



**Submission to the Senate Inquiry into the Council of Australian Governments
(COAG) reforms relating to health and hospitals**

*Imagine a health system
without family carers*

May 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 Inquiry into Planning Options and Services for People Ageing with a Disability**
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The story below taken from a survey around carer health and wellbeing, highlights the impact of caring the overwhelming daily struggle of many carers.

Surveys like this make me sad... then I just get on with life as usual ... expecting nothing different to happen. Why would things change? Never have before ... always the challenge to stay 'balanced' and be 'constructive within life' striving to be 'positive' despite 'overwhelming concern for a future for my disabled adult' which 'petrifies me'.

The future worries me so much ... what will happen to my disabled adult ... how to afford a 'safe and happy' life for her, where will she live, how can I afford her future, will I live long enough to do what I need to do, who will care enough???? I tell myself to keep focused and not worry just now ... and most days I am fine but I know there will be no funding for her ... I know of 'older' mums and days in their 80s and 90s who cannot get funding, they have their disabled children living with them ... some cannot go into aged care because of their situation. So who will help us???

I and a good number of my 'disabled' circle of mums often discuss the horrific choice we might make one day ... we do not want to leave our disabled loved ones here in this world without us. I am crying now because I know how shocking it is to say such a thing. I am a sane and rational person, not depressed or suicidal, or in danger of any self harm, just very stressed about the future.

In the meantime, we struggle to be 'normal'. I have recently taken on a 20hr part-time job which I am going to struggle to keep. I need the job to pay for 'respite/care' in order that my husband and I can go out to dinner or have some time to ourselves ... maybe an overnight break. I recently paid \$350 for a 48 hour respite break, it was lovely and just made me realise how 'not normal' we really are.

Wherever we go ... there is always the 3 of us ... and often our daughter simply does not want to be with us anymore ... she would like to do separate things too. Just to go to dinner We must pay for a carer first ... we have no 'normal' friends anymore They are all travelling and 'empty nesters'. A freedom we simply cannot expect to ever have.

Of course we love our special adult with all our heart ... but still long for some of the things we feel we are missing as a couple.

I also care for my 85 yr old mother who lives alone and has some dementia issues. I do all her cooking ... have an ACAT package for 5 hours per week ... we have a carer Monday – Friday for morning meds but I do the rest. We must pay \$120 per month for this service as my mother owns her own home ... that is her only asset, she receives a basic pension but is struggling to pay her household bills .. she has less than \$1500 in the bank. She does not want to move but she may be forced to do so soon.

My new job will be hard to keep due to all these demands ... Mondays I have to pay for a carer because the disabled daughter is home all day ... it actually costs me more than I earn for this day and I am having trouble finding carers. Working Tuesday – Friday would suit be better but that's not possible. Then there will be the days when I have to deal with sickness with both Mum or my disabled child ... I will not go on, but I feel I am not living ... not really.

I cannot see any real solutions on my horizon ... I am just doing my best.

Thank you for listening.

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Introduction

Carers Australia welcomes the opportunity to provide input to this inquiry. We acknowledge the Government's commitment to health and aged care system reform. However, in reforming the health and aged care systems, the vital role family carers play in these systems as well as the community care, mental health and palliative care systems cannot be ignored.

While our comments may not directly address the terms of reference we would ask the committee to take the time to imagine a health, aged care and mental health system without family carers. Consider, for example the financial implications for government, the emotional and physical wellbeing of the person being cared for, and the stress on hospitals, residential aged facilities and other residential institutions if unpaid family carers were no longer caring. Supporting unpaid family carers is therefore critical to ensuring systems can be responsive, equitable and accessible.

In shaping and designing a health and aged care system of the future, there is a need to take account of the principles in the National Health and Hospital Reform Commission final report. As noted in the report these principles should shape the whole health and aged care system – public and private, and hospital and community-based services. For example Principle 1 states:

*The direction of our health and aged care system, the provision of health and aged care services and our efforts to strengthen wellness and prevention **must be shaped around the health needs of people, their families, carers and communities**....Care should be provided in the most favourable environment: closer to home if possible, with a preference for less 'institutional' settings, **recognising the need to support the important role of families and carers**, and with an emphasis on supporting people to achieve their maximum health potential.*

Family carers sustain our care systems and trends such as the ageing population and the rise in chronic or long term illness and disability will have a significant impact on the demand for informal caring. Additionally, the move towards early discharge from hospitals, the increase in day surgery and an emphasis on providing care within the community rather than hospital or institutional care, point towards implicit expectations for informal care, especially for the care of older people. In shaping our care system of the future government must look at the linkages between all systems.

The future will see an increased demand on the provision of care in the home by unpaid family carers and the government must plan for the future accordingly. In light of these projections the government must take action now to support carers. Decisions made in relation to health should not be based on the assumption that family carers can continue to provide unpaid care without appropriate support or inclusion in the health sector. The government must find a significant place for carers in the proposed health and aged care system reforms.

Government investment in the health, aged care and mental health workforce is to be commended. However, it would appear from funding announcements in the recent Federal Budget around workforce that 'the invisible health workforce' as the NHHRC described family carers are to remain 'invisible'. Paid care workers across all systems have access to training, to workers compensation, to sick leave, to holiday leave. If an unpaid family carer is injured while caring ---- there is no compensation: if an unpaid family carer falls ill, there is often no-one to take on the caring role while they recover: there is no paid leave and they do not have access to structured training.

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.¹

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 rural and remote areas, and may have been born outside Australia.

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."*



The statistics

Carers in Australia cross all age groups, cultural backgrounds and geographical locations:

- 2.6 million carers across Australia
- almost 500,00 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 born outside Australia
- 366,700 of those born outside Australia were born in other than main English-speaking countries.

Older carers

In 2003 ABS¹¹ identified:

- 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
- 28,000 older carers (over 65 years of age) cared for an adult child
- 50 per cent of older primary carers spent 40 hours or more actively caring or supervising.

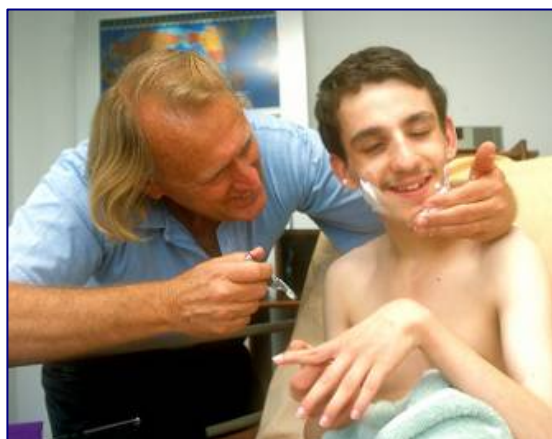
Older carers are often caring at a time when their own health is deteriorating.

Disability

According to the 2004 ABS Survey of Disability, Ageing and Carers (SDAC), there are 3,958,300 people in Australia with a disability. The age ranges for these people are 0-90 and over. The statistics also show that:

- 594,100 people live with a profound core-activity limitation
- 650,400 people live with a severe core-activity limitation
- 700,300 people live with a moderate core-activity limitation.

Of these, 1.07 million people with profound or severe core-activity limitations live in private households. And 79 per cent of people with a disability who live in households receive care from relatives and friends, mainly partners, parents or children.



In addition to people living with a disability there are 4,149,000 with a long-term health condition.ⁱⁱⁱ

According to the Australian Institute of Health and Welfare, and based on projected trends in the ageing of the Australian population, the broad National Disability Agreement target population is projected to grow substantially. For example the number of people aged 0-64 years with profound or severe core activity limitations is projected to increase to 752,100 people (an increase of 4.8%) between 2006 and 2010.^{iv}

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, aged and community care systems.

Role and contribution of carers

With 2.6 million carers providing care for family members and friends 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.



Over the past 20 years policies and programs for people with disabilities, people with mental illness and older people have been premised on the assumption and fact that care in a normal community setting with family and other support is preferable to institutional care. However the shift from institutional models of care has not been matched by adequate development and resourcing of appropriate health, aged and community care services. Choice about how care is provided within families or other community settings is extremely limited. Nor has there been adequate attention to the financial, social and emotional impacts of caring and the costs of care – to carers, their families and the wider community.



The health and social benefits are widely understood by governments, in families and in the community at large. However, until recently Australia has not had data to demonstrate the significant economic value of the contribution of carers and the opportunity costs associated with carers leaving the workforce or reducing their employment.

Access Economics (2005) estimated that carers provided 1.2 billion hours of care in 2005. If this care was provided by aged, disability and other services it would be equivalent to \$30.5 billion annually. The value of carers' contributions is not matched by government-funded services and income support payments. This net benefit to the Australian economy often comes at a great cost to carers and their families. Access Economics estimated that the cost to carers through lost wages was \$4.9 billion annually.

Professor Bettina Cass (2006) said in relation to the Access Economics figures that “What is not costed here is the diminution of leisure time, as well as employment time and the costs to health and wellbeing.”

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.”

The impact of caring

Carers are a vulnerable, ‘at risk’ group. 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.^v

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,^{vi} 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.

Additionally, research from the Australian Institute of Family Studies, *The Nature and Impact of Caring for Family Members with a Disability in Australia*,^{vii} indicates that carers, in particular those under the age of 65 years, have significantly worse mental health and vitality and high rates of depression than the general population. Key findings include:

- the risk of carers and family members experiencing a depressive episode of six months or more was greatest in the first year of caring
- almost twice as many carers (29%) were in poor physical health than the general population (17%)
- almost one in three female carers aged 50 years or less had separated or divorced since they caring, while one in seven over the age of 50 years had separated or divorced
- carers who had multiple care responsibilities or who were caring for children had worse mental health outcomes.

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 health professionals to focus on the patient and overlook the carers' support and health needs.

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.^{viii}

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.

As a specific example, it has been consistently demonstrated in studies over the past decade that the care of Parkinson's Disease (PD) patients imposes a substantial burden on family carers and that such care imposes economic, physical and psychosocial health related burdens on the caregiver.

Two key Australian reports (one from the Royal Rehabilitation Centre in Sydney and the other from Access Economics) show that PD not only affects the health and well-being of the patient with Parkinson's, but also that of their carers. Carers are faced with problems that can impact on both physical and mental health, quality of sleep, social life, relationships, housing, support systems, respite and autonomy. As symptom severity increases, carers assume new and more burdensome responsibilities, typically resulting in increased levels of emotional, physical and financial stress.^{ix}

In their own words

The problems I face day to day are physical health issues cast upon me due to caring. I have developed a stomach ulcer due to stress, fibromyalgia; muscle inflammation that prevents me from doing anything outside my caring role, a degenerative spine condition and depression which are all exacerbated because of caring.

The Carer is not just a "bystander" simply observing the life of the one "CLASSIFIED" as disabled. The Carer of a person such as my son, with Autism, Intellectual Disability and related Mental and Behavioural Disorders, has to virtually "STEP INTO" that life, with the "abnormal mind set", and live, breath and communicate in a realm of what can only be described as an absolute distortion to "normal" reasoning, thinking and behaviour.

Mental health

The number of people in Australia affected by mental illness and disorders is significant and continues to grow. Approximately 20 per cent of the adult population and 14 per cent of young people are affected in any one year (AIHW 2006). Carers Australia acknowledges the government's commitment to an improved mental health system.

Family and other carers are the lynchpin of mental health care in the community. Reforms to the delivery of mental health care in Australia over the past 14 years have shifted the focus of care for people with a mental illness from stand-alone psychiatric institutions to local community settings. The earlier massive under-resourcing of reforms to mental health services has placed a huge responsibility on families, carers and friends to support the care, safety and recovery of people with a mental illness or disorder (consumers).

This disengagement from specialist care and insufficient provision of quality mental health services to meet community need has resulted in a significant burden on families and carers. Research conducted by the Mental Health Council of Australia (MHCA) and Carers Australia through focus groups with carers, mental health service providers and stakeholders in each state and territory indicated that individual carers on average contribute 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 they care for. This indicates that family carers sustain the fabric and operational effectiveness of mental health service systems across Australia (MHCA and Carers Australia 2000).

While the impacts of caring on carers of people with a mental illness are similar to most carers, other factors increase the risks, stress and isolation experienced. These include stigma in the community, the nature of mental illness and likelihood of co-morbid substance misuse, the exclusion of carers by mental health services, and deficiencies in the system. Carers of people with a mental illness can feel traumatised and overwhelmed, and can suffer their own long-term mental health consequences, especially depression, anxiety and stress disorders.

A carer's note

For carers of people with a mental illness there is the added stress of living within a community which often shows intolerance and lack of understanding towards families (and consumers) where mental illness prevails. We are often given a 'wide berth' when we desperately need a friendly chat or even a smile to feel less like 'aliens'.

Conclusions

The increased 'outsourcing' of care-related tasks to family carers will continue. All sectors of the care 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.

For too long, carers have been the forgotten, silent partner in our care systems across Australia. However, by involving carers across all spectrums of health, aged 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.

If we are to be a compassionate society, that acknowledges diversity and values the contribution of each individual in the community, government can no longer continue to undervalue an entire demographic in our population, who, in the words of the Prime Minister are heroes, each and everyone one of them. They are the family carer. These are the people who provide the majority of care to the majority of people needing care in the community. They are the 'invisible health workforce' and the foundation of our aged, disability, mental health, community care and palliative care systems.

Increased investment in carer support is essential. No future health, aged, mental health or community care system will be able to respond to the 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. If carers are not healthy and do not have appropriate support and access to services and opportunities to build retirement incomes, the dollar burden on government will be enormous.

Unpaid family carers need access to education and training, counselling, information and advice. It is essential that government understands the reality of care provision in this country and must not ignore the needs of family carers.

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