



**SUBMISSION TO THE
HOUSE OF REPRESENTATIVES STANDING COMMITTEE
ON FAMILY, COMMUNITY,
HOUSING AND YOUTH
INQUIRY INTO BETTER SUPPORT FOR CARERS
JULY 2008**

About National Seniors Australia

National Seniors is the largest senior's organisation in Australia with over 280,000 individual members in 175 branches across the country. We are a not-for-profit community organisation with the following objectives:

- to provide economic and social benefits for people 50 years and over;
- to represent our members' views to government at all levels; and
- to make donations and provide service and advice to charitable institutions assisting people 50 years and over.

National Seniors offers members a vast range of services and benefits and is an influential vehicle for contributing to policy debates affecting older Australians. National Seniors' policies and policy agenda are developed through a comprehensive grassroots process that enables members to contribute through local Branches, regional Zone committees, State and Territory Policy Groups (SPGs), and a National Policy Group (NPG). The outcomes from this policy formulation provide the basis of the National Seniors policy agenda.

This submission has been prepared by the National Policy Office (NPO), based in Canberra, which facilitates the implementation of National Seniors' national policy agenda, and advocates on behalf of older Australians to government at all levels, to business and the broader community. The NPO works closely with our National, State and Territory Policy Groups and our extensive network of State offices, Branches and Zone committees in determining issues of relevance to older Australians and identifying trends in ageing. The work of the NPO is assisted by the Commonwealth Department of Health and Ageing through its Community Sector Support Scheme (CSSS). The funding received under this scheme better positions National Seniors to:

- grow the operational capacity of the NPO;
- expand communications with the seniors' community;
- increase engagement opportunities for disadvantaged seniors; and
- act as a conduit for information flow between government and the community in order to draw together seniors' views on issues of relevance and provide a consultative mechanism for the government.

The NPO also plays a key role in informing the development of the research program for the National Seniors Productive Ageing Centre (NSPAC), which in turn provides research input to the NPO. The NSPAC, established in 2002, is co-funded by National Seniors in collaboration with the Department of Health and Ageing. NSPAC's role is to research issues that impact on the ability of seniors to contribute productively to the economy and society. The NSPAC is consumer focused in both the development of its research agenda and conduct of research activities.

Consultation

This submission has been developed by National Seniors Australia through a comprehensive grassroots process that enables members to contribute directly through communication with local branches, regional zone committees, State and Territory Policy Groups (SPGs), as well as the National Policy Office (NPO).

The views and life experiences of members were directly sought through our weekly publication *Connect*, our website, and National Seniors extensive local branch system. The contribution by members to this submission provided real experiences of caring.

National Seniors also liaised with representatives from Carers Australia, Alzheimer's Australia and Palliative Care Australia to gain further insight into the challenges carers face.

Summary of Recommendations

Recognition of carers

- **Establish an Office for Carers which would coordinate a whole of government approach to supporting carers and ensure a greater coordination of service provision.**
- **Ensure carers and carer representative groups are consulted and engaged in reviews of carer policy.**
- **Provide greater funding for research into carer issues to ensure changes to carer policy are informed by evidence-based research.**
- **Implement a national information and awareness campaign to recognise the work of carers and assist them in accessing support services.**

Reduce barriers to participation

- **Ensure respite services are appropriate, affordable, accessible and flexible to better meet the needs of carers.**
- **The Commonwealth Government should take the lead in establishing care facilities for frail aged parents in Australian Government workplaces, similar to those provided for employees with young children.**
- **Provide incentives for employers to ensure flexible workplace practices are available to carers.**

Carer health and wellbeing and support services

- **Provide greater funding for carers referred to counselling services by the Commonwealth Carer Respite Centres to better address unmet need.**
- **Provide practical support to carers to ensure they are able to adequately plan for their own and their care recipient's future needs.**
- **Greater funding for case managers to assist carers to plan for the future needs of their care recipients.**
- **Greater funding to provide ongoing support, training and education for carers.**
- **Ensure carer involvement in the review of Carer Payment, Carer Allowance and Carer Bonus currently being carried out under the Review of Australia's Tax System.**
- **Provide free regular health checks for carers through GPs to assess carers' physical, mental and emotional health and wellbeing.**
- **Ensure that carers are included and recognised as part of the health care team.**
- **Fund a national carer health and wellbeing awareness campaign.**

Recognition of carers

In 2003, there were 2.5 million carers, of whom 18% (452,300) were aged 65 and over.¹ Carers Australia estimates the real number of Australians affected by carer policy decisions is well over 5 million, as carer policy not only affects the carers themselves but greatly affects the health and wellbeing of the care recipient and their family members.

With the growing emphasis on home-based care, informal care by family, friends and neighbours is increasingly recognised as an important source of support to people of all ages. Carers play a key role in assisting older people to remain in the community and the need for this support is expected to increase.² The number of older persons with a severe or profound disability in Australia is projected to grow from 539,000 in 2001 to 1,380,000 in 2031, an increase of about 160%.³

It is vital that government at all levels work collaboratively to better support carers and to effectively put in place strategies to address the increased demand for carers that will occur over the coming years. Not only will there be an increase in the number of carers of older persons as a result of the ageing population, but the carers themselves will also be ageing. According to NATSEM, the largest growth in the numbers of informal carers is projected to occur amongst older persons. Between 2001 and 2031, carers aged less than 65 years will grow by some 22,000 persons (19%), while those carers aged 65 and over will grow by 99,100 (110%). As a result, by 2031, older carers will constitute 56% of all carers.⁴

Given that the expected rise in older persons requiring care is likely to outstrip the supply of people likely to be their carers, the challenge for government is how to put in place adequate supports for older Australians. With older Australians increasingly identifying their preference to 'age in place,' the government needs to provide increased funding and greater support services to informal carers and community care services that provide support to people in their homes.

The role of carers is paramount in considering how we are going to care for our ageing population, as the bulk of care is provided as unpaid care by family and friends in the person's home.⁵ The contribution of carers is important also in a fiscal sense, with older persons and their carers meeting a large part of the costs of care which would otherwise fall to government.⁶ Research shows that older Australians would prefer to remain and be cared for in their homes. Maintaining successful independent living is partially a function of access to economic resources and thus living standards and supportive social policies.⁷

A number of studies have highlighted how demographic and social trends will affect the demand for informal care in the future, these include:

- the ageing of the population;
- higher prevalence of chronic illness and associated disability among older age groups;
- greater preference for ageing in place;
- increased female labour force participation;
- an increased incidence of divorce;
- ageing older parent carers of adult children with disabilities;
- greater mobility and dispersion of families; and
- smaller families with fewer children.⁸

¹ ABS (2004)

² AIHW (2007)

³ NATSEM (2004)

⁴ Ibid

⁵ Ibid

⁶ Productivity Commission (2003)

⁷ NATSEM (2004)

⁸ Access Economics (2005)

Carers also assist in reducing the strain on Australia's health care system. Access Economics found that the cost of replacing the care provided by unpaid family carers with services supplied by formal care providers would be more than \$30.5 billion each year.⁹ The availability of carers and the services they need to support them are critical to the sustainability of the current Australian health and community care systems.¹⁰

According to the ABS, as a population group, carers generally have a lower income and a lower standard of living than other population groups in Australia¹¹, which means that carers are at-risk of poor health and wellbeing in the social and socioeconomic determinants of health.¹²

National Seniors Australia represents the views of members who not only care for their partners and relatives who are frail aged but those that care for adult children with a disability. In 2003, around 472,500 carers were primary carers – providing the most ongoing informal assistance with self-care, mobility or communication to a person with a disability – and 24% (113,100) of these were aged 65 years and over.¹³

Carers of older people and people with long-term disabilities differ from carers of children and people with temporary illnesses and injuries. The care for older people and people with disabilities is normally for prolonged periods of time and can involve increased dependency as some care recipients' capacity declines with age or illness.¹⁴ In 2003, one-third (33%) of older primary carers had spent more than 10 years in the caring role, with a further 23% having spent between 5 and 9 years.¹⁵ Care-giving by primary carers can also be intense – 79% of older carers were assisting a person with continuous rather than episodic care needs.¹⁶

Most care relationships emerge from pre-existing close relationships, and carers do not always recognise that the nature of their relationship has changed and they have assumed the role of a carer. This is particularly relevant for older carers of their frail or aged partners. National Seniors believes that there needs to be far greater information and awareness campaigns to help people identify as carers and therefore access the support services available to them.

Carers who do not receive sufficient support from government, community organisations or their informal social and family networks can experience social isolation, develop financial problems, drop out of the labour market, and experience poorer health and stress.¹⁷

Recommendations:

- **Establish an Office for Carers which would coordinate a whole of government approach to supporting carers and ensure a greater coordination of service provision.**
- **Ensure carers and carer representative groups are consulted and engaged in reviews of carer policy.**
- **Provide greater funding for research into carer issues to ensure that changes to carer policy and payments are informed by evidence-based research.**
- **Implement a national information and awareness campaign to recognise the work of carers and assist them in accessing support services.**

⁹ Ibid

¹⁰ Australian Unity Wellbeing Index (2007)

¹¹ ABS (2004)

¹² AIHW (2007)

¹³ ABS (2004)

¹⁴ Braithwaite (1990)

¹⁵ ABS (2004)

¹⁶ AIHW (2007)

¹⁷ Bittman et al (2005)

Reduce barriers to participation

Only 56.1% of carers participate in the workforce compared to 67.9% of non-carers. Primary carers have particularly low rates of labour force participation, only 39% in 2003.¹⁸ Those carers who are unable to participate in the workforce due to their caring responsibilities have reduced access to the positive health and wellbeing aspects that flow from meaningful employment.

National Seniors believes that there is an urgent need for more appropriate, affordable and flexible respite programs. Carers can become isolated and unable to participate in employment and in the community due to respite care services not meeting their needs, which include:

- high costs of respite care;
- lack of flexibility in the hours of operation of respite care services (particularly evenings, overnight and weekends);
- the availability of respite services, particularly in regional, rural and remote areas;
- the availability of appropriate respite care services for people with particular needs (i.e. children with disabilities or older adults with dementia); and
- the availability of respite care services which are culturally appropriate and sensitive.

National Seniors believes there should be far greater support available to carers to enable them to work or participate in the community. We support Carers Australia's position in advocating for increased life choices for all carers so they are better able to make decisions that work for them.

Carers, particularly those that are caring for a person with a terminal illness, often experience difficulties in maintaining employment or accessing flexible employment and leave entitlements. National Seniors believes employers need to develop a greater understanding of the needs of carers in providing flexible work arrangements, such as:

- part-time work;
- flexible work hours;
- job sharing;
- working from home;
- carers leave;
- carer facilities; and
- counselling services.

Recommendations:

- **Ensure respite services are appropriate, affordable, accessible and flexible to better meet the needs of carers.**
- **The Commonwealth Government should take the lead in establishing care facilities for frail aged parents in Australian Government workplaces, similar to those provided for employees with young children.**
- **Provide incentives for employers to ensure flexible workplace practices are available to carers.**

¹⁸ Access Economics (2005)

Carer health and wellbeing and support services

Carers provide quality care for their care recipients, but often experience poor health and wellbeing as a result. In 2005, 44.5% of primary carers (219,400) reported that their sleep was interrupted due to the requirements of their caring role. Of these, around 46.4% (102,000) had frequent interruptions to their sleep.¹⁹ Moreover 72.4% of Australia's primary carers experience some form of detrimental effect from providing care. The most common is feeling weary or lacking energy (33.7% of primary carers); 29.2% often feel worried or depressed and 28.9% feel their well-being has been affected. Clinical studies have also shown increased rates of depression among caregivers.²⁰

Not only do significant numbers of primary carers experience fatigue, emotional and mental stress, caring can also cause physical injury, especially musculoskeletal injuries from incorrect lifting, lowering and carrying or moving the recipient of care.²¹ A 1999 survey by Carers Australia found that 33% of carers reported having been physically injured at least once in the course of providing care, of which over a half were due to lifting or carrying.²²

Primary carers may be eligible for carer education and support, and respite services provided by the government through its Commonwealth Carer Resource Centres and Commonwealth Carelink Centres. The Carer Resource Centres also provide referrals to the National Carer Counselling Program. There are however, reports that the program is unable to meet current demand and National Seniors Australia supports Carer Australia's position in highlighting the need for greater financial resources in this area.

National Seniors acknowledges the other support packages available to carers, such as subsidised community care packages (HACC and CACP) and for higher levels of care provided in the home (EACH). We feel however there needs to be a continual review of the effectiveness of the services provided under these care packages.

National Seniors understands the importance of resourcing of formal care, but is concerned that data from Access Economics shows that the public subsidy for informal care is a lower range (35% - 73%) than the public subsidy for other care models (47% - 97.5%).²³ National Seniors believes the public subsidy to informal carers through Carer Payment, Carer Allowance and the Carer Bonus are currently insufficient to meet the rising costs of living for carers and their care recipients. The financial supports are also insufficient for carers to adequately afford the aids and equipment and home modifications required to care for their loved ones. In order to ensure that carers are able to carry out the important work they do, they need far greater financial support, not only to provide quality care to the care recipient, but to also enable the carer to afford appropriate respite and support services that will enable them far greater participation in employment and in the community.

Older people and their carers meet a large proportion of the costs of care which would otherwise fall to government.²⁴ Analysis by Access Economics found that the average costs of combinations of informal care and community based formal care are generally lower than the cost of institutionalised care, however, the government subsidy for informal care is lower than other care streams.²⁵ Given that older Australians prefer to receive care and remain in their home, National Seniors believe that government should provide greater financial support to informal carers and greater support services through HACC and other community care packages.

National Seniors is calling for greater funding for support services such as respite care, counselling and carer training which would improve carers' ability to carry out their caring role. Studies have shown that caregiver education and training programs increase knowledge about services and

¹⁹ Access Economics (2005)

²⁰ Ibid

²¹ Ibid

²² Ibid

²³ Access Economics (2005)

²⁴ Ibid

²⁵ Ibid

resources for carers, improve psychological and social well-being of carers and increase problem solving abilities.²⁶

National Seniors strongly supports the greater provision of resources for case-managers to provide carers and their family with access to support services. We particularly believe there is a greater need in the area of information and support to enable carers to better plan for their future and those they care for. A number of National Seniors members identified the anxiety they experience as they consider their inability to continue to provide care and worry about what the future holds for the person they care for.

Recommendations:

- **Provide greater funding for carers referred to counselling services by the Commonwealth Carer Respite Centres to better address unmet need.**
- **Provide practical support to carers to ensure they are able to adequately plan for their own and their care recipient's future needs.**
- **Greater funding for case managers to assist carers to plan for the future needs of their care recipients.**
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- **Ensure carer involvement in the review of Carer Payment, Carer Allowance and Carer Bonus currently being carried out under the Review of Australia's Tax System.**
- **Provide free regular health checks for carers through GPs to assess carers' physical, mental and emotional health and wellbeing.**
- **Ensure that carers are included and recognised as part of the health care team.**
- **Fund a national carer health and wellbeing awareness campaign.**

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²⁶ Ibid

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