



Submission to the Parliamentary Inquiry into the Policy Implications of an Ageing Community

Carers WA



July 2014

For inquiries please contact

Dr Donna Turner donna.turner@carerswa.asn.au 9228 7431

Carers WA is the peak body representing people who provide ongoing care to a family member or friend with care needs due to disability or chronic illness, including age-related disability. Currently over 15,000 carers are members of Carers WA.

An Age Friendly WA – is it possible without supporting carers?

Carers WA advocates for and represents people who are in an ongoing unpaid caring role for family and friends who have long term care needs. Much of the caring that takes place in the home and community is undertaken by older people and is on behalf of older people. The ability to live in your home and live the life you wish is therefore strongly linked to giving and receiving care. Until WA develops and implements a whole of government approach to carers and caring, it is difficult to imagine that WA can really be an Age Friendly state.

Carers in Western Australia

A person is called a 'carer' under the Carers Recognition Act 2004 if they provide unpaid ongoing care to a person close to them, usually a family member, who has ongoing care needs due to a chronic illness, frailty, mental health issue, physical or intellectual disability or problems with drugs and alcohol.

The Australian Bureau of Statistics¹ has estimated that there are 236,200 people in a caring role in Western Australia although academic researchers have argued that this is an undercount and there are more likely to be upwards of 307,000 carers in WA.² Access Economics calculated that if the care provided by family members and friends across Australia was replaced by formal services, this would cost over \$41 billion annually.³

Why is caring important to creating an age friendly society?

Most carers are older people. Sixty three per cent of carers in WA are aged over 45 years. That is, almost 150,000 people over 45, including 17,200 aged over 75, are providing care to someone else while they themselves are ageing.⁴

People wish to maintain their physical and mental health and wellbeing. Carers experience low levels of health and wellbeing when they are not supported in their caring role.⁵ Approximately half of primary carers aged over 65 are themselves living with a disabling condition.⁶ Being in a caring role can create financial and time barriers to accessing health care.

People generally prefer to age at home. At some stage in our lives, in order to remain at home, it is likely that we will require the support of other family members such as a spouse or adult child, or perhaps friends and neighbours. The vast majority of care received by older people is provided by family members and others in our networks, not by service

¹ Australian Bureau of Statistics. 2012. *Survey of Disability, Ageing and Carers*. ABS. Canberra.

² Edwards, B., Gray, M.C., Baxter, J. and Hunter, B.H. 2009. *The Tyranny of Distance? Carers in Regional and Remote Areas of Australia*. Commonwealth of Australia and Carers Australia, Canberra.

³ Access Economics. 2010. *The Economic Value of Informal Care*. Access Economics and Carers Australia.

⁴ ABS. 2012.

⁵ Cummins, Robert, Joan Hughes, Adrian Tomin, Adele Gibson, Adele, Jacqueline Woerner, and Lufanna Lai. 2007. *Wellbeing of Australians : Carer health and wellbeing*, Deakin University, Geelong, Vic.

⁶ ABS. 2012.

providers. Support for carers is therefore important to ensuring that older people can age at home.

The population is ageing – more care is required but who will provide it? As we age we require more care, but a number of factors are making it less likely that we will have family members available to provide care in future. Without the support and care of family and friends, is an age friendly society possible?

People want choices in their life and in their retirement. Unfortunately, some family members are in a caring role because they have no other choice. The unplanned expenses associated with caring in later life, such as for grandchildren, can mean an end to retirement plans and restricted expenditure on necessities and other activities.⁷ Carers are more likely than most people to be in the lowest income households.⁸

The remainder of this submission provides more detail on older carers generally and on grandparent carers in particular. Finally, recommendations are made to address gaps in supports and resources for older carers, and also for carers of older people. When older carers, and the family members who support older people, are themselves supported, this will be a significant and necessary move towards creating a truly age friendly society.

⁷ Gong, X., L. Brown and L. Thurecht. 2014. *Meeting hidden household costs of care in the home: Impacts of the presence of disability on expenditure patterns of older Australian households*. National Seniors Productive Ageing Centre

⁸ ABS. 2012.

Older people comprise the majority of carers in WA

People over 45 years of age account for sixty three per cent of all carers in Western Australia.⁹ That is, almost 150,000 people in a caring role are over 45 years of age. Almost 20 per cent of Western Australians aged 65-74 are in a caring role.

Unpaid carers of family members and friends in Western Australia, 2012

Age group (years)	Primary carer	Carer, but not a primary carer	Total carers	Not a carer	Total
ESTIMATES ('000)					
Males					
Less than 15		3.3	3.3	232.6	235.6
15-24	0.0	7.9	7.0	166.9	175.4
25-34	1.3	11.0	11.7	180.8	192.8
35-44	1.7	14.8	16.5	156.9	174.3
45-54	3.2	14.6	16.2	145.5	163.3
55-64	4.5	16.0	22.2	111.7	133.6
65-74	4.5	10.8	15.4	70.1	86.0
75 and over	1.5	6.6	8.1	41.7	50.5
Total	18.1	83.9	101.4	1,109.8	1,208.9
Females					
Less than 15		3.6	3.6	219.4	221.4
15-24	1.2	9.9	10.5	149.1	159.6
25-34	4.6	6.8	11.8	163.4	174.5
35-44	6.6	16.0	22.3	145.3	168.4
45-54	10.5	19.3	31.5	129.8	160.5
55-64	9.4	20.1	27.5	105.5	132.2
65-74	7.1	11.0	18.1	67.1	84.3
75 and over	3.2	4.9	8.3	48.4	57.0
Total	42.5	91.5	135.4	1,025.0	1,160.9
All Persons					
Less than 15		5.0	5.0	452.1	456.5
15-24	2.4	17.5	19.8	317.5	335.9
25-34	5.3	18.8	25.3	343.6	368.8
35-44	8.3	30.8	37.9	302.6	341.9
45-54	14.0	33.6	48.2	275.4	322.7
55-64	13.4	34.9	49.7	218.0	266.3
65-74	10.9	22.3	33.7	137.5	170.3
75 and over	5.1	12.5	17.2	90.6	106.5
Total	61.3	174.5	236.2	2,134.6	2,369.3

Source: Australian Bureau of Statistics. 2012. Survey of Disability Ageing and Carers. ABS. Canberra.

⁹ ABS 2012. SDAC Table 33.

Carers who are over 65 are most likely (approximately 75-80 per cent) to be caring for their spouse who is also ageing, but approximately 9-10 per cent care for their adult children with life-long disability.¹⁰ While many men are in a caring role, particularly older men, women comprise the majority of primary carers. A primary carer is the person who provides the majority of care and support to an individual. In WA, approximately 30,200 women over 45 are primary carers, while 13,700 men over 45 are primary carers.

While many people cite positive reasons for wanting to provide care, and experience benefits to their relationship as a result of the caring role, carers over 65 years of age are more likely than younger carers to state that the reason they are providing care is that no other family member was available or willing.¹¹ This suggests that older carers would accept more help and support in the caring role if it was available. More than half of the carers aged over 65 are themselves living with disability.¹²

Carers are more likely to be in low income households

Data indicates that households comprising a person with disability and a person in a caring role aged over 65 are likely to be in the lowest two household income quintiles.¹³ Carers whose caring role prohibits them from taking on paid work and who meet the income and assets test requirements are eligible to receive Carer Payment which entitles them to receive a Pensioner Concession Card. Carers of age pension age in a caring role may choose between Age Pension or Carer Payment. There are approximately 12,000 Carer Payment recipients in WA and there are many more carers in receipt of Age Pension in a caring role. Some carers receiving the Age Pension may also receive the Carer Allowance, a small fortnightly payment that many families rely on to offset increased costs associated with disability such as transport to medical and therapy appointments, medications and phone calls required to coordinate access to formal services.

A recent Australian report examined the increased costs to older Australians living with disability and concluded that 'older families with members needing assistance had to allocate more of their household budget to meet their basic needs and sacrifice the consumption of luxury goods and services.'¹⁴ Note that 'luxury goods' include recreation and clothing.

¹⁰ ABS. 2014. Caring in the Community. Australia. ABS, Canberra.

¹¹ ABS. 2012. SDAC. Table 43.

¹² ABS. 2012. SDAC. Table 34.

¹³ ABS. 2014. Caring in the Community. Australia. ABS, Canberra.

¹⁴ Gong, X., L. Brown and L. Thurecht. 2014. *Meeting hidden household costs of care in the home: Impacts of the presence of disability on expenditure patterns of older Australian households*. National Seniors Productive Ageing Centre



Older carers in country areas

Carers of all ages in country areas face unique challenges associated with restricted access to and limited choice of supports and the need for private transport to access services in the absence of public transport options. As one family told Carers WA, 'If we didn't have a car we would be buggered'.¹⁵ However, older carers in country areas also have additional concerns as noted in this recent Australian review:¹⁶

In addition to having a larger proportion of people needing care, rural areas are compromised by having fewer people of working age to provide care and support to older people, as well as a shortage of viable residential care facilities. As a result, older people in rural areas are more likely to be required to provide care to ageing partners and other family members.

The review identified the importance of social activities that provided informal peer support for both older carers and older people receiving support. Service providers in country areas are encouraged to generate and then build service provision around these social opportunities so that informal social networks brought people into contact with services they might not otherwise have known about or felt confident in accessing. This conclusion strongly coincided with what country carers told Carers WA they needed which was opportunities to learn from other carers and families and to access services in a hubbed location.

The other stand out issue for carers outside of the metropolitan area was the cost of transport to attend appointments, many of which were with medical specialists not available within their local community.¹⁷ Our recent review of issues around the Patient Assisted Travel Scheme (PATS)¹⁸ clearly highlighted the extent to which out of pocket expenses are adding stresses to families in which there is a family member who needs frequent access to hospital services that are some distance away. Older carers in particular have reported that they are unable to safely drive the return trip from home to Perth within the same day and,

¹⁵ Carers WA. 2011. Carers of Family and Friends in Country WA. Carers WA, Perth.

¹⁶ Winterton, R. and J Warburton. 2011. Models of Care for Socially Isolated Older Rural Carers: Barriers and Implications. *Rural and Remote Health* (11) 1678 (online).

¹⁷ Carers WA. 2011.

¹⁸ Carers WA. 2014. Submission to the Parliamentary Inquiry into PATS. Currently confidential.

as a consequence, have had to pay for overnight accommodation. PATS requires a return trip of more than 200km before people are eligible for a subsidy on the cost of overnight accommodation. In low, fixed income households, costs such as these present a barrier to accessing health care, and reduce the opportunities to live a healthy life in older age.

Having to be away overnight for medical treatment also caused difficulties for one older carer who struggled to find alternative care for her elderly spouse who has dementia. There was no available respite in her home town and she had to postpone her medical appointments until respite could be organised. Being in the caring role can mean that a person is less free to access services that are important to the carers' own wellbeing. Access to emergency respite was identified as the one of the top five issues for older carers in Northern Ireland.¹⁹ Knowing that alternative care was available for their loved one should the carer become ill was considered necessary for the carer's peace of mind.

Grandparents caring for grandchildren with disabilities

A particular group of older carers are grandparent carers. Grandparents are referred to as carers when they provide ongoing care to their grandchild who has care needs due to disability or a long term health or psychological condition. At the same time as providing care to their grandchild/ren, a grandparent may also be in a caring role for their adult child, as well as their ageing spouse.

As with many carers, grandparents may feel a sense of obligation and responsibility and wish to provide a safe and secure environment for the child when the parents are unable to do so. Parents may be unable to provide primary care to their child/ren due to struggles with their own physical and mental health and wellbeing, including domestic violence, drug and alcohol issues, unemployment and financial pressures, homelessness, or pressures resulting from the disabilities or health conditions experienced by the child.

Children may come into the care of their grandparents through informal or formal arrangements. The majority of grandparent caring arrangements are informal. Families wish to keep arrangements informal for many reasons including a fear that they may be considered unsuitable and that the child/ren will be removed from their care; to preserve the relationship with the child's parents; fear of scrutiny by 'authorities' and financial costs.

Major issues for grandparent carers

Grandparent carers may be supporting other people in addition to their grandchild. Grandparent carers may also be caring for their adult children as well as caring or co-caring for their own spouse, and/or their own ageing parents. Coping with their grandchild's medical, mental health, development and behavioural challenges can be stressful and result in declining physical and mental health. Grandparent carers can be vulnerable when

¹⁹ Commissioner for Older People for Northern Ireland. 2014. Supporting Older Carers. COPNI.

adult children or their grandchildren display challenging behaviours related to their disability.

Grandparent carers often experience strained familial and friend relationships. Parental involvement with the children can often be unplanned, periodic, inconsistent and troubled. Social networks and natural support systems often decline due to a lack of understanding. This can further impact negatively on the mental health of grandparent carers.

Grandparent carers may be in employment, retired or nearing retirement and may not have factored the care of a child into their financial plans. Those who have been caring for lengthy periods of time are unlikely to have accrued savings or superannuation. In addition to providing food and housing, grandparent carers may face additional costs related to educational, medical and support needs such as counselling, tuition and speech therapy. Determining their eligibility for financial support is a complex process requiring contact with multiple agencies at different levels of government. Grandparents can experience barriers to supporting their grandchildren if the caring relationship is not formalised. In some cases, institutions, for example, schools, will then refuse to provide the grandparent with access to relevant information in the absence of permission from the parents. This is understandable but places pressure on the grandparent and the grandchild.



Grandparent carers are often informal rather than formal guardians of their grandchildren and lack legal status with some agencies and institutions, for example, the grandchild's school or doctor. An advocate or peer support worker could assist so that the grandparent can access the information they need to give their grandchild the best care possible.

Legal issues include decision making restrictions, guardianship, consent to medical procedures and having authority to enrol children in school or to engage with Centrelink on behalf of the child. Grandparent carers are also often required to undertake complex financial planning such as the establishment of Special Disability Trusts and the management of payments for the child.

While a considerable amount of information is available online, not all carers have access to the internet or the time to navigate between multiple agencies. Some grandparent carers may have limited transport options, which can pose difficulties for those caring for young school aged children particularly for children with mobility restrictions who may need to be

transported in specialised vehicles. Many may lack confidence when attempting to navigate social, legal and education systems that are different to those that were in place when they raised their own children.

Grandparent carers are frequently concerned about who will look after the children if something happens to them; that the children may develop similar mental health issues as their parents; that they will be judged as too old and not up to the task of caring for young children. Grandparent carers may also be grieving due to the loss of their child, a failed relationship with the parent or the adverse judgement of the parent. Grandparent carers may blame themselves where drug and alcohol problems or mental health issues are involved. They also may have difficulty in reconciling their grandparent role with that of being a parent and a carer.²⁰

The impact of an ageing population on carers and caring

Family members, including spouses and adult children, provide the greatest amount of care to older people. The ageing of the population therefore has multiple impacts on carers who are themselves ageing, and on younger family members such as adult children who care for their ageing parents. The ageing of the population will increase the need for care provided by family members due to the increased incidence of chronic conditions, including dementia, and due to the desire of individuals to remain in their homes as they age, a preference strongly supported by government policies.

Reforms to community based aged care and disability care, while potentially delivering some positive results, will impact on older carers in ways that have yet to be determined by state and federal governments. It is important to investigate concerns in the community that there may be a reduction in funding to low care older people living at home when WA moves from Home and Community Care (HACC) for over 65s to the Commonwealth's Community Home Support Packages in 2015/16. If funding to individuals is reduced, the gap in care needs is likely to fall on family members, including older carers caring for their ageing spouses and parents. Similarly, the ceasing of HACC for people under 65 with disability and the shift of this funding into the National Disability Insurance Scheme in WA is likely to result in a significant proportion of previously eligible under 65 HACC clients losing entitlement for individualised funding due to the higher eligibility requirements of the NDIS. The care once provided to these people through HACC is likely to be provided by family members including ageing parents.

Recent shifts in health provision towards Hospital in the Home (HITH) for people with general health and mental health issues and now also for older adult mental health issues will impact on family members providing care in the home. The home becomes a space occupied by professional strangers who are in relatively powerful positions and whose care

²⁰ Cass, Bettina. 2007, Exploring Social Care: Applying a New Construct to Young Carers and Grandparent Carers, *Australian Journal of Social Issues*, Volume 42, Number 2.

of the older person at home may conflict with the care provided by family members, including the spouse. It is important that increased recognition of the carer be given by health professionals and other in home service providers in order to maintain the wellbeing of older carers and the person they care for. It is important that service providers remember that family members are together most of the time whereas service providers may interact with a person for only a few hours per week.

In summary, it appears that Western Australia will not only continue to rely on older carers, but that this dependence may increase. Rates of caring are lower amongst younger population cohorts due to a variety of factors but including the fact that more women are now in paid employment. Additionally, there is a growing expectation on the part of governments that people should remain in paid employment until later in life, also reducing the available pool of people available to provide care for their family members. As has been indicated in the Commission of Audit and the interim McClure Report,²¹ tightening of the eligibility for income replacement payments, such as the Carer Payment and Disability Support Pension, also makes caring a less affordable option for many low income carers who will now be required to juggle paid employment in addition to their caring role. The Commonwealth's recent budget decision to cease funding of concessions to pensioner concession card holders will also impact on low income caring households.

Recommendations to move towards an Age Friendly WA

It is hard to envisage that WA can successfully create and support age friendly communities in the absence of community wide recognition and support of older people in a caring role. The need for increased recognition and support for carers is noted in the current Seniors Strategic Planning Framework. Carers WA therefore puts forward the following recommendations to assist with achieving this goal.

What needs to be done to support grandparent carers?

- There is a greater need for research and understanding of grandparent carers to inform intervention strategies, as well as appropriate supports. Currently, even the number of grandparent carers in WA is unknown.
- As part of whole of government approach, state government agencies should investigate inconsistent policy responses to informal and formal kinship care which has contributed to significant inequities of supports available to grandparent carers in comparison with formally recognised foster parents.²²
- Improved access to information, respite, legal and financial support is required. Given the lack of recognition of grandparent carers and their lack of legal status in many settings, this is likely to require the provision of individual advocacy services focused exclusively on the issues facing grandparent carers.

²¹ Commonwealth of Australia. 2014. A New System for Better Employment and Social Outcomes. <http://www.dss.gov.au/our-responsibilities/review-of-australia-s-welfare-system>

²² Horner, Barbara, Jill Downie, David Hay and Helen Wichmann, 2007, *Grandparent headed families in Australia*, Australian Institute of Family Studies.

- Wider and more targeted promotion of existing training, respite, counselling, behavioural and child rearing supports is required. Many are currently targeted at younger parents and don't support grandparents raising grandchildren with disability.
- Grandparent carers may also benefit from assistance in addressing complex family issues that may often require coordination between agencies and support services. Individual advocacy for grandparent carers would be useful here given the legal, financial and emotional complexities.

What needs to be done to support older carers generally?

- Older carers want to be considered as partners in care and have their views and knowledge respected by formal service providers in health, mental health and aged care settings. This is consistent with current Commonwealth and state legislation in health, mental health and disability settings. However, further promotion of the role of carers is required in these settings including training for clinical and allied health staff and community service providers. When services are being designed or altered, it is important that people using the services, including carers, are included.
- A whole of government approach is required so that carers are recognised across all government agencies. This requires amendments to the Carers Recognition Act 2004 as identified in the 2008 review of the legislation that are yet to be actioned.
- Carers have asked that a statewide Carer Action Plan be developed and implemented by the Government of Western Australia.
- Carers have asked that carer liaison staff be made available in hospitals to help family carers prepare for the caring role when the patient leaves hospital. This is particularly important for older carers who may be taking on physically and emotionally demanding care such as when their partner returns home after a stroke.
- Older carers in country areas need more support from PATS and assistance to cover the costs of travelling to medical and other appointments.
- Older carers and the people they care for in country areas are at risk of social isolation and require a coordinated approach from service providers to assist with continued participation in activities that support health and wellbeing.
- Being able to access support from people in the same situation has benefited carers and therefore carer peer support networks should be widely available. Peer support, either in person, on the phone or online, is a cost effective way to improve carers' coping strategies, knowledge and networks.
- Older carers, in attempting to navigate complex pathways between multiple service providers on behalf of the person they support, should be able to access coordinators or liaison staff able to coordinate cross referrals. In more complex cases, individual advocacy should be available to ensure the carer and the person they support are assisted before reaching crisis point.
- A review of concessions should ensure that older people on Carer Payment are eligible for concessions in the same way as people on Age Pension are eligible.

There is currently low awareness amongst state agencies providing concessions that Carer Payment recipients are Pensioner Concession Card holders.

- Modelling of the impact on older carers of the forthcoming shift from over 65 HACC to the Commonwealth Home Support Packages and modelling of the impact on older carers of the shift from under 65 HACC to NDIS is urgently required.

What needs to be done to support people caring for older family members?

Family members and friends caring for older people will similarly benefit from the recommendations above but additionally, will benefit from initiatives that will help them maintain links to education and paid employment.

- Employers should be supported to provide workplaces that are flexible and carer friendly, with government agencies leading by example. This will allow carers to continue to support ageing parents without having to give up their paid employment.
- Carers should be able to participate in paid employment, education and training keeping in mind that this will require the provision of alternative care to the person with care needs.
- Respite (in home, residential and community based) should be available that is respectful of and beneficial to the person with care needs. This gives carers time to participate in work and other activities, and to spend time with other family members in their care. New models of respite that are culturally appropriate should be developed in consultation with communities including Aboriginal communities where rates of disability and caring are high.