



**Submission to the
National Health and Hospitals
Reform Commission**

Imagine a health system without family carers

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1. Executive Summary

Imagine a health system without family carers.

- Over 3 million people in Australia live with core activity limitations (ABS 2004).
- 79 per cent of people with a disability who live in households receive care from relatives and friends, mainly partners, parents or children (ABS 2004).
- 1.25 million people have disabilities that have profound or severe limitations (ABS 2004).
- 1.07 million people with a disability that has profound or severe limitations live in private households (ABS 2004).
- 64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation (ABS 2004).
- Individual carers on average contribute 104 hours per week caring for a person with a mental illness.
- It is estimated that carers provided 1.2 billion hours of unpaid care in 2005 (Access Economics, 2005).
- Annual replacement value of this care is estimated at over \$30.5 billion (Access Economics, 2005).

The Carer Payment (child) Review Taskforce in its report to the Australian Government that was released in February 2008 stated....*"The caring role is one of immense social and economic value. It cannot be overemphasised that the care provided is often the difference between life and death."*



Carers are an integral part of Australia's health system and are the foundation of our aged, disability and community care system. As health care increasingly moves away from 'institutional' settings into the home who manages the often complex requirements of those with chronic conditions, profound disabilities, mental illness, terminal illness or the frail? Australia's family carers do. They can no longer be the forgotten partners in health care.

Not all Australians, whether by birth, accident, chronic illness or mental capacity are able to make decisions about their lifestyles or health care choices. For these people, carers often take on this responsibility on an informal basis as advocates and substitute decision makers. Carers then become partners in the health care team. The concept of a partnership highlights the need for health care professionals to understand and respect the role of the carer in achieving maximum health outcomes for their patient.

The rapidly ageing population of Australia and the carer ratio will be a key element in the design and shape of Australia's future health system. The National Centre for Social and Economic Modelling

(NATSEM) estimates a 160 per cent increase in the number of people aged over 65 needing care from 539,000 people in 2001 to 1,390,000 in 2031. In 2000 the caretaker ratio was around 2.5 and over the next 50 years the caretaker ratio is projected to fall below one (NATSEM, 2004 and AMPNATSEM, 2006).

Care provided by family carers can delay entry into residential aged care facilities and not only improves the quality of life for the older person but can also have important ramifications for the cost of aged care.

The availability of Australia's carers and their ability to continue their caring role, is therefore critical to the long-term sustainability of the Australian health and community care systems.

As health care increasingly moves away from 'institutional' settings into the home family carers shoulder greater responsibility for providing care. There is an urgent need to ensure they are adequately prepared to provide that care.



This view is reinforced by the Carer Payment (child) Review Taskforce:

...."Caring for a child with severe disability or medical conditions required the carer to develop the skills necessary to recognise, understand and manage the nature and complexities of the disability or condition, often to a high level of proficiency."

Over recent years the Australian Government has boosted funding for research to keep Australian scientists and researchers to the fore globally. But, there has been little funding for research into carer issues. Specific research into carer issues is required to better inform long-term planning for the shape of the health system of the future.

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 that carers have the lowest level of wellbeing of any group yet discovered and carers also will often put their own health and wellbeing after that of the person for whom they care.

No future health system will be able to respond to changing demographics and health needs, clinical practices and societal influences in the long term without carers. The reliance on carers to provide ongoing, unpaid care without appropriate support structures and ongoing training is misguided and dangerous.

Carers Australia believes there needs to be a change in thinking if the government is serious about designing and shaping a health system that is people and family centred and that is equitable with access for all based on health needs, not the ability to pay.

Carers Australia also believes by involving carers across all spectrums of health and community care, and ensuring they are supported effectively, the benefits will be immeasurable, not only to the health system, but to the caring relationships and the community in general.

1.1 Recommendations:

Carers Australia recommends that:

- governments formally acknowledge carers as essential partners in the health care system
- the principles be amended to better reflect the role and importance of carers
- carers be represented on all key health advisory groups
- carers have access to ongoing, nationally consistent, training, education, information and resources
- training and education for health professionals include carer modules
- carer research be undertaken to inform education and training policies for health professionals and carers, develop best practice models of service delivery, inform long-term planning and mapping of primary health care frameworks and provide governments at all levels with data to develop support programs for carers
- investment in carer capacity and wellbeing be a priority for governments at all levels.

2. Introduction

The health profile of Australian society has undergone many changes in the last two decades. Our population has aged significantly, the incidence of disability and chronic illness has increased, and we are living longer with disabilities (AIHW 2006a).

At the same time two major policy shifts have occurred. There are shorter hospital stays and an overall shift from institutional care to community care. As a consequence family members are increasingly called upon to provide care and assistance to other family members at home, often with little training, guidance, information or resources.

Care provided by family carers can delay entry into residential aged care facilities and not only improves the quality of life for the older person but can also have important ramifications for the cost of aged care.

Not all Australians, whether by birth, accident, chronic illness or mental capacity are able to make decisions about their lifestyles or health care choices. For these people, carers often take on this responsibility on an informal basis as advocates and substitute decision makers. Carers then become partners in the health care team. The concept of a partnership highlights the need for health care professionals to understand and respect the role of the carer in achieving maximum health outcomes for their patient. It also highlights the need for carers to be prepared to take on the caring role.

The maintenance of carers' health is considered to be a significant public health issue, as it determines their capacity to provide care for people in their homes who otherwise may have to rely upon publicly funded institutional health care. Governments will need to invest in carer capacity and wellbeing if the health system is to be fair, equitable and sustainable.

Currently the Australian Government provides income support for family carers and carer support services through national respite and other programs but there is little to support the health and wellbeing of carers through targeted health programs and interventions.

3. 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.

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.

3.1 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 (ABS, 2004). Carers are from all walks of Australian society.

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. The majority of these carers are women.

Prime Minister Rudd has acknowledged that carers "save the state a bucket load." While it is essential to recognise the value and impact of this contribution, it is also important to acknowledge that carers are clients in their own right, with their own health needs.



Carers are diverse and each carer has individual support requirements to improve their care situation and quality of life. The impact of providing care on the carer's own health and wellbeing is well documented with many carers experiencing a significant decline in their own physical and mental health, as well as a negative impact on their employment and education prospects, their financial position, and their ability to participate in social and community life (Cummins RA et al, 2007; Briggs D and Fisher H, 2000 and Gill T, 2007).

According to the ABS 2003 Disability, Ageing and Carers Survey, there are almost 1.25 million people with disabilities that have profound or severe limitations and of those 1.07 million live in private households. 79 per cent of people with a disability living in households received care from relatives and friends, mainly partners, parents or children. (ABS 2004)

64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation (ABS 2004). Additionally, family carers sustain the fabric and operational effectiveness of mental health services systems across Australia with individual carers on average contributing 104 hours per week caring for a person with a mental illness. For many carers this time includes periods they are 'on call' or alert for early warning signs arising with the person for whom they care.



Carers are an integral part of Australia's health system and are the foundation of our aged, disability and community care system.

Access Economics estimate that carers provided 1.2 billion hours of unpaid care in 2005 with the annual replacement value of this formal aged and disability care estimated to be at over \$30.5 billion. The cost to carers through lost wages in 2005 is estimated at \$4.9 billion dollars (Access Economics, 2005).

This data clearly indicates that the availability of Australia's carers, and their ability to continue their caring role, is critical to the long-term sustainability of the Australian health and community care systems.

The Carer Payment (child) Review Taskforce in its February 2008 report said:



" The Taskforce recognises the vitally important role of carers and acknowledges that the willingness and ability of carers to provide care is an integral component of the broader care system. Their contribution is central to sustaining the current system of community-based, person-centred care."

4. Changing demographics

The rapidly ageing population of Australia will be a key element in the design and shape of Australia's future health system. An implication of an ageing population is that many more Australians will require assistance because of age-related disability. According to the ABS the rate of disability increases with age. Only four per cent of children 0-4 years have a disability, but 41 per cent of people aged 65-69 and 92 per cent of people aged 90 and over have a disability (ABS, 2004).

The ABS estimates that the number of Australians with disabilities will increase over the next 50 years as the population ages. This is influenced by people living longer and acquiring disabilities as they age, as well as people with existing disabilities living longer.

Congruent to the ageing population is the diminishing carer ratio. NATSEM estimates large increases in the ageing disabled population over the next 25 to 50 years, but a steady fall in the caretaker ratio. It indicates:

- a 160 per cent projected increase in the number of people aged over 65 needing care from 539,000 people in 2001 to 1,390,000 in 2031, and only
- a 25 per cent projected increase in the number of people with disabilities under 65 years
- a steady fall in Australia's "caretaker ratio" – the ratio of the number of people most likely to provide care to the number of people most likely to need care
- in 2000 the caretaker ratio was around 2.5 over the next 50 years the caretaker ratio is projected to fall to below one (NATSEM, 2004 and AMPNATSEM, 2006)

The projections on ageing and disability and the availability of carers have obvious implications for a future health system for Australia as well as community, hospital and residential care.

5. Carer preparedness

Currently there are no long-term, nationally consistent education and training packages for carers. There is a very limited infrastructure to maintain a sustainable education and training program, particularly one that focuses on quality assurance and ongoing evaluation and development of good practice models. Similarly, there is very little training for health providers around the role and contribution of carers, nor how to effectively support them in a health setting.

As health care increasingly moves away from 'institutional' settings into the home family carers shoulder greater responsibility for providing care. Early identification and support for carers is critical to their ability to manage mid-to-long-term care. Providing information and appropriate and meaningful support as early as possible can help to prevent crises, improve health outcomes and maintain supportive, caring relationships.

... "Caring for a child with severe disability or medical conditions required the carer to develop the skills necessary to recognise, understand and manage the nature and complexities of the disability or condition, often to a high level of proficiency."

(Report of the Carer Payment (child) Review Taskforce 2008)

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 (Gerontologist 2002).

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. According to the ABS 2006 census of population and housing there are 31,600 Indigenous carers over the age of 15 in Australia. After adjusting for differences in the age structures of the Indigenous and non-Indigenous populations, Aboriginal and Torres Strait Islander people were more likely to be caring for another person with disability, long-term illness or problems related to old age (ABS 2008).

Currently there are 350,000 Australians under the age of 26 and 170,000 under the age of 18 who provide care to a family member who has a disability, or a mental or chronic illness (ABS 2004).

Dedicated support and training are needed which appropriately reflect the level of care provided, the age of the carer, the cultural diversity of the carer and the needs of the carer. These packages should be available consistently and continually.

On the current availability of training packages, there would seem to be an assumption that with very little formal training, carers can step in and provide ongoing management and coordination of care for people who may have complex medical conditions such as chronic disease, mental illness, or a terminal illness. Often people with these conditions require multiple medications and higher levels of care.

The reliance on carers continuing to provide high level care without appropriate training, support and assistance is misguided and dangerous.

The Carers Engagement Project, funded through FaHCSIA and run by the Mental Health Council of Australia throughout early 2008 is a welcome initiative. The workshops will provide opportunities for family members and carers of a person with a mental illness to further develop their coping and

management skills. It is particularly pleasing that there will be specific workshops for carers who are Indigenous, from a culturally and linguistically diverse background and young carers. However, workshops such as these need to be ongoing – not a 'one-off' project.

In 2005-2006 the Independent Living Centre of WA (ILC), with the assistance of the Office for Seniors Interests and Volunteering conducted research examining the physical impact of caring on family carers through an extensive survey and a small scale manual handling training project (ILC 2007).

A number of findings and outcomes are relevant to carers being prepared to take on the caring role:

- 43 per cent of carers said they had been physically hurt or injured as a result of providing care
- most injuries sustained were back injuries which were general caused by lifting, lowering or carrying, ie manual handling tasks
- of those carers who had been injured, 46 per cent said their injury had recurred or been made worse by continuing to provide care
- 42 per cent of carers who had been injured said they had to get extra assistance to continue providing the care
- only 36 per cent of carers said they had received information or training on injury avoidance or risk management.

The Manual Handling Training for Family Carers Project ran concurrently with the carers survey and focused on developing a best practice model for delivering manual handling training to carers.

- All carers who completed the training and the evaluation questionnaire agreed that it was beneficial to have the training in their own home.
- Training delivered in the home was relevant to their particular situation and they could use their own equipment and furniture.

Outcomes and conclusions of the Manual Handling Training for Family Carers Projects included:

- training effected a positive change in carers' manual handling behaviours
- the level of risk to carers was reduced as a result of the training
- training in the home environment was particularly beneficial, and for some this was the only option
- action needs to be taken to ensure that the maintenance of carer health be given a higher priority, and that injury prevention in particular becomes a focus of health and disability policy developers, decision makers and service providers.

6. Research and innovation

Over recent years the Australian Government has had a commitment to funding research to keep Australian scientists and researchers to the fore globally. Consequently, significant funding to boost Australian health and medical research, fellowships and specific research agendas have been allocated in recent years. But, there has been little funding for research into carer issues. Improved storage, access and dissemination of carer research and carer program information is essential for Australian governments, research organisations, and carer and other peak organisations to develop good health policy and practice.

For example, research is needed to better understand the relationship between patient outcomes and the levels of preparedness of the carer to provide ongoing care at home. This research should be undertaken at all levels of the health system. Outcomes of this research could be used to inform education and training policies for health professionals and carers, develop best practice models of service delivery, inform long-term planning and mapping of primary health care frameworks and provide governments with data to develop support programs for carers.

7. Keeping carers healthy

As family carers are providers of health care, they should be recognised as partners in health care because they are often carrying out extensive around-the-clock responsibilities. It is therefore essential to provide support which helps them to maintain physical and mental 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
- sole parent carers had the lowest wellbeing of any carer
- 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.

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, (Carers SA and SA Department of Health) 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.

These statistics confirm that carers can become physically and emotionally exhausted influencing their capacity to care and the quality of care they are able to offer. Carers also will often put their own health and wellbeing after that of the person for whom they care. Yet, there is a tendency for the health system to focus on the patient and overlook the carers' support and health needs. Governments will need to invest in carer capacity and wellbeing to meet the changing demographics.

8. Conclusion and recommendations

Carers Australia does not believe that the proposed principles to guide reform and future directions of the Australian health care system are adequate. Carers must not be overlooked or dismissed in designing and shaping a health care system of the future. They must be included in the principles. They are an intrinsic and important partner in health care, alongside the person requiring care.

The increased 'outsourcing' of care-related tasks to family carers will continue. All sectors of the health system will continue to use carers to manage complex health conditions whether this is on discharge from hospital, or at the primary care level. However, many carers are not equipped with adequate support and training to enable them to carry out these responsibilities most effectively. Consider the formal training and support provided to health professionals to ensure they are able to deliver services to the highest standards. A simple example - a nurse would always have appropriate training in lifting patients. Many carers don't.

No future health system will be able to respond to changing demographics and health needs, clinical practices and societal influences in the long term without carers. The reliance on carers to provide ongoing unpaid care without appropriate support structures and ongoing training is misguided and dangerous.

Carers Australia believes there needs to be a change in thinking if the government is serious about designing and shaping a health system that is people and family centred and that is equitable with access for all based on health needs, not the ability to pay. We also believe by including carers in the principles this will assist in reorienting the health system, and deliver value for money.

For too long, carers have been the forgotten, silent partner in health and community care in Australia. However, by involving carers across all spectrums of health and community care, and ensuring they are supported effectively, the benefits will be immeasurable, not only to the health system, but to the caring relationships and the community in general.

8.1 Recommendations

Carers Australia recommends that:

- governments formally acknowledge carers as essential partners in the health care system
- the principles be amended to better reflect the role and importance of carers
- carers be represented on all key health advisory groups
- carers have access to ongoing, nationally consistent, training, education, information and resources
- training and education for health professionals include carer modules

- carer research be undertaken to inform education and training policies for health professionals and carers, develop best practice models of service delivery, inform long-term planning and mapping of primary health care frameworks and provide governments at all levels with data to develop support programs for carers
- investment in carer capacity and wellbeing be a priority for governments at all levels.

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