



**Submission to the Productivity Commission  
Inquiry into Caring for Older Australians**

**The true nature of aged care in Australia**

**July 2010**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education. These rights should be mandated in legislation.

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**Title:** **CA Submission to the Productivity Commission Inquiry into Caring for Older Australians**

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## **Introduction**

Carers Australia welcomes the opportunity to provide input to this inquiry. It is important that when working towards the best outcomes for care for older Australians, we challenge assumptions about the sector in order to break out of old ways of doing things and find real reform. Any redesign must begin with a rethinking of the way care is currently thought about and framed in policy, procedure and service delivery.

Currently, the system is often approached from the perspective of those delivering services and this perspective then shapes outcomes. It is important to consider more broadly where care for older Australians fits in our society and how it impacts on the individuals involved in it.

The 'typical' residential client is often seen to be a lone person. The links with family and carers must be considered. Not all will have it, but for those that do it is an essential part of the picture to consider when examining care needs of individuals and getting the best outcomes for users of services.

If we examine the true nature of how care is provided to older Australians, the role of unpaid family carers in the aged care system must be understood.

Once there is an understanding of the role of family carers within the system, it is then possible to understand where the aged care system would be without carers, in both the immediate future and long-term. An aged care system would simply collapse without family carers. If care provided to older Australians is to be sustainable in the long-term it must properly support and be inclusive of the needs of family carers.

A change in perspective is also needed regarding the importance that is placed on care provided in different settings and the current divide between community and residential care. The disparity in government expenditure is clear (as provided on the table on pg 16 of the inquiry issues paper) and given the allocation of places, with community care making up less than two per cent of all aged care places.<sup>1</sup>

As care moves increasingly towards the home, care delivered in the community must be better valued. Further, a large proportion of older Australians receive care but never come into contact with the formal care system and have their care needs met solely by family members and friends. Older Australians receiving this form of care and their carers should not be left out of government reforms.

As a society we need to take off the blinkers resulting from many years of assumptions and consider how care is really provided in our communities and how the needs and realities of those accessing care can be most closely matched with services and support. Our perspective needs to be broader.

Carers Australia believes strongly that any reforms to the aged care system must be people-centred rather than economically driven.

When discussing previous reforms to systems it should be remembered that there has never been a system reform in the aged care sector that has put carers at its centre. Carers Australia wants to see changes that make use of carers' expertise and provide real inclusion for carers in the sector.

## **Terms of reference**

Considering the role of family carers in the provision of care for older Australians, Carers Australia puts forward the following discussion of the key areas outlined in the inquiry terms of reference.

## **Redesign and reform**

A reframing of the conceptual issues in aged care is an essential part of reform. Carers must be recognised for the valuable contribution they make. When it comes to residential and other aged care services they are often the decision makers and the consumers alongside residents. This should be acknowledged in all related government policy.

## **Challenges**

The caretaker ratio, preferences for care delivery and the conceptualisation of aged care are key challenges for the future of aged care provision in Australia. There is a need not only understanding the true nature of how care is delivered in our society but ensuring our systems and support reflects this. To meet these challenges, family carers must be better supported.

## **Social Inclusion**

There is clear evidence that older people experience much higher rates of social exclusion and carers have been included under one of the six priority areas for inclusion under the government's social inclusion agenda. Family carers often experience social isolation as a result of their caring role and this may also have negative mental health outcomes.

## **About Carers Australia**

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community through a network of over 60 sites that cover the length and breadth of the country. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

## **About Australia's carers**

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care.<sup>2</sup>

Carers are sometimes referred to as 'family carers' to distinguish their role from other caring roles in our society such as paid care providers, foster carers, parents or guardians.

Many carers are termed 'sandwich carers' or 'the sandwich generation' because they care for more than one person – a frail parent, a partner or a child with a disability or chronic condition.

Anyone, anytime can become a family carer and the caring journey can last a lifetime. This can be from the birth of a child through to their own inability to continue to provide care because of age or illness. Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. Carers are young, of working age, older, Aboriginal and Torres Strait Islanders, they live in our cities and towns and rural and remote areas, and may have been born outside Australia.

The ABS has found:<sup>3</sup>

- 2.6 million carers across Australia
  - almost 500,000 of these are primary carers
- 380,000 Australians under the age of 26 provide care to a family member who has a disability, or a mental or chronic illness
- 170,000 carers under the age of 18
- 31,600 Indigenous carers over the age of 15
- 620,000 of Australia's carers were born outside Australia
  - 366,700 of those born outside Australia were born in other than main English-speaking countries.

## **The role of family carers in aged care**

The information paper states that informal carers (unpaid family carers) "provide a wide variety of care and everyday living support services and play a fundamental role in the coordination and facilitation of formal community care services."<sup>4</sup> However, carers do much more than this:

- they provide emotional support
- they act on behalf of the person to advocate or decision-making, many carers are the sole decision makers for those with impaired decision-making capacity
- they improve the quality of life of the person receiving care
- they keep older Australians out of residential care often to the detriment of their own health.

It has been shown that older people who are dependent on family carers may move towards formal sources of care as they age, often because of the complexity of care required. However, family carers provide an increased amount of support as people age with decision making, maintaining relationships and helping older people coping with feelings or emotions.<sup>5</sup>

There are several key groups of carers who may be engaged in the provision of care or involved with the care provided to older Australians through formal services:

- older carers caring for a partner or friend
- older carers caring for a partner and adult son or daughter
- older carers caring for an adult son or daughter
- younger carers of older people

To provide examples of each of these caring situations:

- an 80 year old man who cares for his wife
- a 70 year old woman who cares for her husband and adult son
- a 65 year old woman who cares for her adult daughter
- a 40 year old man who cares for his elderly mother

### **Carers of older people**

239,400 primary carers provide care to people over 65 in Australia and over half of these primary carers are aged between 35 and 64. There are also a significant number of young carers under the age of 26 providing care to people over 65. This group must have consideration in any reforms to the aged care system.

### **Older carers**

Where carers are older, there are a number of specific considerations that should be taken into account. Those providing care to older Australians are themselves also often older. Older carers are caring at a time when their own health may be deteriorating, or subject to the same health concerns as other older Australians.

The two most common family situations involving older carers are:

- older carers caring for a son or daughter with disabilities, including psychiatric disabilities
- older carers caring for a partner or friend with dementia, chronic conditions, terminal illness or disabilities resulting from ageing.

In 2003 ABS identified:<sup>6</sup>

- 454,000 persons aged 65 and over were carers – almost 1 in 5 persons
- people over 65 accounted for 18 per cent of all carers and 24 per cent of primary carers
- 391,000 provide care for someone living in their household and of these:
  - 48% were caring for someone with a profound or severe limitation in core activities – 187,680 people
  - 36% were assisting someone with a moderate or mild limitation – 140,760 people
  - 8% were assisting someone who had a long-term health condition without disability – 31,280 people
- 50 per cent of older primary carers spent 40 hours or more actively caring or supervising.

Older carers of adult sons and daughters have usually been caring a long time, sometimes as long as 50 years. Long-term caring can take its toll, socially, emotionally, physically and economically. Older carers are caring at a time when their own health may be deteriorating and they are at risk of the normal range of health issues that arise for older Australians. Yet the caring responsibilities do not necessarily diminish or the level of support increase as these issues present.



In many cases carers are living the consequences of long-term exclusion from the workforce and costs of caring over time. They have little savings or resources to call upon to help them arrange alternative support for the time when they can no longer care or to achieve a different balance of care that recognises their current capacity to care.

### **Where family carers provide care**

Informal caring doesn't only happen in the home, many carers live apart from the person they provide care to, carers may visit the person they care for on a daily or weekly basis in a residential facility. And importantly, family also provide care to those who are not engaged in either system.

Many carers continue to be heavily involved in the lives of older people in residential facilities. They may visit several times a week, sometimes carrying out care tasks for the person for whom they care. The caring role does not always end at admission to residential care. The positive and ongoing involvement of family and friends is essential for the majority of older residents of aged care facilities because it

- contributes to maintaining the emotional health and well being of residents by providing understanding, affection and encouragement<sup>7</sup>
- can assist in reducing depression, which affects 51% of residents of high care facilities and 30.2% of residents of low care facilities<sup>8</sup>
- provides continuity of relationships of the resident with family members, and with significant friends and other relatives
- can assist residents with restricted functioning to continue to feel in touch with their home, family, neighbourhood and history
- contributes to quality assurance and continuous improvement within aged care facilities as family members may act as 'care guardians'<sup>9</sup> and advocates for their relative<sup>10</sup>
- contributes to the quality of care through the direct work of family carers both in supporting and assisting their relative and assisting other residents (the extent and value of family contributions to the day-to-day operation of aged care facilities may be significant)
- can contribute interest, variety and new perspectives to the residential care environment.<sup>11</sup>

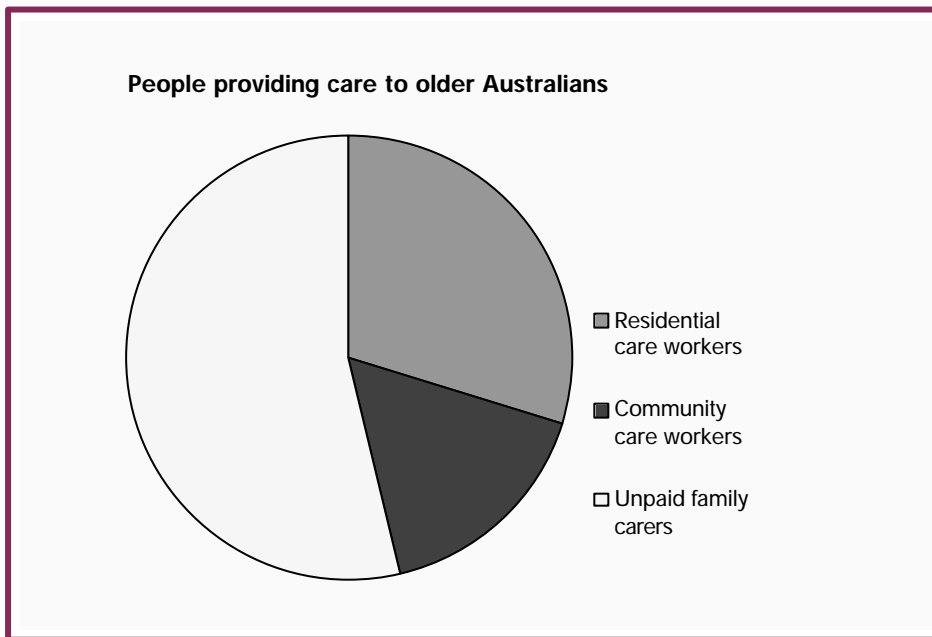
The involvement of carers as advocates is particularly important when 97.2 % of residents have communication difficulties and require some assistance or support with communicating with staff, relatives or friends.<sup>12</sup> In addition, estimates indicate that 55% of low care residents and 90% of high care residents have a degree of cognitive impairment indicate the importance of support and advocacy by their family or friends.<sup>13</sup>

There is also an assumption commonly that carers merely support the delivery of community care. Many carers also play a significant role in residential settings and not only supplement formally provided care in the community, but are the sole source of community care for many older people. The true nature and relationship of family carers to the aged care sector is often overlooked or forgotten.

## The value of family carers to aged care

As acknowledged in the discussion paper for the inquiry, family carers are the providers of the most care delivered in the community. They provide the majority of care for the majority of time.

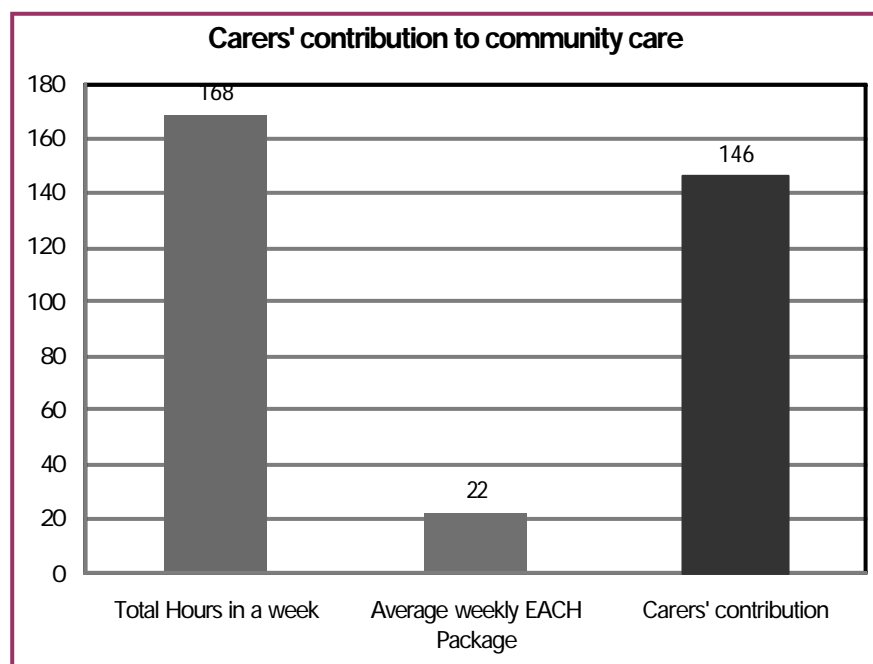
32.4% of HACC clients classified as care recipients reported that they were also receiving assistance from a relative or friend/carer.



Considering the care provided by family carers alone, 239,400 unpaid primary carers are caring for someone over the age of 65. This far outweighs the number of paid care workers providing direct care in both the residential and community sectors (133,000 and 74,375 people respectively).<sup>14</sup>

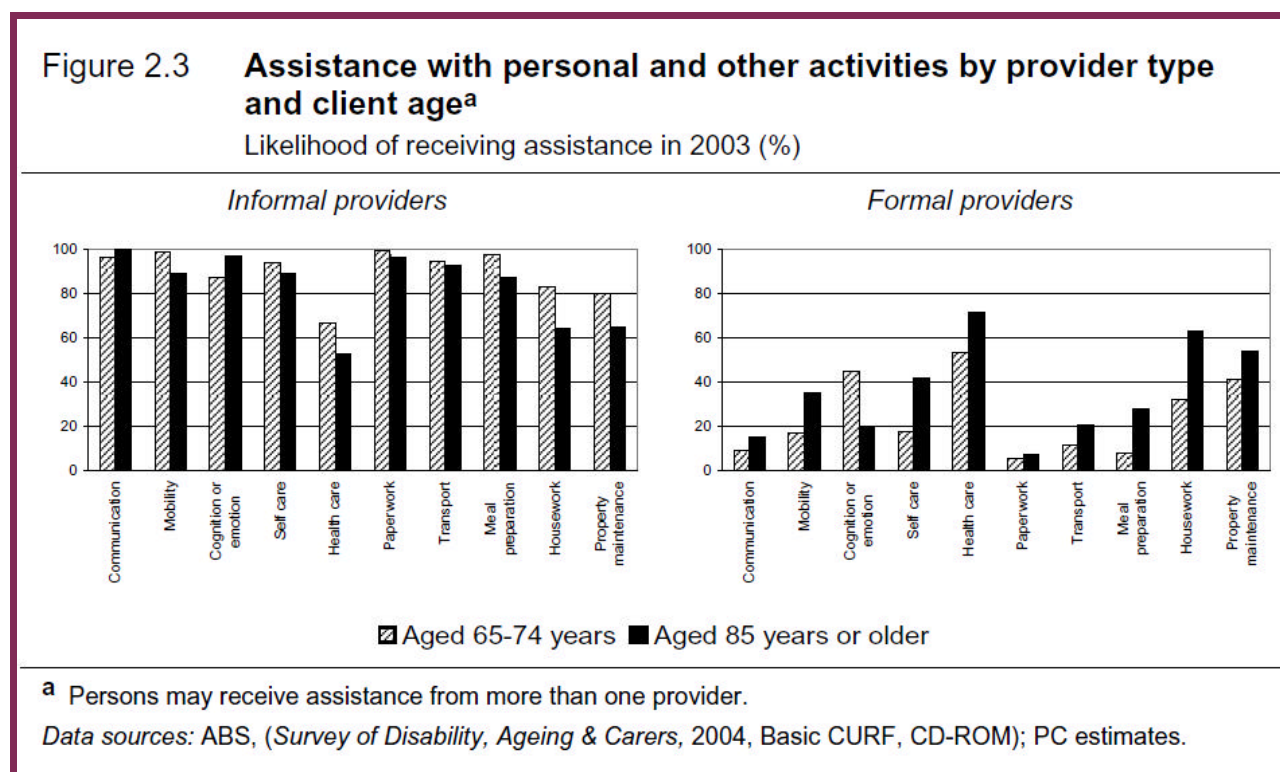
Data provided in PC Issues Paper, taken from Trends in Aged Care 2008 and data on the number of unpaid primary carers is taken from ABS (2008) A Profile of Carers in Australia.

An older person receiving a CACP package receives an average of about seven hours a week in personal care. People receiving an EACH package are typically provided with 18-22 hours of assistance each week.<sup>15</sup> However this means that even where there is 22 hours of formal assistance provided, for the remaining 146 hours of the week, care will be provided by an informal carer.



At a cost to government, on average, of \$41,500 per resident each year in an Australian Government funded nursing home or hostel,<sup>16</sup> it is easy to see the enormous contribution carers are making to society and the savings to government. The value of this contribution will continue to increase, making maintaining support for carers and recognising and enhancing their role in the provision of care a vital part of the economy. This cannot be taken for granted and carers should not become simply a cost-saving measure for governments.

Family carers provide care in a way that is very different from formal care. Carers often are able to provide a quality of care that cannot be found in formal care settings. The following data reveals that older Australian needing care are much more likely to receive it across a range of areas from family carers.



**Figure 2.3 as cited in Productivity Commission (2008) Aged Care Trends Paper**

It is not hard to describe the importance of their contribution:

- people needing care can remain at home in a familiar environment with people they know
- family carers can provide care in a highly individual and flexible way
- carers can support family members with disabilities or illness to maximise their life and independence in the community
- family structures, values and relationships are at the centre of the care.

### **A unique stakeholder in the system**

In the issues paper for this Inquiry, the Commission has included the central discussion of family carers under the 'workforce' section. This is problematic, because by including family carers in this way, there is an assumption made that family carers are not very different from volunteers or paid care workers in terms of their place within the aged care system.

However, there are very clear and important differences between these roles. They are not officially a part of the aged care workforce, although they may have similar responsibilities and provide more care.

Aged care workers are paid to care, family carers are not. Family carers have no automatic entitlement to training, workplace protections, regulations or legislation to protect them from injury, or support them when they need to retire. They have no union, and they have no leave provisions.

They are also very different from volunteers, despite the unpaid nature of both roles. Volunteers in the aged care sector can make the choice to provide care, or to cease providing care, many family carers cannot; they care because of their relationship to the person requiring care.

This issue was also repeated in Productivity Commission trends paper on aged care from 2008. We would request that the Commission take a new approach to 'locating' carers in the provision of care to older Australians and identifying their role.

The National Health and Hospital Reform Commission has identified carers as the 'invisible health workforce' and this is a fairly accurate concept that acknowledges the vital yet often unrecognised role they have in supporting and caring for people across all age groups and all conditions. If they are any part of a 'workforce', we believe that they are also the 'invisible workforce' of the aged care sector.

Further, it is important to consider that the needs of carers and their place in the system may in fact be more closely aligned with the needs of aged care consumers than the needs of the aged care workforce, they themselves often become the decision-makers on many aspects of formal care provision while still providing informal care.

Much more consideration needs to be given to the portrayal of the role of carers in the provision of care to older Australians. Their valuable third-party perspective has much to offer, particularly where the people they advocate on behalf of those with impaired decision-making ability.

## **Costs of care**

The costs borne by carers when taking on a caring role go far beyond financial impacts. There is a need to examine the true costs of care and the impact of this on those households where the carer is saving the government money by keeping the care recipient out of residential facilities. These costs include:

- practical care – eg day to day costs of personal care, special food, additional electricity, water, washing powder and continence products
- medical care – eg therapy, aids, medications, physiotherapy (etc), equipment and aids
- other costs – eg home modifications, training, respite, counselling, transport
- opportunity costs – eg impact on carer of not being in the labour force (therefore impact on government of lower tax bucket and additional costs in income support), replacement value of the care provided by families – this is a significant part of the cost of care. In 2005, the total replacement value was estimated to be \$30.5 billion.
- social and emotional costs – eg relationship breakdowns and cost impact of that, social exclusion – ie not being in the workforce.

## Financial costs

Many carers face financial hardship through reduced capacity to engage in employment and the high costs related to care provision. Carers must manage the extra financial costs related to caring such as medication, equipment, transport, therapies, continence products, electricity and alternative care.

The 2003 ABS SDAC indicates that carers are over-represented in the lower household income quintiles and under-represented in the higher quintiles, particularly primary carers.<sup>17</sup> This is linked to carers reduced levels of paid employment because of their caring responsibilities.

On average, their gross personal income is more than 25 per cent lower than for non carers. For almost half a million carers, the disparity is even greater at more than 40 per cent. If a single person on an average wage were to give up work to become a carer their weekly income would drop from \$1030 to \$294.<sup>18</sup>

Carers who need to rely on the Carer Payment and the Carer Allowance for lengthy periods of caring can be particularly disadvantaged with their reduced capacity to save, accumulate superannuation and fund their retirements. The Australian Institute of Health and Welfare (AIHW) indicated that 34 per cent of primary carers of children with a disability identified more financial support as their greatest need.<sup>19</sup>

*"We are financially virtually destitute, just attempting to survive and keep up payments like our mortgage etc. There are a few days every fortnight, when we do not eat."*

— Carer of wife

## Health costs

Carers often place the needs of the person they care for ahead of their own, or neglect their own health. As discussed, the cost to carers of providing care that keeps people out of residential facilities is often their own health and wellbeing.

Carers are a vulnerable, 'at risk' group in terms of health and wellbeing. The largest survey of carers' health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found the following:

- carers have the lowest level of wellbeing of any group yet discovered
- the wellbeing of carers decreases linearly as the number of hours spent caring increases
- carers are more likely than is normal to be experiencing chronic pain
- carers are likely to have an injury and this is associated with reduced wellbeing
- carers have an average rating on the depression scale that is classified as moderate depression, and over one third are classified as having severe or extremely severe depression
- carers are not receiving appropriate treatment for themselves as they have no time or they cannot afford the treatment.<sup>20</sup>

The key findings of a ten year longitudinal study *The Health and Wellbeing of Adult Family Carers in South Australia 1994 – 2004* released in February 2008, <sup>21</sup>showed:

- 70 per cent of carers reported chronic conditions such as diabetes, asthma, arthritis and cardiovascular disease

- carers are more than 40 per cent more likely to suffer from at least one chronic health condition when compared to the rest of the community
- carers were statistically significantly more likely to report high blood pressure (41.6 per cent), high cholesterol (28.8 per cent), or be categorised as overweight or obese (55.7 per cent), when compared to non carers
- also, though not significantly different, there were a higher proportion of carers who reported undertaking insufficient levels of physical activity.

Research recently commissioned by Carers Australia also confirms the negative long-term health impact of caring. The study, undertaken by NATSEM, examined the impact of taking on a primary carer's role on the health and economic wellbeing of women in Australia over the course of their 'working' life at two life stages – women aged 30 with primary caring responsibilities and women aged 50 taking on a primary care role for their partner.<sup>22</sup>

This research found that on average, primary carers aged 30 years would expect less than 80 per cent of their life up to 65 years to be healthy. As individuals age, the impact of caring on health becomes more pronounced. For example, at 50 years of age, primary carers would expect to live 73 per cent of the next ten years in a good state of health compared with 88 per cent for other women.

Carers must be supported to find the time and finances to attend to their own health needs.

*"My own health is deteriorating. I suffer severe back pains, my teeth are falling apart, my migraines are getting more frequent, sciatica is worsening, arthritis is beginning to surface and the list goes on. I am unable to tend to these problems because of the enormous cost associated with caring for our daughter."*  
 – Carer of adult daughter with severe disabilities

## Opportunity costs

Opportunity costs are particularly relevant for the aged care sector on a number of levels. For example, there is lost tax revenue when a family carer is unable to participate in the workforce. There is a greater demand on government expenditure around Centrelink payments and long-term pensions. Carers who are unable to work and unable to save for retirement.

If a carer becomes ill because of lack of adequate support and services and is unable to care the impact is twofold.

### Case study

A husband and wife are both in their 80s, he has a chronic illness and she cares for him at home. She has access to minimal respite: 2 hours per week and he is able to stay home with her support.

Because she is able to access only 2 hours respite this carer is not able to take care of her own health, buy medication, or see her doctor regularly despite ongoing health concerns.

This carer suffers a heart attack and because of a lack of alternative care, both the carer and her husband are admitted to hospital, and later relocated to residential facilities.

If this carer had been able to access more respite and look after her own health this would have kept two people out of formal care. Often it is assumed carers keep one person out of care for a period of time. However the provision of support for carers themselves clearly has the potential to keep two people out of the health and formal care systems.

### **Social and emotional costs**

Caring can have a significant impact on carers' emotional wellbeing and may have related psychological impacts.

Carers are also a group that have been recognised as at risk of social exclusion.<sup>23</sup> There is a significant chance that social networks will be affected when people become carers. The ABS 2003 Survey on Disability, Ageing and Carers found that 35% of primary carers had lost touch with their circle of friends due to their caring role. Many carers report that their employment status can have a dramatic impact on their social inclusion as they lose social contact in their working lives if they need to disengage from the workforce.

*"Having to step away from one's career and forfeit the security of superannuation as a result is a bitter pill to swallow." – Carer of husband for 15 years and son for 28 years*

*"I feel very lonely and alone [...] it is the disappearance of my professional, sporting and social friends that hurts." – Carer of husband*

### **Support for carers**

Quality support that is timely, appropriate and affordable can protect against the negative impacts of caring. Increased support for carers is crucial as we move toward a future care system in which carers play an increasingly important role. As discussed in the issues paper, it has been predicted that this is likely to occur for a number of reasons including trends in government policy, population changes and preferences for care.

The aged care system has an obligation, not just to residents, consumers, or the aged care workforce, but to the millions of carers who are supporting the sustainability of the aged care system.

Family carers need specialised and targeted support specifically designed to meet their needs and assist them in their role.

### **Carer Assessments**

Carers Australia believes broad consideration should be given to the introduction of Carer Assessments in the aged care sector as an innovative approach to supporting carers in the aged care system.

Carer Assessments could be delivered in a similar way to the current ACAT assessment and this approach would provide a much more holistic approach to the needs of people who are engaged in aged care in Australia.

Carer Assessments would take into account the needs and opinions of carers regarding the support they require and would provide a clear process, with standards across the sector. This simple introduction could easily provide a tangible reflection of a conceptual change in the sector.

They could also prompt referral to other services, allocation of respite or an avenue to prompt health checks for carers. All of these supports would greatly improve the lives of carers.

## Respite

Respite is an essential support for carers, providing a break from the caring role. However many carers find that the respite system is difficult to access, does not meet their needs or is simply not enough to allow them to have a real break.

The issues paper discusses that there is 4.7 million hours of respite accessed annually. It is estimated that carers provide an average of 40 hours of care per week. The hours provided by all carers would then be roughly equivalent to over 5.4 billion hours annually.

*“One becomes accustomed and adjusts to the circumstance. So I have adapted accordingly. We are always together, our leisure is reading. My husband is very dependent so I don't get time out to do things by myself, he is always THERE! Sometimes I could scream. He is a good man, and supported I every way, so I have adjusted. BUT I am not sure that's how I would like it to be. I would like to just go somewhere by myself sometimes”*

— Carer of husband

## Education

Evidence shows that education, as well as other interventions, is beneficial in helping carers to manage their caring responsibilities. Education and training at the right times in the caring journey is an essential component of carer support.<sup>24</sup> Education is also shown to be an important psycho-social intervention that can lessen that negative impact and improve the carer's capacity to manage and continue in their caring role.<sup>25</sup>

## Financial

The issues paper inquires about financial sustainability both for government and individuals. Caring is not financially sustainable for many carers and this is just one of the pressures that can increase the difficulty of providing care in the home. Carers currently carry an unfair burden of the cost of care for older people comparative to government expenditure on supporting their needs.

Many carers receive financial support through Centrelink in the form of Carer Payment and Carer Allowance, but still find that it does not offset the costs related to caring.



## **Consideration of diversity**

In the provision of support to carers it is essential that the needs of carers from different populations groups will need to be considered including:

- CALD
- Indigenous
- GLBTI
- Young carers
- Rural and remote

## **Carers in rural and remote Australia**

- 733,000 in regional areas
- 224,000 in outer regional areas
- 46,000 in remote areas
- 27,000 in very remote areas.

The percentage of carers themselves who have fair or poor health increases with remoteness. 18% of those in major cities have identified as having poor health and this increases to 22.1% in outer regional and remote areas. The figures for carers with profound, severe or moderate disability shows a similar increase for those in outer regional and remote from 14.3% in major cities to 20.0% in outer regional and remote areas.<sup>26</sup> The higher population of Indigenous carers in outer regional and remote areas contributes to this difference.

System must provide for people with particular needs. The introduction of one stop shops for example announced recently by the government must be accessible to all.

## **Quality care for older Australians**

Carers want assurance that they will be able to access quality, affordable and accessible aged care services on behalf of the person they care for.

## **Involvement and information**

Carers must be involved and able to access information to assist them in their decision-making.

A good example is the accreditation process for aged care and ensuring carers are informed about the status of residential facilities. Although there has been a move to publish details of sanctions and accreditation and other audit processes on the Department of Health and Ageing website, the general public is not well informed about health risks or negative experiences of residential or community care. Carers then as part of this groups are unable to access the information that would allow them to make the most informed choice. Often the choice to place someone in residential care must be made quickly and assisting carers with the right information during this stressful time would be greatly beneficial to overall outcomes for all concerned.

Further, an accreditation process measures facilities against a set benchmark and does not reward those who are providing a service that results in markedly better outcomes for residents and their carers. There is currently a gap in the sector for a process that encourages competitive improvement within residential facilities. There should be a greater use of carer experience of service to improve service delivery.

Recommendation 28 and 29 that focus on a review of the system that is client-based and the move towards a client-centred aged care system are also of merit. However, there needs to be clarity around the definition of client beyond the individual directly receiving services to consider those who may need to arrange services on their behalf. Again, this is about the conceptualisation of stakeholders in the aged care system and the place of family carers.

### **Affordability**

Affordability is a concern for many carers when accessing a variety of services. It is essential that there is equitable access to services for those from lower socio-economic backgrounds. There is a need for greater consideration of the introduction of Government regulation on fees and bonds and concessions for special groups across the formal aged care sector.

This key principle of aged care delivery— the access to care regardless of economic circumstances must be strengthened if we are to have a sustainable aged care system.

### **Interaction with other sectors**

This submission addresses the need for a change of perspective in the system. The issues paper asks about a broader conception of care and disability with the needs of the aged being part of this continuum.

A continuum approach may not be as useful as an approach that considers all care needs but with a focus on the very unique circumstances of the individual. People need to be able to access the services that best suit their needs regardless of the sector delivering the service.

Carers often discuss the difficulties in moving from the disability to aged care sector, or the issues caused when they are caring for someone who does not fit the design of the aged care sector, for example those who are younger being placed in residential facilities. There is a clear need to examine better ways of delivering care across sectors.

One area that would clearly benefit from a broader conception of care is the introduction of a Long-term Care and Support Scheme (currently under review by the Productivity Commission). Carers Australia believes that there are many difficulties raised by cutting aged care out of this scheme and that a broader view of care delivered in our society should be the underlying focus of support for the scheme.

### **Other housing options**

It is our understanding that there has been recent consideration of the positioning of other retirement housing options such as Retirement Villages which are covered by separate legislation in most jurisdictions. Carers Australia supports a simplification of this system which would bring legislation for these living options in line with Aged Care regulation and legislation.

### **Improvements from other reviews and inquiries**

Carers Australia encourages the Commission to closely consider the findings and recommendations of the following reports as part of the current inquiry.

Recommendation 4 of the Senate Standing Committee on Finance and Public Administration's *Inquiry into Community and Residential Aged Care*, which recommends an analysis to establish a benchmark of care costs in consultation with all aged care stakeholders including clients.

While the review does not explicitly state this, any review of care costs must include the costs experienced by carers as a direct result of the care they provide.

### **Review of the Aged Care Complaints Investigation Scheme (CIS)**

Carers and family members often act as advocates and may make complaints regarding care services both in their own right and on behalf of those who do not have the confidence or capacity to do so themselves. The CIS provides an avenue for carers to have their concerns about formal care provision to their family members heard. It

Carers Australia has provided a submission to the process and would encourage the Commission to consider the findings of this inquiry and reflect the recommendations in its own findings.

Carers Australia would direct the commission in particular to the discussion of training needs of CIS assessors. We believe there is a pressing need for broader training in carer issues for all formal aged care staff.

### **National Health and Hospitals Reform Commission (NHHRC) Review**

The Health and Hospitals Reform Commission Review provided important recognition of carers as Australia's 'invisible health workforce' as discussed. Carers Australia would recommend that the Commission consider the findings of the report *A Healthier Future for All Australians*, and its perspective on family carers.

Recommendation 14 of the report is of particular importance:

*"We acknowledge the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty. We recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications. We also recommend improved access to respite care arrangements to assist carers sustain their role over time and that the health of carers should also be a priority of primary health care services dealing with people with chronic conditions."*

Recommendation 82 also provides important recognition of the need to make use of carers' experience of the mental health system:

*"We acknowledge the important role of carers in supporting people living with mental disorders. We recommend that there must be more effective mechanisms for consumer and carer participation and feedback to shape programs and service delivery."*

A similar approach to aged care that values carer's expertise would be a positive improvement to the sector.

## **Innovative approaches**

There is a clear need for innovative ways of funding the care provided to older Australians and for solutions that provide more choice and flexibility for those accessing the system.

## **Carer Assessments**

As briefly outlined above, Carer Assessments could act as a prompt for access to other supports for carers and assist them to stay in good health. This is an innovative solution that should be given serious consideration as a part of this inquiry.

## **Long-term care and support scheme**

Caring should be a shared community responsibility, Carers Australia believes therefore that the application of long-term care insurance scheme which is publicly funded to the aged care sector would have positive outcomes for the sector, carers and those they care for. As discussed, Carers Australia believes that a broader conception of the care delivered in our society could be achieved through an overarching Long-term Care and Support Scheme that encompasses disability, aged care and other forms of care required in our communities.

## **Consumer-directed care**

Carers Australia supports the investigation and introduction of options for achieving consumer directed care for Australia's carers at a national level. Carers Australia believes that carers should be provided with the maximum amount of choice and control regarding the services they receive wherever possible. Depending on the program, consumers may be able to choose which services they receive, who will deliver these services, and when.

Freedom of choice in decision-making can enable all carers and those for whom they care to experience greater independence, take control of their own needs and find services that more closely match their preferences.

The introduction of Consumer Directed Care models more broadly across the aged care sector would be a positive introduction. This may include initiatives to further explore the efficacy and suitability of consumer directed care in addition to some CDC models that have already been tested in the aged care sector.

Carers Australia believes that any model of consumer directed care introduced must:

- operate under an opt-in rather than opt-out framework
- always have a carer focus, not only a care recipient focus
- be able to sit alongside existing models of care provision
- assist carers and those for whom they care through information provision, and provide supported decision-making processes where required
- allow carers engaged in CDC to return to a non-CDC model of care should they so choose
- be inclusive of the needs of specific caring groups such as CALD, Indigenous and young carers
- be accessible for all carers regardless of financial or geographic disadvantage
- be accountable and measurable against quality standards
- include a comprehensive system for the reporting and investigation of complaints
- not be introduced purely as a budget-saving measure
- be economically sustainable
- result overall in positive outcomes for carers and the people for whom they care.

In addition, there is a need to ensure that a CDC model does not result in

- a reduction in the quality, variety or availability of services in the long-term
- additional pressure on carers' time and resources to access, monitor and coordinate services
- added requirements for carers to demonstrate and record the appropriate use of funds.

Further, it is essential that

- carers are not left to 'fend for themselves' with little or no support from government bodies or professional supervision
- specific groups of carers who may find a CDC model of care difficult to navigate are supported.

### **A carer focus**

The adoption of a carer-focus in aged care alongside other guiding principles and objectives would be greatly beneficial. Where carers are dissatisfied, the outcomes for all parties will be negative.

With consideration of their needs supported by a good quality system, carers would need to be supported to make the often difficult choice not to care where they felt they were unable, and the system would need to provide a high-quality alternative to the care they would otherwise provide.

The inclusion of a carer-focus in the delivery of care is perhaps the most essential reform that could occur to introduce a new perspective and reflect the reality of the provision of care to older Australians and the vital contribution of family carers.

## References

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- <sup>1</sup> Productivity Commission (2010) Caring for Older Australians Issues Paper, May 2010, Canberra.
- <sup>2</sup> Australian Bureau of Statistics (2004) 2003 Disability, Ageing and Carers: Summary of Findings, Australia, Canberra
- <sup>3</sup> *ibid*
- <sup>4</sup> Productivity Commission (2010) Caring for Older Australians Issues Paper, May 2010, Canberra.
- <sup>5</sup> Productivity Commission (2008) Trends in Aged Care Services: some implications, Productivity Commission Research Paper, Canberra
- <sup>6</sup> Australian Bureau of Statistics Summary of Findings: 2003 Survey of Disability Ageing and Carers, Canberra, 2004
- <sup>7</sup> The Hammond Care Group (2001) 'Challenge Depression. A manual to help staff identify and reduce depression in aged care facilities'.
- <sup>8</sup> *ibid*
- <sup>9</sup> Schofield, H. et al, ed. (1998) 'Family Caregivers: disability, illness and ageing' Allen and Unwin, St Leonards.
- <sup>10</sup> Carers Victoria (2003) Outside looking in: Resource kit on carer friendly practices in aged care facilities, Melbourne
- <sup>11</sup> *ibid*
- <sup>12</sup> Australian Institute of Health and Welfare (2005) Australia's Welfare, Canberra
- <sup>13</sup> *ibid*
- <sup>14</sup> Productivity Commission (2010) Caring for Older Australians Issues Paper, May 2010, Canberra.
- <sup>15</sup> Steering Committee for the Review of Government Service Provision (SCRGSP) (2009), Report on Government Services 2009, Productivity Commission, Canberra.
- <sup>16</sup> The Hon Justine Elliot MP, Media Release(2008) Achievements in Aged Care- First Anniversary Report Card December 2008, Canberra
- <sup>17</sup> Australian Bureau of Statistics (2004) – see 1 above
- <sup>18</sup> AMP NATSEM (2006). Income and Wealth Report 13 – Who Cares? The cost of Caring in Australia 2002 to 2005, May 2006, Canberra
- <sup>19</sup> Australian Institute of Health and Welfare (2006). Disability Updates: children with disabilities, Canberra
- <sup>20</sup> Deakin University and Carers Australia (2007). Australian Unity Wellbeing Index, Survey 17.1 Report 17.1, October 2007, Melbourne
- <sup>21</sup> Carers SA and SA Department of Health (2008). The Health and Wellbeing of Adult Family Carers in South Australia 1994 – 2004
- <sup>22</sup> Nepal B., Brown L., Ranmuthugala G. and Percival R. (2008). *Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia*. Report prepared for Carers Australia. NATSEM, University of Canberra, Canberra. 2008
- <sup>23</sup> Australian Government (2010) A Stronger Fairer Australia: The National Social Inclusion Agenda, Canberra
- <sup>24</sup> Sörensen S, Pinquart M, Duberstein P. *How effective are interventions with caregivers? An updated meta-analysis*. *Gerontologist* 2002; 42:356-372.p.356.
- <sup>25</sup> Sörensen S, Pinquart M, Duberstein P. *How effective are interventions with caregivers? An updated meta-analysis*. *Gerontologist* 2002; 42:356-372.p.356.
- <sup>26</sup> Carers Australia, Commonwealth Financial Planning and The Australian Institute of Family Studies (2009) The Tyranny of Distance...? Carers in regional and remote areas of Australia, Canberra