

Submission to Carer Leave Inquiry

Background

Merri Health welcomes this opportunity to provide a response to the Productivity Commission Inquiry into Carer Leave Issues Paper.

Merri Health creates healthy, connected communities through local health services for people at every age and stage of life. Our approach is holistic, addressing the medical, social, environmental, and economic aspects that affect health. Our services span across children and young people, carer support, chronic disease management, mental health, disability support, dental services, population health, and aged care. We've been the trusted health service of local communities for over 40 years.

Merri Health is the lead agency delivering the Carer Gateway program in Victoria in partnership with six other health and community organisations across the state. This consortium includes Alfred Health, Ballarat Health Services, Barwon Health, Bendigo Health Care Group, FamilyCare, and Uniting (Victoria and Tasmania) Ltd. This consortium represents decades of experience providing services and supports to informal carers. Merri Health also delivers the Victorian Support for Carers Program, as do our consortium partners, adding to our breadth and depth of knowledge of matters impacting informal carers.

Merri Health has established a Carer Gateway Advisory Group and Young Carer Gateway Advisory Group to support our delivery of the Carer Gateway program in Victoria. These Advisory Groups include Carer Representatives and Young Carer Representatives from across the state of Victoria. These carers represent diverse lived experiences and a broad range of caring experiences. These groups are part of Merri Health's ongoing commitment to consumer engagement and continuous improvement.

This submission has been developed by Merri Health in partnership with Carer and Young Carer Representatives who participate in our Advisory Groups. This submission focuses primarily on the personal stories and lived experiences of informal carers and those who work with them. All Carer names herein have been used with their approval. We hope the experiences of Victorian carers will provide a living context for the research and data provided to this inquiry in other submissions. We also include insights from an organisational perspective, in relation to our significant experience in carer issues and, given the gendered nature of informal care, operating in a sector which has a primarily female dominated workforce.

We provide the following responses regarding the specified questions of the inquiry:

Section 1: Role of informal carers of older people

- ***How often does the decision to become a carer necessitate changed work arrangements or leaving the workforce?***

The experiences of our Carer Representatives highlight that becoming a carer often necessitates changes to work, including resignation or working reduced hours. Carers describe their caring role as a priority over employment, but express concerns about the impact this has for them. Young carers may put off seeking employment due to their caring responsibilities and study commitments.

“Since becoming a carer, I have been unable to sustain paid employment. I have tried several times when I believe my caree (care recipient) is stable. However, as I prioritise my caring role, employers often feel that I am not committed to the workplace.” – Bek, Carer Representative

“I had to resign as she needed more care... Our aim was to keep her out of a nursing home for as long as I could. I felt this was better for her physical and emotional health plus it would not be placing a burden on the health system. I was proud that I was doing my bit for society.” – Julie, Carer Representative

“I decided to work less than I used to. I used to work fulltime and looked for opportunities to grow and to enhance my employability skills. However, since becoming a main carer... I chose to work as a part time employee until now.” – Chi, Carer Representative

“When I was caring for my dad, I was studying part time whilst being a young carer. Primarily my focus was on balancing study and being a young carer of a person with a terminal illness. During that time, I wasn’t actively seeking work, as being a young carer was a full-time job to ensure that your loved one receives the care they deserve.” – Sahar, Young Carer Representative

- ***How often is this a planned decision versus an impromptu decision triggered by an emergency?***

These changes to employment and caregiving are often prompted by an emergency. During these emergencies, carers often do not have the time to seek other supports or explore other options.

“My elderly mother was 80, living alone, when she fell and broke her hip in September 2017. Her dementia was also on the decline. My husband was working away from home, so there was only me. I was a sick child, always at hospital, so I felt I owed it to my mother who had been such a wonderful mother to care for her in return. I did not even think about whether I could return to work or my financial situation. It all happened so fast like a whirlwind that I did not have the time, energy, or inclination to put any care services in place.” – Julie, Carer Representative

“Becoming a carer for my father was brought about by the unexpected death of my mother who had been his primary carer, and by a deterioration in his health a few months later. It was determined that I was the only family member who was in a

position to go and care for my father. So, I left my job, hastily, and painfully culled most of my possessions so I could rent out my house to make it financially feasible for me to relocate to my father's home and become his carer.” – Anonymous carer

- **To what extent do informal carers perform similar or different roles to formal carers?**

Many informal carers of older people provide supports which differ from those provided by formal carers. These may be significant emotional, financial, and personal supports. Informal carers often take on a significant workload of support coordination, which can be time consuming and frustrating. Carers note that the time commitments of navigating service systems and coordinating care can further impact capacity for paid work. Informal carers who have previously been employed in care professions note that informal care was more difficult and more damaging to their own wellbeing. Merri Health staff note many areas where the supports provided by informal and formal carers are similar. However, where the roles are similar, many protections and supports for formal carers, such as occupational health and safety procedures and tailored training, do not apply to informal carers. Informal carers often cannot take breaks or ‘clock out’ from their caring role, and many take on the caring role due to obligation or lack of other options.

“The care I provided my father varied depending on his state of health. I arranged meals and laundry, accompanied him on errands etc. However, I also had to assess his cognitive ability from moment to moment. As would be the case for many elderly carees, he was negotiating the sale of assets, as well as getting medical assessments and making decisions about treatments. So, at times I had to diplomatically make him delay critical decisions until he was alert and capable, and my other siblings were on hand to help with decisions. It was hard but crucial to get these things right. I don't believe that formal aged care workers would have been able to navigate the complexity involved” – Anonymous carer

“We are running errands in our lunch breaks, supporting our caree before or after work and taking time off work to manage appointments. We also spend many hours co-ordinating services, appointments and organising the household of our caree. Often at the detriment of our own needs and health.” – Bek, Carer Representative

“I had been in the health care profession, so I thought I had a pretty good handle on caring for another. Nothing prepared me for the onset of her dementia and the state of her fragility. That was a huge wake up call. I worked 10 times harder as a carer for my mother than I did in any of my professional paid jobs. I was exhausted, burnt out and my health was deteriorating. Now I needed the caring!” - Julie, Carer Representative

“To a certain extent, informal carers and formal carers do in fact perform similar roles, such as the examples quoted. Formal carers also offer emotional, social, and personal supports, they attempt to support care recipients and their informal carers to navigate the service system, or the organisation they may be receiving supports from. They take care recipients to medical and other appointments, translate for them, take them to the bank, shopping, to physio or other. The differences between formal and informal carer roles are in the areas where OHS restrictions for example limit and protect the formal carer while the informal carer has zero such protection placing their physical wellbeing at risk also. Policies and procedures keep

professional boundaries in place whereas for an informal carer there is no such thing. Funding limitations also place limitations on 'hours' of formal supports that are available whereas an informal carer is always 'on the clock'. Informal Carers are the unsung heroes of our economy and unfortunately in many instances, at the expense of their own mental and physical health.” – Heleni Bagiartakis, Interim State Manager, Merri Health Carer Gateway

“Informal carers provide more emotional support to the care recipient and with their role, it is around the clock (greater than a full time job) with not many breaks. Informal carers carry enormous stress that formal carers do not. Whilst tasks such as shopping, transport, personal care etc. are interchangeable between formal and informal carers (depending on circumstance), the constant pressure of ensuring the care recipient is supported and respected, as well as managing appointments and services sits solely on the informal carer.” - Grace Webster, Community Navigator, Merri Health Healthy Ageing Team

“I believe informal carers do perform similar roles to formal carers with regards to cleaning a care recipient’s home, making them meals and taking them to appointments etc. However, informal carers tend to provide more financial and emotional support whilst managing a care recipient’s personal life.” - Mariam Mohamad, Community Navigator, Merri Health Healthy Ageing Team

“Informal carers may not have the specific experience or training to provide some of the more technical hands-on support for the care recipient, however they often fulfil other equally important roles required to satisfy a care recipient’s needs. These include flexible transport options to attend health appointments or access the community, individualised care coordination or advocacy when care recipients have sub-optimal understanding of health system pathways, and vital psycho-social support which helps care recipients feel secure enough to engage with more formal carer or health services.” - Chris McCarthy, Physiotherapist, Merri Health Independent Living Team

“Many informal/family carers undertake tasks for their family members that could be provided by formal carers, e.g. personal care, home care, shopping, escort to appointments. For many informal carers ... They would rather have the funding available for services they are not easily able to provide... such as gardening, allied health services, aids and equipment for the home or continence products... Informal carers do not leave a lot of time for themselves and their family member has a reliance on them which, can be problematic in introducing formal carers for services” - Cheryl McInerney, Senior Care Advisor/Intake, Care Management Team, Merri Health Home Care Packages

“To some extent, informal carers perform the same role as formal “paid” carers however with significantly increased duties and stress. Generally, a formal carer would have some understanding of the aged care system and funding whereas an informal carer would not necessarily have this insider knowledge.” - Amy Cussen, Occupational Therapist, Merri Health Specialist Aged Services

“From running errands to managing bills, providing in-home supervision on your day off to organising medical appointments, the role of an unpaid carer can be extremely challenging. Juggling personal and professional duties whilst informally caring for a close family member or friend, requires a lot of time, patience, and

resilience. Providing informal care at the cost of one's own health is undertaken due to the moral obligation to provide care, the lack of formal care arrangements, or because people are not often aware about formal services or a combination of the above reasons." - Anonymous carer

- **What formal services would be difficult for some older Australians to access without informal support?**

Carers and Merri Health staff expressed that most formal services required informal support to access. This can include travel assistance, technological assistance, support coordination, and renegotiating supports as needs change. The care needs of an older person can limit their ability to access services without support.

"My mother would not have been able to access any of these services on her own as her dementia had stopped her from driving, holding a phone conversation, and not to mention all the new computer, app, pass code, pin numbers, appointments - - She would have given up right at the start." - Julie, Carer Representative

"Older people find the aged care system very difficult to navigate without assistance from younger family members, and even they can struggle. A certain level of computer and health literacy is required to navigate the current aged care system, which some older people do not have. Many carers do not know where to go, and there are few services that help carers do this." – Anita Craike, Carer Engagement Coordinator, Merri Health Carer Gateway

"Older clients often rely on informal carers, such as family support networks, to transport them to health appointments. Within the physiotherapy department of Merri Health, exercise groups participants are typically driven to clinic sites by family members. These family members not only provide logistic support, they also often provide motivational support by encouraging client to engage with physiotherapy intervention which improves compliance and attendance. Without this holistic support from informal carers, many older clients would not be able to access physiotherapy appointments consistently." Chris McCarthy, Physiotherapist, Merri Health Independent Living Team

"Without informal support, some older Australians may face barriers when accessing formal services such as those provided by the Healthy Ageing Team at Merri Health, which involves community connection services. In order for us to connect older Australians to appropriate services and programs within the local community, it is vital that they have access to timely and flexible transport, and this is where informal carers become so pivotal. Informal carers can also help to address language barriers, and facilitate a better understanding of available supports. The key role played by informal carers to break down these barriers leads to better access to formal services for the care recipient." Mariam Mohamad, Community Navigator, Merri Health Healthy Ageing Team

"Quite a number of the informal carers would like to be able to continue to work either part-time or full-time, however the availability of services such as in-home respite or social support groups is limited and makes this difficult for the informal carer. A number of informal carers try to work their hours around the available

services though in the current climate with available support workers services are often cancelled leaving them without support.” - Cheryl McInerney, Senior Care Advisor/Intake, Care Management Team, Merri Health Home Care Packages

“Everything... particularly if you have diversity barriers, e.g. non-English speaking background, cognitive diversity. Even if they can navigate the system and get other services, there are often limitations to accessing culturally appropriate supports and services in their own language so they often end up heavily relying on carers to access.” Amy Cussen, Occupational Therapist, Merri Health Specialist Aged Services

“Many Senior Australians find navigating the health system and accessing some of the allied health services available out there is quite hard without the assistance of younger family members who are technologically forward.” Anonymous carer

Section 2: Carer employment entitlements

- ***When do employees use paid or unpaid leave or request flexible working arrangements to care for an older person? In what circumstances are the provisions inadequate?***
- ***Do the eligibility requirements for the paid and unpaid leave entitlements allow them to be used by informal carers of older Australians? If not, why? Are there barriers that limit informal carers of older people from using the entitlements?***

Our Carer Representatives have used paid leave and flexible working arrangements to provide care. Our Carer Representatives do not report using unpaid leave to provide care. Merri Health staff report that carers can exhaust paid leave entitlements and then require unpaid leave to provide care. Carers report that leave entitlements and workplace flexibility are important factors in their choice of employers. Greater flexibility and leave entitlements are appealing to working carers. Carers note that uncertainty about future care needs can deter them from using leave entitlements at a given time. Carers worry that if they use their entitlements, they may not be able to use them again if needs change or escalate. This may indicate that once-off entitlements may not meet the needs of many carers.

“My current employment is flexible and understandable with my family’s situation. I can negotiate the work hours or days, taking carer leave when needed. I have not got any experience regarding eligibility requirements or barriers that prevented me using these leaves. Most of the time, when I needed to take leave to provide support, they approved my leave without any issues. However, I have not used any unpaid carer leave.” - Chi, Carer Representative

“My experience in HR has found that employees with caring responsibility quickly exhaust their paid personal leave entitlements, including carer’s leave, due to their caring responsibility and often will go into unpaid personal leave or utilise their annual leave entitlements to meet their caring responsibilities.” Vicki Wright – HR Business Partner Experience, Merri Health Human Resources

“There were flexibility arrangements. The employers were sought out for this reason. The only barriers experienced in this circumstance was travelling further to a job to get the flexibility required and doubting whether to use leave as I may need it more later on.” – Kylie, Carer Representative

Eligibility requirements for leave entitlements can also limit access for many carers. Carers may need leave at any time, including early after starting in a new role. Carers perceive barriers to asking for flexibility or entitlements within the first six months of starting a role and fear they will be viewed negatively if they require leave to provide care. These barriers may prevent carers from re-engaging in employment while they provide care. Entitlements which accrue over time may therefore not be suitable. Merri Health staff note that different employers may define caring differently, and this can cause inconsistency in eligibility. Clear definitions regarding eligibility in the relevant legislature and flexibility in organisational policies about leave use order may address a barrier for some carers, however, operational impact would need to be considered.

“I was working full time but on a casual basis so I could not ask for any leave... I had also only been in this new job for six months so time off paid or unpaid was not an option if I wanted to keep my job.” - Julie, Carer Representative

“As I prioritise my caring role, employers often feel that I am not committed to the workplace. Being a new employee, requesting workplace flexibility can be problematic. Additionally, I found leave entitlements needed to be accrued, so are not an option initially” – Bek, Carer Representative

“Some agreements have a very finite description of who is eligible as a ‘carer’. The definition of a carer from the Carer Recognition Act 2010 is much broader and closer to reality. Applying this as a minimum employment standard across the board could increase consistency and eligibility.... Organisational policy that dictates the order in which leave types must be used may also be a barrier for carers. For example, many organisations require all paid leave first be used before unpaid leave is approved. Consideration should be given to the impacts on carers and on organisations if informal carers had the option of electing to use paid or unpaid leave entitlements. This may apply flexibility for carers, however, is challenging from the organisational perspective, as leave accruals have a cost impact.” – Heleni Bagiartakis, Interim State Manager, Merri Health Carer Gateway

Section 3: Effects of an entitlement to extended unpaid carer leave

- ***We seek your feedback on how many employees who would take extended unpaid carer leave would subsequently return to work once they had ceased caring.***

Carers expressed that, if extended unpaid carer leave had been available to them, they largely would have utilized it. Many, though not all, believe they would have returned to work afterward. The timeframes for returning vary significantly, reflecting the diversity of care experiences and needs.

“If I had had the option of unpaid carers leave, I would have jumped at the chance as it would have given something for me to work towards.... My mother was admitted to

[residential care] in 2021. I have not returned to fulltime work. If I had had unpaid carers leave, I would have. It would have shown me that my employment valued me and has encouraged me to get back into mainstream. I feel a bit lost; my skills and confidence have waned.” - Julie, Carer Representative

“If extended leave was available, I certainly would have utilised it. It would have allowed me to balance my carer and employment roles. It would have allowed me to have better mental health and wellbeing and thus enhanced my work life balance. Given my experiences, I am hesitant to return to employment.” – Bek, Carer Representative

“If extended unpaid leave was available to me, it would be a good source for me as I know when my care recipient needs my care, I can support them without worrying I am able to take leave or not. I would take it. It is hard to know what duration of unpaid leave is helpful, as it depends how much support is needed at that time.... I would have returned to the workplace and appreciated the employer keeping the position for me to come back.” - Chi, Carer Representative

- **How do women and men experience different pressures to provide informal care?**

Carers expressed that there are often gendered pressures around providing care. Several carers highlighted that there is a social expectation that women are better at providing care. The experience of staff suggests that there are also gendered differences in the types of care, and gender expectations may contribute to employment disruptions. Some carers identified these pressures are due to social vulnerabilities and suggested they cause compounding disadvantage for women who care. Caring responsibilities may also increase the risk of family violence and make it difficult for carers to leave unsafe conditions.

“Absolutely, it is expected that the woman will take on the role. The male may provide additional support, but societal expectations are the primary responsibility falls on the woman.” – Kylie, Carer Representative

“It may be more of a social norm for a woman to provide care for a family member.... My mum, sister and I were praised from people for the care and support we provided to my dad. From my experience, when my dad was diagnosed with his illness, as a family we did everything we could to provide home based care and I wouldn’t have had it any other way.” - Sahar, Young Carer Representative

“From my experience women are expected to take on the caring roles, like they are better suited or its in their nature; whilst men are positioned as bread winners” - Bek, Carer Representative

“In our experience, the split of informal caring tasks is also gendered and this is largely proportionate to families of diverse backgrounds. For example, female informal carers will be responsible for all the cooking, cleaning, emotional and social support while male informal carers will assist with physical care such as transfers to toilet, shower, or bed. In some cultures this is the norm. One further point is that even in households where both male and female carers work, the majority falls to the female just the same. The female is often the one expected to eventually move to part time and/or resign as the caring needs increase over time.” – Heleni Bagiartakis, Interim State Manager, Merri Health Carer Gateway

“Statistics bear out that caring work is heavily gendered, for long ingrained cultural reasons. Women aren’t actually ‘better at caring’ or ‘more compassionate’. Most often, we are just more vulnerable and afraid to say “no” because of coercive control, or more overt patterns of intergenerational domestic violence. Many women buckle to social pressure and take on caring roles to their detriment ... Often this is expected, when nobody would expect a male family member to take on the same caring duties.”
Anonymous carer

“I planned to care for my father for the rest of his life. however, living in my father's home exposed me to domestic violence from another family member. So, when my father's health improved and he moved into town where formal supports and other family members were available to support him, I moved back to my own home.” – Anonymous carer

Several carers noted that female dominated workforces might be more understanding or accepting of the need for carer’s leave than male dominated industries. This highlights a need for employers to consider the caring responsibilities of both male and female employees and to respond to requests equitably. Enshrining consistency and transparency in policy may help address these gendered pressures.

“A woman’s employer may be more sympathetic to flexibility for a caring role, whereas a man’s employer would question why he was doing it.” – Kylie, Carer Representative

“My husband is not often able to provide informal care, as the pressures of his workplace made him feel it is not easy to take carer leave as often as mine.” - Chi, Carer Representative

“There is an intersection between gender expectations and sectors of work. Sectors that employ greater proportions of women, such as community and health services, may be more understanding of the needs of informal carers. Even within sectors or organisations, employers may have different expectations of male and female employees. This has been found previously in reference to males accessing parental leave.” Anita Craike, Carer Engagement Coordinator, Merri Health Carer Gateway

“From my experience, traditionally female dominated workforces are likely to be more considerate versus male dominated workforces Carers may be more likely to secure employment that is community based or not-for-profit, that demonstrates understanding and supports the needs of carers through flexibility, more than private or traditionally male dominated industries.” - Vicki Wright – HR Business Partner Experience, Merri Health Human Resources

- **What costs, perverse incentives or unintended consequences should the design of the entitlement aim to minimise or avoid? How might this be achieved?**

Carers note that there would be significant need for community education and awareness raising about informal carers if such an entitlement were delivered. Carers worry about hiring discrimination and highlight the need for carers to know their employment rights. Merri Health staff suggest hiring discrimination against carers may be more likely to occur in industries which

have demonstrated hiring discrimination against parents, due to carers appearing to be needing more time off work and flexibility versus employee's without caring responsibilities. Carers note that access to workplace flexibility can already depend on organisational culture and understanding.

"When these changes are implemented, they need to coincide with a campaign to raise awareness to the complexities and challenges of carers. To assist employers to be compassionate to carer needs and understand the benefits that carer bring to the workplace and its culture.... I am concerned that employers may avoid employing carers as a result of the changes." - Bek, Carer Representative

"I think not all workplaces would embrace the Carers leave. If businesses had an incentive of some sort, it would be more attractive like other government initiatives to return to work such as after an injury." - Julie, Carer Representative

"I would agree that some employers may avoid hiring carers. Research shows that some employers or industries who are less likely to hire female parents due to the perception they will need additional flexibility or leave or someone recently married, on the perception they are likely to need time off to have children shortly." Vicki Wright – HR Business Partner Experience, Merri Health Human Resources

"From my experience, informal carers rely on their employer's empathy, understanding their circumstances and being able to support informal carers where needed. Informal carers need to know their rights when they ask for support with their employer, so that they can focus on their caring role." - Chi, Carer Representative

Merri Health staff also identified a need to design any carer leave entitlements to minimise impacts on other staff members and the wider organisation. Additionally, carers often prioritise caring for others over their own needs, which can lead to burn out and distress. Therefore, there is a need to design entitlements to support carers to use their leave entitlements for their own respite and wellbeing, not just in the provision of care.

"It's important to consider the impact to employers, fellow staff, or clients, particularly the operational impact the unpaid leave would have on the days an individual was not attending work. This is particularly challenging if limited notice is provided and the individual is in a client facing role." Vicki Wright – HR Business Partner Experience, Merri Health Human Resources

"It is important to minimise burn out and excess workload on existing workforce due to gaps that unpaid leave may create i.e. workloads being absorbed by other colleagues which would have a negative impact on them. ... We also need to think about balancing leave to ensure a carer has some left to truly use for their own 'respite'. A way of ensuring this could be to maintain a minimum amount of leave accrued for personal and annual leave, as opposed to expending all accrued leave before you can apply for unpaid leave." – Heleni Bagiartakis, Interim State Manager, Merri Health Carer Gateway

Section 4: Alternative policies to support informal carers of older people

- **To what extent does eligibility for the existing payments affect carers' employment decisions?**

Carers report that eligibility for carer payments does affect carers' employment decisions, but that this is not the only factor. Many carers wish to remain engaged in work to maintain their personal identity, interests, and goals. However, engaging in work can leave carers worse off if they are no longer eligible for payments, which is difficult and distressing. This can also increase insecurity for carers and their household if ability to work changes over time. Many carers are strong participants in the voluntary sector.

"I used to think being a fulltime carer ... would be the best based on their conditions. I used to look up the eligibility of carer payments. But then I decided to keep my employment, as I could see the benefit to be able to work and keep up my personal life and interest." - Chi, Carer Representative

"Financial strains may make it difficult, which is why many carers only take employment hours that will still allow for carers allowance. This is to ensure a back up if they can no longer work even for a brief period." - Kylie, Carer Representative

"Although working significantly reduces carer payments, my motivation for working was not financial. However, when you are employed and it's not financially viable, it can be disheartening. Personally, I have transitioned into the voluntary sector that offers the flexibility I require." - Bek, Carer Representative

- **What challenges do informal carers of older people face in accessing the supports they need?**

Carers note many challenges in accessing formal supports they need. Challenges include long or inconsistent wait times, lack of service access in rural areas, and lack of responsiveness to changing needs. Carers highlight that coordination is time consuming and slow. Merri Health staff members echo these challenges, and also identify the emotional barriers to seeking support. Carers report that they often need to share their story to multiple contacts at numerous services, which is distressing.

"Aged care package adjustments aren't agile enough to keep up with the fluctuating care needs of elderly people. If their health slips in such a way that they aren't able to re-negotiate their supports, they will suffer, whatever those supports may be. ... It's very obvious that the system is overwhelmed, especially obvious during Covid 19 was the lack of surge capacity. The aged care package provision was slow, communication was slow, and the lack of continuity of care was exhausting, mostly because of the repeated re-explaining it required." - Anonymous carer

"Many people with disabilities are supported through the NDIS system as well as informal carers. Likewise older people are supported by aged care packages. However, in my experience when care packages are approved, the capacity to implement them is not always available. This is further exacerbated as the care package level increases. Additionally, this is even more evident in rural areas." - Bek, Carer Representative

“After quitting work, I could spend the time on hold with various agencies trying to get the help I needed to care for my mother. We could not get much formal care as we lived over 40 minutes from the closest service. We could only get someone for 1 hour a week as they had to use the other hour to travel.” - Julie, Carer Representative

“Some challenges may be: Financial strain, being afraid to ask for help, being under a lot of stress, managing their personal life’s and feeling self-guilt to look after personal needs.” - Mariam Mohamed, Community Navigator, Merri Health Healthy Ageing Team

“Challenges are numerous... Lack of awareness about what services are available, not realising what an informal carer is, so not identifying their role and then accessing support for it, challenge to put their own needs first, challenge trusting service providers and transfer some of their responsibilities to a formal carer, isolation, time constraints, and digital literacy.” - Grace Webster, Community Navigator, Merri Health Healthy Ageing Team

“The most common difficulty is access to flexible respite at times that suit the informal carer who may want to attend their own appointments or to just have a break. In the current environment of support worker availability the informal carers have to work around availability of those workers.” - Cheryl McInerney, Senior Care Advisor/Intake, Care Management Team, Merri Health Home Care Packages

“There are some hidden costs of informal care to carers which include the opportunity costs of lost job earnings and any payment entitlements, and also health impacts due to the psychological burden of caring. Without adequate support, informal care can put carers at risk of financial loss, poor health, and social isolation.” - Anonymous carer

“Having to share your story every time... It’s like having a wound that you have to unwrap and scrape open, not to clean it or for anything therapeutic, but just to prove that you have a wound. You have to prove that you deserve help.” – Anonymous carer

- **What are the main types of supports that informal carers rely on?**

Carers utilise a mix of formal and informal supports for their caring role. Formal supports include carer pensions and other payments, the NDIS, and carer services like Carer Gateway. Practical assistance like cleaning, meals, respite, and support workers are valuable for carers. Aged care supports for the person with care needs, such as Home Care Packages (HCP) and Commonwealth Home Support Service (CHSP), also provide support to the carer. Tailored mental health support like counselling is also valuable and can provide most meaningful support via a whole-of-family approach. Broadly, carers identify that it is difficult to rely on formal supports, due to the challenges listed above. However, informal supports like the assistance of family and friends are also unreliable. Informal supports lack the knowledge and training to be a reliable support for many carers.

“I do rely on Centrelink, and on the NDIS. I have learned over almost two decades of experience that while services from Carer Support organisations can be of huge help, I can’t really rely on Carer Support services. Things that help most: Cleaning, respite, meals, counselling, brokerage for critical things. These help pull me through periods of depression and despair.” – Anonymous carer

“Having access to experienced support workers to provide adequate care for a person with a terminal disease is very important, as it relieves the stress off family members and allows family time away from care duties. Being linked into services such as Eastern Palliative Care, during the latter stages of my dad’s illness ensured we had support for all my family. My dad had access to great nurses, was able to have a biography of his life written by their volunteers, music therapy to provide solace and social workers to support both my dad and the rest of my family.” - Sahar, Young Carer Representative

*“Meal provision and cleaning were most crucial to my father and I. What would have been more helpful was if there were a family counsellor or similar, to help other informal supporters and my dad to know what they needed to do to keep things going without me burning out. ... Informal carers rely on formal supports, which are scant and clearly inadequate, but much more reliable than informal supports.... Too often, overwhelmed and inadequately trained carers have to fill in the gaps when care needs suddenly exceed what’s provided in care plans, which is dangerous, and unfair to all concerned.”
Anonymous carer*

“As a Carer, I rely on family, friends and quality formal supports. Without these I burn out and am unable to perform my caring role effectively. As much as family and friends mean well their capacity and understanding of the situation, means their ability to help is limited. Therefore, the most support comes from formal supports through a care package.” - Bek, Carer Representative

Section 5: Extensions to carers other than carers of older people

- ***In which ways does informal care of older people differ from the care that other people might require?***
- ***Are there reasons to have different policies for informal carers of older people than for informal carers of other types of people?***

Carers note that caring experiences are diverse and complex. Carers value flexible supports that can be tailored to their unique or changing needs. The unpredictability of care needs over time is highlighted for older people by both carers and staff members. Staff members identify unpredictability of care for people with mental health challenges and difficulty of formal supports for this cohort. Caring for younger people is generally believed to be more long-term, and carers may need to plan for when they can no longer support a younger care recipient. The difficulty of providing care and risks to the wellbeing of the carer are similar for various caring types.

“In my view, the policies should be designed based on care recipients age range, their conditions, or how urgent care they need. It would be good to have different policies for carers of older people and for other types of care needs because it will be more suitable and more relevant to the care circumstances which require carer to be present to support.” - Chi, Carer Representative

“Caring is a hard role, regardless of the circumstances. In my experience caring for people with mental health and disabilities the needs are relatively stable or there are predictable patterns to the care. With aging the condition is deteriorating at an unknown rate.” – Bek, Carer Representative

“The care needs of older people can be unpredictable but are likely to get harder over time. This increase in care requirements can be seen individually, but as our society ages, informal care for older people will also increase... Care for people with mental health challenges is another area which is unpredictable. The episodic nature of mental illness, and hence the sporadic nature of their care needs, can be very difficult for carers and can cause significant workplace disruption. Formal care options, like respite and in-home services, are often not appropriate for carers of people with mental health challenges, as the care recipient may not need personal care or community access support. It’s important for carers of people with mental health challenges to be considered and included. Carers have more traditionally been identified in the aged care system and disability sector, but mental health caring is under-identified.” Anita Craike, Carer Engagement Coordinator, Merri Health Carer Gateway

“There are similarities in what is required from the carer. The carer becomes responsible for all aspects of the care of the person. Each situation is different but the impact of responsibilities are all the same.... A carer of a young person with a disability may do this over the lifetime of the individual. There is more concern of what may happen to them if the primary carer can no longer look after them. Whilst there are similarities in all caring roles, each case is unique and needs to be looked at for the individual cases needs and situation. A “one size fits all” approach is therefore not appropriate.” – Kylie, Carer Representative

End of life care is an area where care for older people is often seen to differ from other types of care. However, these experiences are not entirely unique to carers of older people. Carers of people with terminal illness must also address the challenges of end-of-life care. This can happen at any age of life, and can affect carers of any age. This highlights that supports for carers supporting someone through palliative care should be accessible regardless of the care recipients age.

“I can’t think of any carer-related issues that are 100% exclusive to the elderly, except the tacit understanding that, sans the unexpected, the carer will outlive the caree. There are tasks that are almost ubiquitous among elderly carees that are less likely among younger carees; downsizing, estate-wrangling, working with palliative care and aged care services, ever increasing amounts of hospital visits, funerals, etc... Therefore, viewing carers of elderly people as a carer subset with a specific set of needs seems wise and efficient. This may enable carer supports to have a tailored and extended tool-kit for this particular group.” – Anonymous carer

“My dad was diagnosed with progressive terminal illness (MND), and his care needed to be tailored towards the progression of his disease. Terminal illness’ can affect people at any age, and the progression of their disease is varied. Those with a terminal illness can’t wait around for funding to be accessed, they need quality palliative care immediately. In some instances, a person with MND may be put in a nursing home if they don’t have a good support network to assist with home-based care.... I was lucky that I was able to share my caring role with my family, and we were able to support one another throughout my dad’s illness.... Regardless of age, everyone has the right to home based care.” – Sahar, Young Carer Representative

Concluding statements

Informal care is complex and diverse. While many carers feel pride at being able to support those close to them, providing care can be difficult, draining, and detrimental to the carer's health, wellbeing, and work. Disruptions to employment opportunities or the ability to sustain employment, including working reduced hours and resignation, are common. These disruptions have significant impacts on lifetime earnings and financial security of carers and caring families, especially in retirement age.

Feeling forced to cease work because of caring responsibilities can increase carer's feelings of isolation and loss of their own identity and goals. Carers report that an opportunity to remain connected to work would improve their confidence and self-determination. Carers also suggest that being able to remain connected to workplaces would decrease their vulnerability to homelessness and family violence.

"The longer I have been not working the harder it is to get back into working mainstream. Knowing I had job security would have improved my confidence and self-esteem. I would have stayed in touch with my fellow work colleagues instead of retreating into a lonely world of me and my mum and the merry go round of caring for a loved one with no help or support of colleagues." - Julie, Carer Representative

"Many women ... take on caring roles to their detriment; they lose work, they lose work experience, they lose workplace opportunities and promotions, they lose wages, they lose superannuation, they lose contact with their professional cohort, their professional skill set becomes outdated.... It isn't appropriate that women who have spent decades of their productive potential working as unpaid carers often have no savings or superannuation, so are very vulnerable to housing stress, poverty, and domestic violence." Anonymous carer

In principle, informal carers support efforts to assist them in remaining connected to employment while providing care. The right to return to work may be an effective support, however, community education and awareness raising about informal carers and carer issues is also required. Any supports for carers need to be adaptive and flexible to respond to the changing needs of carers, recipients of care, and their families.

Submission compiled by Georgia Gardner, Carer Engagement Advisor, Merri Health Carer Gateway

For further information on this submission please contact:

Heleni Bagiartakis – Interim State Manager, Carer Gateway