



QUALITY AGED CARE ACTION GROUP INC



Joint submission to the Productivity Commission:

Carer leave Issues Paper

August 2022

Submitting organisations

About QACAG

Quality Aged Care Action Group Incorporated (**QACAG**) is a community action group in NSW that aims to improve the quality of life for people in residential and community aged care settings. QACAG is made up of people from many interests and backgrounds brought together by common concerns about the quality of care for people receiving aged care services.

QACAG Inc. was established in 2005 and became incorporated in 2007. Membership includes older people, some of whom are receiving aged care in NSW nursing homes or the community; relatives and friends of care recipients; carers; people with aged care experience including current and retired nurses; aged care workers and community members concerned with improving aged care. Membership also includes representatives from: Older Women's Network; Combined Pensioners & Superannuants Association of NSW Inc.; Kings Cross Community Centre; Senior Rights Service; NSW Nurses and Midwives' Association; Carers Circle; Aged Care Reform Now and the Retired Teachers' Association.

QACAG members welcome the opportunity, through this submission, to provide input to the Carer Leave consultation.

Margaret Zanghi

President

QACAG Inc.

About Aged Care Reform Now

Aged Care Reform Now (**ACRN**) is a non-partisan grassroots organisation, consisting of aged care services recipients, families and friends, and current and retired aged-care workers – all who have personal experiences with aged care and want to make a change. ACRN advocates for aged care reform that delivers improved benefits to all Australians receiving residential and in-home aged care services.

ACRN's vision is a transparent and effectively regulated aged care system that is focused on the human rights and quality of life of older people.

ACRN is a platform for people interacting with the aged care system. ACRN provides a strong voice in the delivery of quality services, complaints management and for practical solutions to advance the care and wellbeing of aged care recipients. It does this through:

- Engagement in the reform process with politicians and government departments
- Media advocacy to highlight issues and potential solutions
- Collaboration with like-minded stakeholders to influence change
- Consulting and mobilising its membership – giving voice to the real needs of people interacting with the aged care system.

For more information please visit our website www.agedcarereformnow.com.au or contact info@agedcarereformnow.com.au

About Carers' Circle – caring for ageing parents

Carers' Circle is Australia's only general website dedicated to helping the children (or nieces or nephews) of ageing parents. The website covers a wide range of issues that will help both the children and their older loved ones – written from the perspective of a carer.

Navigating the complex aged care system, changing family dynamics, and just understanding the road ahead, is daunting and difficult. Carers' Circle aims to make it a little easier by having the information readers need all in the one place, and in language that makes it easier to understand.

Founded by Michelle Chaperon while navigating her own father's care needs, the website draws on contributions from experts as well as everyday people navigating their own care journeys.

More information can be found at www.carerscircle.com.au or contact info@carerscircle.com.au

For full disclosure and transparency, the Founder of Carers' Circle is also a member of ACRN and QACAG as an ACRN representative.

Our organisations welcome further dialogue on the provision of carer leave and importantly the other support services that impact the need for carer leave provisions and entitlements.

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Objectives of this submission

In providing this response we wish to:

- draw attention to the various issues facing informal carers, particularly the lack of in-home respite which forces them to take on more caring responsibilities, and suggest solutions that would reduce the need for informal carers to take as much time out of the workforce that they do currently
- discuss how a flexible carers leave entitlement and an entitlement for extended unpaid leave inserted into the National Employment Standards would impact the behaviour and quality of life of older people and their informal carers
- promote the fact that there is not a one size fits all solution and that there needs to be a myriad of policies and services must in place to support the variety of caring situations Australians face.

It is without doubt there is an urgent and pressing need to provide financial support and flexibility in working arrangements to enable people to provide care to family and significant others at home. As many people continue to choose to work beyond retirement age, any arrangements would also need to extend to accommodate older workers. Barriers to accessing good quality, appropriate formal in-home and residential aged care identified through this submission should also be addressed to maximise the benefit of carer leave entitlements and minimise impact on the wider economy.

As we are community organisations, the membership of our various organisations primarily consists of older people who have previously or currently care for older loved ones, children of ageing parents who are still in the workforce or retired and aged care workers, we are not able to comment on government budgets or design, detailed pay and employment matters for the wider workforce. We can just share our experiences and offer possible solutions.

Please note that while we refer to older people in this submission, we are also including the needs of carers of people who have conditions traditionally associated with older people, such as Younger Onset Dementia. These conditions and others, don't wait until a person is 65 years or older. In some cases, our members have been helping their loved ones since they were in their 50s.

Key recommendations

This report outlines the experiences of our members who call for:

- Better access to telehealth services
- Increased access to GP, geriatrician and other specialist home visits
- National Employment Standards changed to separate personal/carer leave from sick leave
- **Most importantly - increased accessibility and availability for in-home respite, particularly in emergency situations**
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Role of informal carers of older people

Definition of informal carer

As per the Issues Paper, the Carer Recognition Act 2010 (Cth) established a broad and encompassing definition of an informal carer. It defines informal carers to be:

“...individuals who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue, or who are frail aged.”

Our respective organisations agree with this definition yet believe when designing policy to support carers, the Government should recognise the different levels of care required and how that impacts workforce participation.

Public benefit

Informal carers are a vital part of our community. There are increased public benefits through their role, particularly as they understand the older persons needs and medical history which saves time in dealing with the medical system and allied health. They also support the person in the home and can save the health system from unnecessary ambulance calls and hospital admissions (in the case of falls). Without their support the hospital, ambulance and aged care system can be over-burdened. This submission will show that carers need support to fill that role.

Advocacy role key

In our experience, regardless of the level of care needed, carers act as advocates for their loved ones. Whether it's helping them set up their My Aged Care account, or liaising with medical staff at doctor's appointments or in hospitals, this **advocacy role is vital to their loved one's wellbeing.**

A good advocate listens to the person receiving care and conveys their wishes. This is a role many informal carers perform without considering themselves "carers". More often than not, they just consider themselves a good partner, daughter, son or friend.

When designing an entitlement system, the role of advocate should be recognised as well as the time taken to perform this role.

"My late mother-in-law (mum) had Chronic obstructive pulmonary disease, along with many other related issues and dementia. Over nearly 5 years I was the main one taking time away from my business to attend hospital with her, fill in when carers couldn't make shifts and advocate for her when dealing with issues with missing funds with her aged care provider. I spent over 12 months taking time out of my business sifting through legislation, calculating the misappropriated funds, etc. fighting the provider and the Aged Care Quality and Safety Commission to get the funds back so she could have the services she needed.

We eventually got the funds back but it was too late for Mum to use and she passed recently. Tens of thousands of dollars of unspent funds that could have gone to her care to were wasted, in addition to the countless hours I spent advocating for her, when I could have been focused more on spending what limited time she had left with her.

My business is on its knees thanks to that and covid.

I found no support from virtually everyone we approached.

It's broken me."

Gary, South Australia.

Culturally and Linguistically Diverse (CALD) considerations

The need for advocacy increases with people from CALD backgrounds because often the carer also acts as an interpreter. While many services in public hospital settings have translation services available, not all health and aged care service providers have this, therefore the need for carers to attend more appointments and be more involved, increases.

Our organisations note there is a free interpreting service available to service providers via the Commonwealth Translating and Interpreting Service, however we believe more can be done to make translation services more readily accessible to the general public.

The circumstances in which people become informal carers of older Australians

People are living longer, and this has extended the length of time people are living with chronic comorbidities and dementia-related conditions. This has also impacted the demographic of informal carers and it is becoming increasingly common for informal carers to be retired and experiencing their own health challenges.

Lack of availability of high quality and reliable home care provision increases the burden on informal carers who often accommodate the schedule and scope of duties of home care workers rather than having their own respite and support needs met. In addition, waiting lists for higher level care packages means people are struggling at home even before support is provided. This is compounded by inadequate funding and high administration charges.

The Royal Commission into Aged Care Quality and Safety confirmed what we already knew; residential aged care is severely understaffed and poorly regulated leading to widespread neglect of residents. This means options such as respite (which is already hard to secure) or placing a loved one in residential aged care would be a last resort option resulting in prolonged and intensive informal caring responsibilities in the home. Many of our members also identified issues with residential respite being the main provision of respite available (if it's available). More often than not, people receiving high-level care in the home would not cope with a different environment. Some of our members who have availed themselves of this option for respite note that their loved one often declines when placed into residential care – this is particularly the case with people who have dementia.

Our members report informal care is less likely to be triggered by an emergency. An emergency would often arise once informal care had commenced and often results in short term admission to hospital then residential aged care. These episodes impact workforce participation with informal carers often having to take their own sick leave to attend to such incidents.

Informal care commences at the point where the nature of the care delivered, and time components start to impact their own time significantly and they lack time to attend to their own personal needs, including psychological and social needs.

Many of our members have or are caring cared for loved ones with dementia type illnesses which has required their caring responsibilities to commence at the point where it has been unsafe to leave their loved one alone, or where their loved one has not been able to perform essential personal tasks like cooking or bathing.

Those in the workforce at the time the informal care commenced may rely upon their employer to allow them to work flexibly, often leading to reduced income. This impacts their mental wellbeing but also impacts their future financial security through reduced superannuation contributions.

Different levels of care and carers

We have created a number of scenarios to illustrate the various levels of care, care needs required and impact on workforce participation to draw attention to the various issues facing informal carers and promote the fact that there is not a one size fits all solution. Please note these are merely examples for illustrative purposes and do not address all of the care needs and carer situations.

1. Supporting carers – loved ones start needing assistance

Many carers in this situation would not consider themselves carers – rather they are simply “helping out” their loved one.

The older person’s needs

This is the stage where older people are generally still active and independent, but might need assistance with some tasks such as going to medical appointments, doing the shopping, yard maintenance etc.

How the supporting carer helps

While tasks like shopping and yard maintenance can be outsourced to support services funded by the CHSP or lower level Home Care packages, it’s often the partner or child of the older person that is required to assist with medical appointments. They might also help with financial matters, taking their loved ones to the bank, the pharmacy or other appointments.

At this stage of the older person’s care journey, the supporting carer is generally still working full time.

Impact on workforce participation

Depending on workplace flexibility, supporting carers might need to take time off to accompany their loved ones to appointments. Currently they could access the 10 days of paid personal/carer leave (inclusive of sick leave), however this can be taken up quite quickly, especially considering the impact Covid is having on individuals and families.

For example, a supporting carer has to take her mother to the GP once a month and two specialist appointments a year. If we assume these are taken during work periods (not on annual leave), that’s 14 appointments.

On top of that, the supporting care has had Covid and needs to isolate for 7 days. In addition, the supporting carer has two children who got Covid at the same time and had to care for them. That's another 7-14 days.

By having carer leave incorporated with sick leave, a supporting carer might not be able to take time off when they themselves are sick, because all their leave has been taken by caring for others.

What support services should be available?

QACAG, Aged Care Reform Now and Carers' Circle believe there should be wider adoption of telehealth services with supporting carers being able to dial in and assist. This would allow the older person to either make their own way to the appointment and have the supporting carer dial in with a minimal impact on their work day. This could also enable the older person to do the call from home if appropriate, however our organisations believe that face to face medical appointments are the preferred option.

In addition, there should be wider provision of home visits by GPs. The need for this service increases as care needs increase.

What employment provisions can be made?

In addition to the right to request flexibility, personal/sick leave should be a separate provision to carers leave.

2. Informal carer at home – lower level needs

The older person's needs

This is the stage where older people need more assistance. They generally cannot go out unaccompanied, and may need assistance doing tasks such as bathing, changing continence care, cooking and cleaning. Either the informal carer lives with the older person, or visits their home regularly to assist.

How the supporting carer helps

The informal carer will likely co-ordinate life administration (medical appointments, service provision, create menus or shopping lists), provide supervision, encourage independence, assist with personal care, administer medication, provide emotional support and night-time care. This is

where the older person will likely be on a level 2 or level 3 home care package which the informal carer often helps to administer.

Impact on workforce participation

Like the option above, depending on workplace flexibility, supporting carers might need to take time off to accompany their loved ones to appointments. Currently they could access the 10 days of paid personal/carer leave (inclusive of sick leave), however this can be taken up quite quickly, especially considering the impact Covid is having on individuals and families.

At this time, informal carers also may have to undertake personal care duties. This is either because the level of home care support doesn't cover all the older person's needs, or when formal paid carers do not show up for their shift.

We often find with our membership that at this stage of the journey, the carer has often reduced hours, or in the case of older informal carers such as partners, they often take retirement early.

What support services should be available?

First and foremost, higher provision of home care services should be available to offer in-home respite as it's more often than not, people's preference to stay at home. There are also often medical issues as to why it's best to stay home – such as incontinence or dementia.

There should also be more community day respite services available where older people can spend the day in a drop in centre – similar to the concept of daycare for children. This is where older people can socialise, do activities and be cared for, in a community setting. They can also be opportunities for intergenerational activities which can help build cognitive, physical and emotional strength. The second series of the ABC Television show Old People's home for 4 year-olds was a wonderful example of how this can work in practice. <https://iview.abc.net.au/show/old-people-s-home-for-4-year-olds>

What employment provisions can be made?

For those who wish to/can continue to work full time, in addition to the right to request flexibility, personal/sick leave should be a separate provision to carers leave.

For those closer to retirement or who wish to split their carer and earning duties, the option for part time work or job share, should be more readily available. Extended carers leave may also be helpful here, however there should be flexibility as to whether this is taken in smaller blocks of time (say a week or two), rather than months or years.

3. Informal carer at home – higher level needs

The older person's needs

This is the stage where older people need extensive assistance and the informal carer either moves in with the older person, or vice versa. They are usually on a level 4 home care package.

How the supporting carer helps

The informal carer will undertake all caring activities such as assisting with toileting, bathing, dressing, feeding, medication administration etc. At this stage many older people are unstable on their feet or may be completely immobile. This poses a falls risk, particularly at night and some carers report having to take shifts to sleep in order to look out for their loved ones getting out of bed.

"As a carer there is no respite - it's a 24 hr job. As a trained Registered Nurse, the medical side was easy to manage, but the physical side was backbreaking (literally) you can't just a press the buzzer for help. Many times I felt I had let my Dad down, as I couldn't meet his physical needs.

The emotional side was overwhelming - sure there is token help via the phone, but this doesn't change the fact that you are absolutely alone in overwhelming emotional torment, and them being your loved one makes it devastating.

Sadly many of us are left disillusioned about the support available, no respite, no financial support and no emotional support, giving up all social activities, leaving us absolutely exhausted and for many of us forgoing the ability to earn a wage or resuming our place in our previous work force and continuing to contribute to our superannuation. "

Helen, Victoria

Impact on workforce participation

It's often at this stage that the informal carer ceases to work. Many of our members reported that they could not continue to work and care for their loved ones at the same time as the care needs exceeded those that could be met by home care packages. This has both financial and social impacts on the carer

"In my case it meant leaving the workforce. It was a considered decision, but it has broken me. It wasn't a 'choice': there was no-one else who would support the person, who was diagnosed with a Younger Onset Dementia."

Lynda, New South Wales

What support services should be available?

In addition to the support services recommended in the previous care examples above, QACAG, Aged Care Reform Now and Carers' Circle believe there should be changes to the Carers' allowance to make it easier to access. Our members report that the hourly rate is extremely low and they have to jump through too many hoops to access it. Trying to navigate this bureaucracy while dealing with your loved ones care needs means that many people give up and suffer as a consequence.

"A carers wage is a pittance. In many cases it is mostly spent on the older person's needs. Then we are having to use our savings to support paying for our own home needs, even when we are not there (i.e. rates, electricity, handy man jobs and general house hold jobs, lawns and gardening).

Our superannuation suffers as we are caring for a loved one and not bringing in a wage."

Aged Care Reform Now anonymous member, Victoria

What employment provisions can be made?

This is where extended unpaid leave would be necessary. Ideally, it could be flexible to allow the informal carer to work if they chose to and had the right amount of support available for their loved one.

The right to return to work is also essential. Many carers leave the workforce to care for their loved ones, however find it very difficult to re-enter once their caring responsibilities lighten because their loved one has gone into residential care, or cease because they have died.

4. Older person is in residential care

The older person's needs

The older person's physical needs have increased where they may require help toileting, feeding and bathing among other things. Sometimes they are bed bound so will need to be moved regularly to prevent bed sores. They can be completely dependent on another person.

How the supporting carer helps

Just because a person is in residential care, it doesn't mean that the carer ceases to have a role. It's simply a change in the type of help required. While there is less physical work, the need for

advocacy increases. In addition, the lack of staff in residential aged care often means that carers are required to “lend a hand” and help support their loved one with tasks like eating or toileting.

The informal carer will continue to act as an advocate for their loved one, help manage their clinical requirements and provide emotional and social support.

Impact on workforce participation

At this stage of the journey, the carer has often left work as they have been caring for their loved one at home. If they are still working, it may be with reduced hours.

This is when the long-term impact on a person’s financial wellbeing can be most keenly felt. If the person was on a carers’ allowance, they’re no longer eligible. If they have been out of the workforce for a number of years, they often find it difficult to get re-enter.

What support services should be available?

In addition to the support services outlined in the above carer scenarios, our organisations believe there should be further assistance to help carers get back into the workforce – either part time or full time.

What employment provisions can be made?

As mentioned in the above scenarios – flexible work, a return to work provision and flexible extended leave.

Additional information on how formal and informal care interact with the aged care sector

As can be seen through the examples above, our members have varying level of interactions with the aged care sector.

Consistent themes we hear are:

- Our members report formal in-home care is sporadic and unpredictable, allowing for only the most essential of support such as bathing, cooking, cleaning and wound care. Informal carers are more likely to provide supervision, encourage independence, provide emotional support and night-time care. It could be argued the sustained nature of the

latter has a high risk of burnout and is 24/7 in nature so leaves the informal carer with no respite.

- Lack of access to higher level home care packages means informal carers take what they can get and are grateful for at least some assistance, whether it is meeting their needs or not. The process for increasing to higher level care packages is lengthy, meaning there is little scope for additional support as and when care needs might increase, temporarily or permanently. While the funding is often seen as inadequate for those with higher care needs.
- Access to good quality, timely and local respite through residential aged care is virtually impossible and this exacerbates the situation. All these factors combined increase the risk of a person having to enter residential aged care prematurely, a situation our members would see as a last resort when all other options have failed.
- Once in residential aged care our members report their informal carer responsibilities, although no longer 24/7 continue to dominate their daily life. Many feel compelled to spend time with their loved one owing to chronic understaffing in residential aged care. Many of our members have spent hours helping their loved one to receive adequate companionship, nutrition, bathing and ensure clothes and belongings are not lost, or interfered with by other residents lacking supervision.
- We often hear our members identify themselves as an 'extra pair of hands' to prop up staffing. A situation greatly exacerbated during the Coronavirus pandemic.

All of the activities described above are done with a sense of loyalty and obligation. However, our members, rather than seeing this as burdensome, deliver informal care out of a deep sense of love for their significant other. However, it is shameful that they cannot and do not feel confident to reduce their caring responsibilities because of a failure to provide adequate numbers of staff, including registered nurses in residential aged care facilities. If both home care and residential aged care were viable, reliable and safe options this would significantly benefit them.

"I left the workforce to care for my partner. She'd had to retire due to her dementia and was lonely at home alone, although still quite independent. It was a planned joint decision. Despite missing my work very much, I'm glad I retired when I did as she's increasingly needed me and is now totally dependent 3 1/2 years later."

Marion, Queensland

How an entitlement to extended unpaid carer leave ought to be designed.

Given that many informal carers may be working part time or beyond retirement age whatever arrangements are made should encourage this option to be adopted with the minimum tax burden. In addition, given that many families tend to be smaller, there may only be one or two family members who can provide informal care. They may be called upon to provide informal care more than once, so proposals should allow for multiple episodes of carer leave.

Having flexibility in the scheme, for example, being able to use this part time rather than in a block would be more beneficial. This would enable people to work at times when others were available to care for their loved one or allow work to continue whilst fitting around ongoing respite arrangements. We believe this leave would be useful for multiple family/significant others to access in respect of shared informal caring responsibilities in a 'pooling' arrangement. For this to occur the leave would need to be allocated to a person requiring care, accessible to those providing informal care to them.

We recognise that it can be difficult to administer extended unpaid carer leave from an employer perspective because of the uncertainty as to how long the carer will need to take off. However we believe that with open communication and flexibility on both sides, a fair solution can be provided for all.

We believe that this will encourage greater workplace engagement and loyalty as has been the case when employers have introduced extended paternity leave provisions.