognition of unpaid carers noted that:

Many people who provide care, including young people, First Nations carers and carers from culturally and linguistically diverse (CALD) communities, may not recognise the term 'carer' or identify themselves as carers. This can be a barrier to seeking support. The prevalence of 'hidden carers' means that current data collection about carers may underestimate the number of carers, which can impact policy and funding decisions.⁷

2.10 Mental health carers seek support from a range of sources, but more is needed

Respondents to the online survey were more likely to turn to family and friends for support in their caring role, with just over a third of respondents accessing this kind of support. Smaller numbers of respondents have sought help from supports such as system navigation, counselling, support groups and support lines, information services and respite services (see Figure 8).

Although all but a handful of respondents had accessed at least one type of non-clinical support, these results highlight the fact that there are only a small proportion of mental health carers accessing each type of support.

There is more work to be done to understand why mental health carers do and don't access

support. However, the consultations did highlight a difficulty amongst carers to think of themselves and their own support needs. This was particularly evident in focus groups, where participants had to be prompted to think about their own needs and not just those of the people they care for. There was also evidence of this in survey responses, as well as indications that the support that is needed by mental health carers was not readily available.

“

Many discussions have been held about the terms "carer" and "consumer". No-one seems to feel they are appropriate, but no-one seems to have the answer. I certainly don't, although I have given it great thought. When I told my son I was attending Carers Qld meetings, he commented "but you're not my carer". The only reply I could think of was "no, but I care about you". I believe it is well known that many "carers" miss out on support because they do not see themselves as carers. I was one of those until a lovely lady introduced me to Carers Qld (pre-Carer Gateway).

Survey respondent

“

As an Aboriginal woman, I was raised that family is family and if we have the ability to help we help. I went through a lot as a child myself and didn't get the supports I needed at all! But when niece and nephews came into my care I didn't and don't view myself as a carer, I just view myself as an aunty being there for her family the way they deserve to have. Sometimes being called a carer to us mob can be confronting and scary because we don't think of it as a role, it's just what we do and how we were raised.

Survey respondent

“

*I'm not his parent.
I'm his partner.*

Focus group participant

“

I know I can get the support but find it hard. I've never had to ask for help before but now I need all the help I can get but I'm struggling to ask for it.

Survey respondent

“

When you lose yourself in your life due to caring, that's when you become a carer. You aren't just a mum or dad.

Focus group participant

“

I am only now just realising there are supports out there for us. I'm yet to push my shame aside as I feel like getting supports mean I am failing but I hope to soon have the strength to reach out for some supports.

Survey respondent

⁷ House of Representatives Standing Committee on Social Policy and Legal Affairs (2024). *Recognising, valuing and supporting unpaid carers: Inquiry into the recognition of unpaid carers*. Parliament of Australia. p3

03.

What's needed to better support mental health carers?



What's needed to better support mental health carers?



Personal and practical support



Financial assistance



Information, education and training



Improvements to the mental health system



Recognition by the mental health system and wider community



Support to balance work and caregiving

Respondents to the survey identified a wide range of elements that would make a difference to them in their caring role. For example:

“

Someone to help navigate the systems. Advocates. Professional counselling for coping strategies for selves and for dealing with person. How to deal with delusions etc. Being listened to and heard. More preventative measures from the beginning of this roller coaster journey and more education on what to expect and how to care for ourselves and assistance to do so. More support around family relationships and how to solve issues with that. Services and supports tailored to our specific circumstances and needs - a holistic approach.

Survey respondent

“

A health system that is holistic and collaborates, a mental health system that works and is less siloed. Practical support with daily living, respite, advocates/counseling. More information to have more understanding and education and strategies to deal with the person and also coping strategies for ourselves and lives.

Survey respondent

Across different consultation methods there were many common themes about what would help mental health carers to feel more supported. Some of these themes relate to support for carers themselves, while others relate to changing aspects of services or supports in order to make the caring job easier.

3.1 Personal and practical support

The most common need expressed by mental health carers across the different consultations was for greater recognition and support for their own emotional wellbeing. Carers highlighted feelings of isolation and stress and spoke of the need for stronger community connections and access to social networks for both practical and emotional support.

Access to professional support, including regular health check-ups and psychological counselling, as well as access to mental health resources and self-care opportunities, were mentioned by caregivers as important for maintaining their own health and wellbeing. The consultations revealed a desire amongst mental health carers for support systems that recognise the importance of their personal time and provide opportunities to recharge and maintain their own health, and that this support needs to be received early in the caring journey.

The need for breaks and respite care was commonly mentioned across consultations, suggesting that caregivers are at risk of burnout without adequate rest. Carers emphasised the importance of accessible respite services, as well as access to sufficient leave to be able to take a break from caregiving.

Assistance with daily tasks and care responsibilities was another frequently

mentioned need, underscoring the all-encompassing nature of caregiving.

The importance of support from family and friends was also emphasised in consultations, indicating the value of strong personal networks.

Many respondents to the survey spoke about the need for support for the whole family, not just the primary caregiver.

3.2 Financial assistance

The need for financial assistance to help mitigate the economic burden caregivers face due to their caregiving responsibilities was a frequent topic of conversation during consultations. Survey responses highlighted the impact caring responsibilities have on carers' ability to access employment. At the same time, carers often face substantial costs in providing care and covering medical expenses for those they care for, creating financial strain.

The recently released report of the Australian Government's Inquiry into the Recognition of Unpaid Carers, noted that amongst submissions to the inquiry:

There was support for a new strategy that includes policies that address the financial disadvantages carers face over their lifetime and make it easier for carers to balance their caring responsibilities with work, which would reduce gender inequality in Australia.⁸

One of the inquiry's recommendations is that "the Australian Government introduce an income tax credit for carers returning to the paid workforce and consider other options to incentivise and recognise the impact of caring through the income tax and superannuation systems".

The findings of our consultations suggest that there is more to be done, not only to address

⁸ House of Representatives Standing Committee on Social Policy and Legal Affairs (2024). *Recognising, valuing and supporting unpaid carers: Inquiry into the recognition of unpaid carers*. Parliament of Australia. p70

Respondents on the need for personal and practical support

“

One thing that was missing was emotional support. While there were resources available for practical assistance, such as information and advice, there was a lack of support for the emotional challenges that come with being a caregiver. It would have been beneficial to have access to counseling or support groups to help navigate the emotional aspects of my caring role.

Survey respondent

“

If you can take care of yourself, it flows onto your loved ones. Putting yourself at the top of self-care, nature and water and doing self-care is crucial. Funding for self-care would be helpful.

Focus group participant

“

Medical professionals never ask if I am ok.

Focus group participant

“

It would have been helpful to have someone come in and provide temporary relief so that I could take a break from my caring responsibilities.

Survey respondent

“

I was receiving home help before NDIS came in, but I personally didn't quite tick all the boxes when it rolled out. Then I got dropped with no assistance in the home which I really needed.

Survey respondent

“

[What would make a difference is] greater support in the home during acute episodes.

Survey respondent

“

We need to focus on early intervention for carers, before intergenerational trauma takes over.

Focus group participant

the financial inequalities faced by carers over time (and by mental health carers over longer periods of time than most), but also to address more immediate financial impacts. This includes impacts on mental health carers' ability to earn an income and the gaps between carer pensions and allowances and the combined cost of living, coverage of medical expenses, transport costs and other financial demands placed on mental health carers.

3.3 Information, education and training

Mental health carers often lack the necessary information, education and training to effectively manage the complex needs of the people they care for. There was a significant call from carers for access to reliable, easy to understand information about mental health conditions to support them in their caregiving roles.

There were also numerous calls for better access to caregiver training and educational materials. Access to education and training about the caring role can empower carers, improving their ability to provide care and advocacy for those they support. Carers highlighted the need for accessible, practical training programs that cover a range of topics, from health management to navigating support systems. Such education would not only benefit carers personally but also improve the overall quality of care they can provide.

3.4 Improvements to the mental health system

The need for accessible mental health professionals and services was a common theme across consultations. The responses highlighted a need for services that are accessible beyond regular business hours and that are responsive to crises. Carers discussed the difficulty in accessing support during

emergencies and the lack of follow-up care, which can leave them feeling abandoned by the system when they are most in need.

The consultations highlighted a desire for services that are more responsive to the needs of carers, as well as those they care for, with an emphasis on clear communication and support to access necessary services. This need highlights the importance of co-designing services with mental health carers and consumers to ensure they are responsive.

Carers expressed a strong desire for individualised care plans, tailored to the specific needs and circumstances of the person they care for. They observed that a one-size-fits-all approach to treatment often fails to acknowledge the personal characteristics and life histories that impact mental health. They advocated for a more holistic strategy that values quality of life alongside medical interventions, recognising the unique individuals they support.

Cultural sensitivity in caregiving also emerged as a key theme, with carers discussing the importance of culturally appropriate care for the people they support. The consultations highlighted instances where cultural differences impacted the caregiving experience. Carers emphasised the importance of services that respect and accommodate different cultural beliefs and practices, ensuring that care is both respectful and effective.

The need for systems that support both the immediate and long-term needs of carers and their loved ones was a recurrent theme. The discussions touched on the importance of having clear plans and support for the transition of care once carers were no longer able to provide support. Carers expressed a desire for more information and assistance in planning for the future, including understanding legal and financial implications.

Respondents on the need for Information, education and training and improvements to the mental health system

“

There are safe spaces, however they have restricted opening times. If someone is appearing very unwell, they then won't take them. They are left with Emergency being the only option, which only exacerbates the situation. They need to beef up safe spaces to help manage crises and make them more accessible.

Focus group participant

“

[We need] regularity and consistency from people who are committed to getting to know and understand the person long term. Learn over time how the person sees the world, how they communicate, how the family interact together, know when extra supports are needed and help engage those supports. When a crisis is imminent or happening, it is not always possible for the carer to be able to then get the extra help because they are in the thick of things and basically treading water to save themselves as well as the person they care for. AND RESPECT.

Survey respondent

“

Our son was released from the mental health unit after a suicide attempt. There was no follow up or any advice on how to support him afterwards.

Focus group participant

“

We need advocacy and information. Once you get a diagnosis, we need a simple explanation in plain English of what it is and how we can support.

Focus group participant

3.5 Recognition by the mental health system and wider community

Effective collaboration with health professionals is essential for carers, yet often challenging to achieve. The focus groups revealed instances where mental health carers felt excluded from important discussions and decisions regarding the people they care for.

Carers emphasised the need for open communication and partnerships with health professionals. They want better communication with healthcare providers and to be included in treatment and care planning. Their insights, born from close relationships and daily interactions with those they care for, are invaluable. However, carers often feel that these insights are overlooked, leading to a sense of exclusion from critical decision-making processes that directly affect their lives and those they care for.

They seek to be acknowledged as key contributors to care and wish to be involved in treatment decisions. Better collaboration between carers and healthcare providers can lead to more holistic and more effective care, ensuring that the needs of both the carer and the cared-for are met.

These findings echo the recommendation of the Queensland Government Mental Health Select Committee that "the Queensland Government investigates and implements strategies to better involve families, carers and support persons in the mental health care and treatment of individuals"⁹; a recommendation that was supported by the Queensland Government and is also reflected in Queensland's Better Care Together strategy.¹⁰

Similarly, the Productivity Commission Inquiry Report recommended that "All mental health services should be required to consider family and carer needs, and their role in contributing to the recovery of individuals with mental illness".¹¹

Further work is needed to turn these aspirations into reality across the whole mental health system.

In addition, there was a clear call across consultations for greater public empathy and respect for the caregiving role, to combat stigma. Carers often feel isolated in their responsibilities and expressed a desire for recognition of their knowledge and experience in caring for people with mental health challenges. Carers often feel that their contributions and challenges are not fully appreciated by health professionals or the wider community.

Understanding the carer role involves acknowledging the diverse responsibilities carers undertake, from healthcare coordination to emotional support.

The discussions showed that carers seek validation and appreciation for their roles, which are integral to the wellbeing of the people they care for. Carers suggested that greater recognition of carers' roles could lead to improved support and resources, and acknowledgement of their vital role in the healthcare system.

3.6 Greater support for balancing work and caregiving responsibilities

Caregivers involved in consultations also expressed a need for better support to be able to balance work and caregiving responsibilities.

Various recommendations have been made in recent government inquiries to address carers' access to work and workplace supports, including recommendations for:

- changes to the Fair Work Act 2009 regarding definitions of 'immediate family' for the purposes of an employee accessing carer's leave, and a review of the adequacy of current leave arrangements¹²
- a campaign to drive positive workplace cultures for carers¹³
- introduction of an income tax credit for carers returning to the paid workforce¹⁴
- mandatory reporting by large companies on implementation of flexible work practices.¹⁵

In their submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into unpaid carers, Arafmi put forward a number of work-related recommendations to be considered by the Australian Government in making changes to the Carer Recognition Act 2010. These included:

- **Recommendation 1:** Establish Supportive Workplace Policies: Encourage employers to create supportive work environments that understand the unique needs of mental health carers. This includes flexible work arrangements and adequate paid and unpaid extended leave provisions for carers.
- **Recommendation 2:** Provide Government Support for Transitions: Implement government payments and infrastructure, such as aged, disability, and childcare, that facilitate mental health carers' transitions into and out of the workforce.
- **Recommendation 3:** Develop Flexible

Workplace Practices for Young Carers: Promote flexibility in workplace scheduling, allowing young carers to balance their responsibilities without the fear of stigma or missed opportunities.

- **Recommendation 4:** Create Awareness and Support Programs: Implement programs that educate employers about the unique skills and challenges of young carers, fostering an environment that acknowledges and supports their dual role as caregivers and employees.

Recommendation 5: Reform Superannuation to Recognise Gender Differences in Caregiving: Implement superannuation reforms, including Superannuation Guarantee Contributions on the Carer Payment, to alleviate the gendered financial impact of caregiving, especially for women.

- **Recommendation 6:** Introduce Tax Incentives for Unpaid Carers: Develop a tax incentive akin to Canada's Caregiver Credit to financially support those consistently providing care to family members, recognising the predominantly female nature of this role.

Recommendation 7: Create a Comprehensive Social Contract Around Work and Care: Enact policies that reflect a modern understanding of work and care, including provisions for paid leave, flexible job opportunities, prevention of retirement poverty, and gender equality in caregiving roles.

The mental health carer consultation findings provide further evidence of the need for such reforms.

⁹ Queensland Parliament Mental Health Select Committee (2022). *Inquiry into the opportunities to improve mental health outcomes for Queenslanders*. p46

¹⁰ State of Queensland (Queensland Health) (2022). *Better Care Together: a plan for Queensland's state-funded mental health, alcohol and other drug services to 2027*.

¹¹ Productivity Commission (2020). *Mental Health Inquiry Report (No. 95)*. Commonwealth of Australia. p868

¹² The Senate Select Committee on Work and Care (2023). *Final Report*. Commonwealth of Australia. pxxvii

¹³ House of Representatives Standing Committee on Social Policy and Legal Affairs (2024). *Recognising, valuing and supporting unpaid carers: Inquiry into the recognition of unpaid carers*. Parliament of Australia. pxx

¹⁴ House of Representatives Standing Committee on Social Policy and Legal Affairs (2024). *Recognising, valuing and supporting unpaid carers: Inquiry into the recognition of unpaid carers*. Parliament of Australia. pxx

¹⁵ The Senate Select Committee on Work and Care (2023). *Final Report*. Commonwealth of Australia. p190

04.

Areas for action

In response to these insights from mental health carers across Queensland, we have identified six areas for action that will guide our advocacy work over the next two years.



Areas for action

These action areas are a response to the challenges and needs expressed by carers, with the goal of increasing the availability and awareness of support for the mental, emotional, physical, social and financial wellbeing of mental health carers in Queensland, as well as enhancing the effectiveness, accessibility, and responsiveness of the mental health system more broadly.

1

Raise awareness of mental health carers so that they can be better recognised and supported

Actions may include:

- Implementing initiatives to increase public awareness and understanding of the role that carers play in supporting mental health, with the aim of reducing stigma and social isolation. This may include initiatives implemented by Arafmi, as well as input to the development of community education campaigns as part of the new National Carer Strategy.
- Building relationships and forming partnerships with individuals and organisations that may have contact with people who are mental health carers (whether they recognise it or not), to assist with:
 - better identifying mental health carers (including young carers)
 - understanding the particular experiences and needs of mental health carers and families
 - referring mental health carers to available supports.
- Conducting further consultation with 'less visible' groups of mental health carers and those who may not recognise themselves in the term 'carer', to identify any needs that are not captured in existing research and support services. This includes carers from First Nations, LGBTIQ+ and Culturally and Linguistically Diverse communities, young carers and male carers.
- Implementing initiatives to raise awareness amongst employers of the experiences and needs of mental health carers and the importance of supportive work environments. This may include initiatives implemented by Arafmi, as well as contribution to, or promotion of initiatives implemented by State and Commonwealth Governments.
- Advocating for recognition of mental health carers within relevant services and in relevant policy decisions throughout Queensland.

2

Advocate for physical, emotional, social, mental health and practical support for mental health carers

Actions may include:

- Implementing initiatives to raise awareness amongst mental health carers in Queensland of the availability and importance of accessing supports and services. This may include educating and supporting other services (such as Carer Gateway and Carer Peer Workers) to increase the visibility of available supports for mental health carers.
- Identifying gaps in available supports, including for 'hidden carers' and mental health carers in rural, regional and remote areas.
- Advocating to the Queensland and Australian Governments and other relevant organisations to increase availability and access to supports for mental health carers and families, particularly in relation to respite care, mental health system navigation, social and emotional support and practical supports, and in terms of improving access during times of crisis. This may include opportunities within NDIS reform work to advocate for restoration of state-based carer and family supports that existed before the introduction of the NDIS.

4

Promote carer inclusion in mental health treatment planning and implementation

Actions may include:

- Advocating for greater recognition and involvement of carers and families in the planning and implementation of mental health treatment by health practitioners, including improved communication with carers and families during and after periods of crisis. This may include developing resources or initiatives that support health practitioners to better include carers and families in mental health treatment discussions and decisions.
- Contributing to the design and implementation of initiatives arising from the Queensland Government Mental Health Select Committee Inquiry and the Better Care Together strategy, to put individuals, as well as their families and carers, at the centre of mental health service delivery in Queensland.

3

Facilitate access to relevant information and training for mental health carers

Actions may include:

- Offering a range of education and training opportunities for mental health carers to better equip them for responsibilities such as managing specific mental health conditions, navigating the health system, advocating for someone in the mental health system, and managing their own health and wellbeing.
- Identifying any gaps in available information and training opportunities, or barriers to access, including for 'hidden carers' and mental health carers in rural, regional and remote areas.
- Promoting available sources of information and training opportunities that support mental health carers. This may include raising awareness amongst the broader community of information sources and training opportunities (such as mental health first aid) that enable them to be a part of broader community support for individuals with mental health challenges.

5

Increase financial assistance for carers

Actions may include:

- Ensuring mental health carers are aware of available financial supports and advocating for the removal of any barriers to accessing these.
- Advocating to the Australian Government for reforms that will better support carers' access to paid work and financial security. This may include contributing to the design of initiatives arising from recommendations of the Inquiry into the recognition of unpaid carers.
- Advocating to the Australian Government for more substantial financial support for mental health carers, to cover expenses such as transport, health assessments and other healthcare costs for the people they care for.

6

Advocate for inclusion of the voices of mental health carers in mental health reform

Actions may include:

- Advocating to Queensland and Australian Governments and service providers for mental health carers to be included as an essential part of mental health-related policy and service development and reform. Areas of reform that are of particular interest to Queensland mental health carers include:
 - Support for long-term care planning that ensures sustainable arrangements are in place for individuals when their carers are no longer able to provide unpaid support
 - Funding increases to improve availability and access to Community Mental Health services
 - Simplification of processes for accessing mental health services and reduction of waiting times and bureaucratic complexities that create barriers to effective mental health care
 - Improvements in service accessibility to ensure mental health services are accessible beyond regular business hours and are responsive to crises
 - Implementation of individualised care plans for individuals needing mental health services and support, which take into account their personal characteristics, life histories and specific needs and circumstances, and inclusion of carers in the development of these plans
 - Improved collaboration and communication amongst health and wellbeing services (including mental health, general health, and emergency services) to provide integrated care
 - Provision of mental health services that cater to the unique needs of individuals from diverse backgrounds, including cultural competency training for health professionals and service providers and the employment of a diverse workforce within the mental health sector.
 - Supporting mental health carers to develop systemic advocacy skills so that they can effectively participate in mental health system reform.

Appendix A. Methodology and participation

Between September and December 2023, Arafmi conducted a series of consultation activities with mental health carers in Queensland. These consultations included 10 focus groups, a brief questionnaire and an online survey.

Focus groups were conducted with 83 mental health carers across metropolitan and regional locations in Queensland (see Table 1).

The short questionnaire was completed by 126 carers from across these same locations, as well as by carers in Charleville and carers from across the State who attended Arafmi's 9th Annual Carer Forum in Brisbane.

Respondents to the short questionnaire were asked who they were primarily caring for. Across the 126 responses:

- 71% were caring for a child
- 19% were caring for a partner
- 11% were caring for a parent
- 15% were caring for another family member, friend or other person
- 21% were caring for more than one person.

The **Online survey** asked respondents a number of questions about themselves and the people they care for. Of the 305 carers who responded to the online survey:

- 68% were aged 25-44 years
- 4% were under the age of 25
- 60% were female, 39% male and 1% identified as 'other' (Note however that only half of the respondents answered this question)
- 20% identified as Aboriginal and/or Torres Strait Islander, 22% identified as Multicultural, 5% as refugee and 9% as LGBTIQA+
- the large majority spoke English at home, but First Nations languages, Chinese

languages, Vietnamese, Arabic, Greek, Italian and Tagalog/Filipino were also spoken

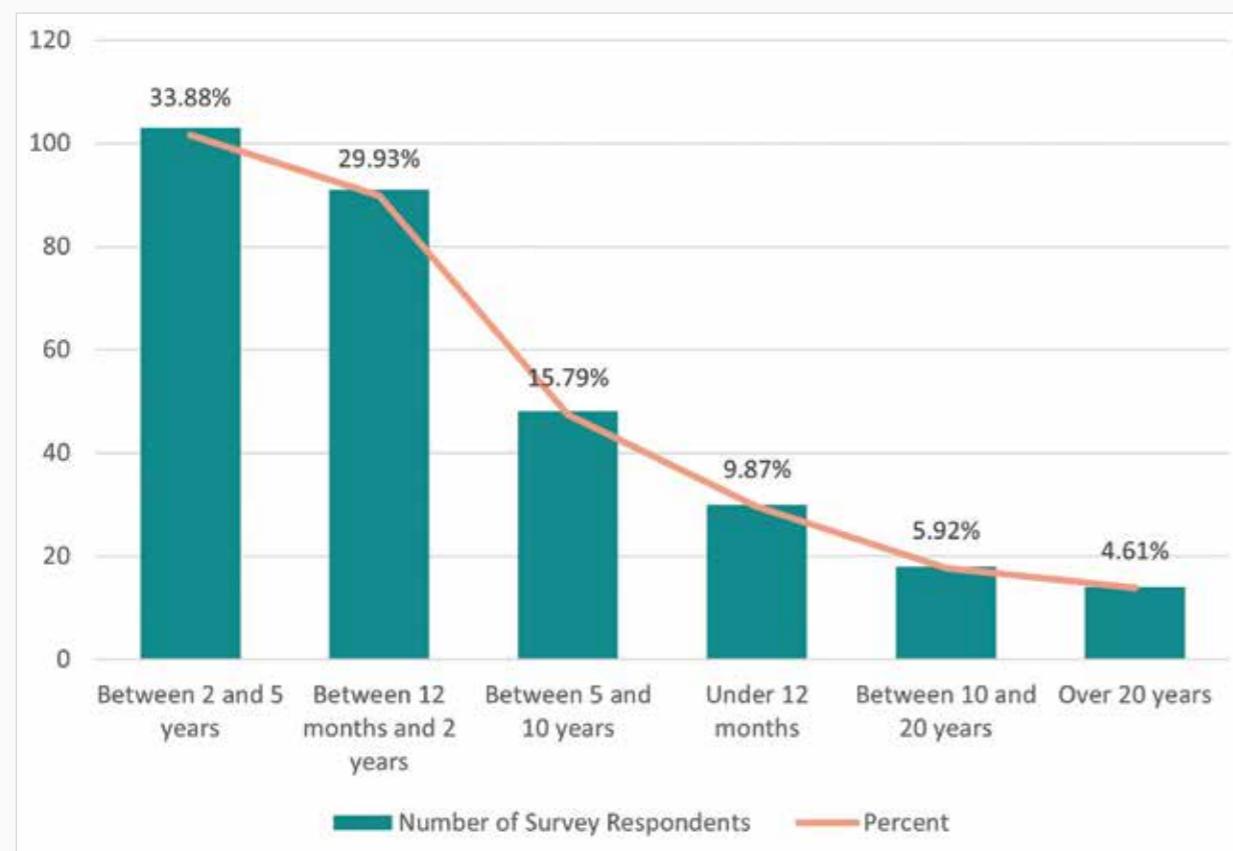
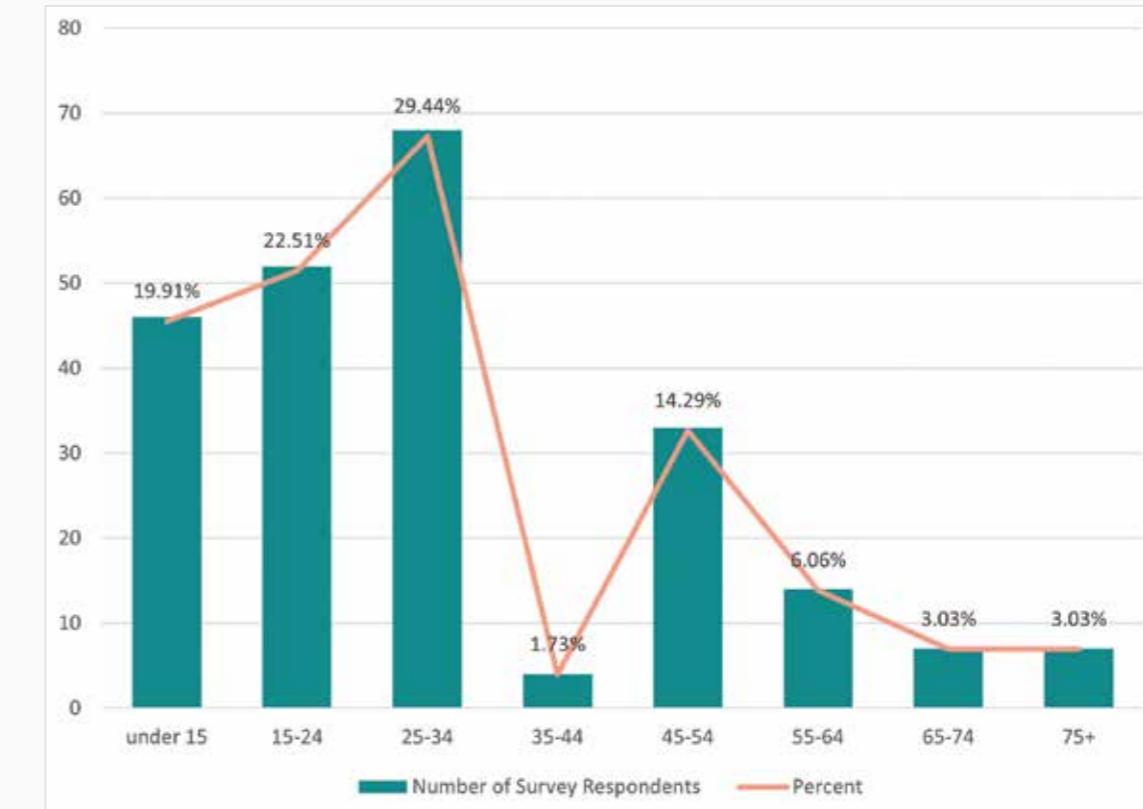
- a third have been caring for someone with mental ill-health for 2 – 5 years, another 30% for between 12 months and 2 years, and 11% have been caring for more than 10 years (see Figure 9).

In relation to caring responsibilities:

- 70% care for one or two people, but 9% were caring for 5 or more people
- 68% of online survey respondents live full time with those they care for, while 13% never do and 19% sometimes do
- 30% of the people respondents care for were in the 25-34 years age bracket, with around 20% in each of the under 15 and 15-24 years age brackets (see Figure 10)
- The largest proportions of respondents were primarily caring for a parent or a child under 25. Although significant numbers of respondents were caring for a friend, child over 25, or a partner (see Figure 11)
- 56% of those being cared for were male, while 40% were female and 4% were identified as 'other'
- 80% of those being cared for have a diagnosis.

Table 1. Focus group locations and participant numbers

Location	Number of participants
Caloundra	13
Carindale	4
Chermside	12
Emerald	8
Gold Coast	17
Gympie	5
Logan	5
New Farm	6
Rockhampton	5
Kawana Waters	8
Total	83

Figure 9. Length of time that survey respondents have been caring for someone**Figure 10. Age of the primary person being cared for by survey respondents**

Contact Us

PO Box 248
New Farm QLD 4005
07 3254 1881
advocacy@arafmi.com.au
arafmi.com.au

