
The Parliament of the Commonwealth of Australia

Who Cares ...?

Report on the inquiry into better support for carers

House of Representatives
Standing Committee on Family, Community, Housing and Youth

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Foreword

Carers – usually spouses, parents, grandparents, children, siblings and sometimes friends or neighbours – have asked to be heard – to have a voice of their own. So when the Committee embarked on this Inquiry into better support for carers, it clearly indicated that its objective was to learn more about the needs of carers from the experts – that is from carers themselves. And carers responded. Through written submissions to the Inquiry, and through participation in public hearings, more than 1300 carers shared their very personal and often distressing experiences with the Committee.

Many carers have observed that it is not possible for anyone to understand what caring entails unless they are, or have been, a carer – that reality is not disputed. However, thanks to the generosity and candour of so many carers, the Committee has been able to gain a degree of insight. The Inquiry's body of evidence clearly illustrates the profound physical, emotional and financial effects that providing care has on carers and on their families.

Becoming a carer is not a choice. Some people find that they are thrust into the role without warning after the birth of a child with an illness or disability, or following a traumatic event or accident involving a loved one. For others, becoming a carer is a more gradual process, though ultimately equally devastating. When does a husband, or a wife, recognise that they have also become a carer for their partner with dementia for example? While every caring situation is unique, the love, grief, guilt, fear, anger and frustration, coupled with sheer physical and mental exhaustion are all part and parcel of carers' lived experiences.

Despite the uniqueness of each caring situation described in evidence to the Inquiry, several consistent themes have emerged. The Committee has heard loud and clear from carers that they want choices – choices for themselves, for the people they care for and for their families. The Committee has also been reminded repeatedly that the needs of carers and those they care for are inextricably bound. While the carers are the focus of this Inquiry, the Committee has sought to achieve

a balance in the report that reflects the interrelationship of the needs of carers and care receivers without transgressing the Inquiry's terms of reference.

Over the years, the shift from institutional care to care in the community has greatly increased reliance on informal care provided by family and friends. In the absence of adequate support, carers are already in crisis. Emerging demographic and social trends are predicted to result in larger numbers of people requiring care and smaller numbers of people able and willing to provide it. Existing pressures on systems of support for carers which have been building over decades are therefore projected to increase. This means that action needs to be taken urgently.

With this in mind, the Committee has given consideration to diverse options for reform to address deficiencies in the current systems of support for carers. In some areas, such as respite care and in-home assistance, the Committee has recommended an increase in expenditure so that supply of services more closely matches demand.

Consideration has also been given to options for the more efficient use of existing resources. To this end, some recommendations have called for a reduction in the red tape associated with accessing some forms of carer support, and for greater cooperation across jurisdictional and portfolio divides to encourage the development of more coherent and coordinated systems.

The Committee has also considered the case for significant fundamental reform. Of particular note, is the recommendation for an examination of income support for carers to determine whether the system of carer payments can be restructured to better reflect the level of care provided. In addition, the Committee has also recommended consideration of increasing access to individualised or self-managed funding packages to provide carers with greater choice and flexibility to purchase the services they need.

Importantly, the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned – carers, care receivers, governments and society – to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities.

In concluding, I would like to extend my sincere thanks to all those carers who have contributed to this Inquiry. It is your experiences, described in your own words that have provided the foundation for this report and its recommendations. I also thank the Deputy Chair, the Hon Judi Moylan MP, and the other Members of the Committee for their participation and commitment to the Inquiry.

As Chair of the Committee it is my view that many of the report's recommendations are a starting point only, providing a baseline for more fundamental and significant reforms to systems of support for carers. In considering the report, I urge the Australian Government and others to look beyond the specifics of the recommendations and to also consider their context and intent - that is to significantly improve the lives of carers and those they care for. Importantly, implementation of reform will be key to effecting meaningful change. It is my sincere hope that this report and its recommendations will act as a stimulus for action.

Ms Annette Ellis MP
Chair



Membership of the Committee

Chair	Ms Annette Ellis MP	
Deputy Chair	The Hon Judi Moylan MP	
Members	The Hon Tony Abbott MP	Mrs Louise Markus MP <i>(until 25/9/08)</i>
	Ms Jodie Campbell MP	Mrs Sophie Mirabella MP <i>(from 10/11/08)</i>
	Ms Julie Collins MP	Mr Scott Morrison MP <i>(from 25/9/08)</i>
	The Hon Sussan Ley MP <i>(until 10/11/08)</i>	Mr Brett Raguse MP
	Ms Kirsten Livermore MP	Mr Chris Trevor MP

Committee Secretariat

Secretary	Mr James Catchpole
Inquiry Secretary	Dr Alison Clegg
Research Officers	Ms Siobhan Carrigan <i>(from 8/9/08)</i>
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	Ms Tarran Snape



Terms of reference

Carers play a vital role in sustaining Australia's current system of community-based person-centred care. However, they are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment. Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

In examining each of these issues, the committee will also inquire into the specific needs of particular groups within the caring population including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities.

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.



List of abbreviations

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACT	Australian Capital Territory
ACTU	Australian Council of Trade Unions
AIHW	Australian Institute of Health and Welfare
ATAPS	Access to Allied Psychological Services
CACP	Community Aged Care Package
CALD	culturally and linguistically diverse
CAP	Carer Adjustment Payment
CENA	Carer Eligibility and Needs Assessment
COAG	Council of Australian Governments
CSTDA	Commonwealth State Territory Disability Agreement
CYCLOPS	Connecting Young Carers to Life Opportunities and Personalised Supports
DEEWR	Department of Education, Employment and Workplace Relations
DIG	Disability Investment Group
DoHA	Department of Health and Ageing

DSP	Disability Support Pension
DVA	Department of Veterans' Affairs
EACH	Extended Aged Care at Home package
EACHD	Extended Aged Care at Home Dementia package
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
GP	general practitioner
HACC	Home and Community Care program
HCDSMC	Health, Community and Disability Services Ministerial Council
HREOC	Human Rights and Equal Opportunities Commission
NATSEM	National Centre for Social and Economic Modelling
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NES	National Employment Standards
NNAAMI	National Network of Adolescent and Adult Children who have a Mentally Ill Parent
MND	Motor Neurone Disease
NRCP	National Respite for Carers Program
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PM&C	Department of Prime Minister and Cabinet
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers

SDT	Special Disability Trusts
SPP	Specific Purpose Payments
TOCC	Taskforce on Care Costs
WA	Western Australia



List of recommendations

Recommendation 1

That the Treasurer direct the Australian Bureau of Statistics, either through an extension to its Survey of Disability, Ageing and Carers or through the development of an alternative carer specific survey, to expand the information it collects on carers to include information on:

- secondary carers;
- carers providing episodic care;
- carers providing palliative care; and
- carers aged 15 years and under.

The Australian Bureau of Statistics should also consider increasing the frequency of the Survey of Disability, Ageing and Carers to three yearly intervals.

Recommendation 2

That the Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs and the Department of Health and Ageing support a national community education campaign to promote a better understanding of the role and needs of carers, and an appreciation of the contribution that carers make to society.

The campaign should also include components to promote increased awareness of their role among 'hidden' carers who may not readily self-identify and to address the concerns of carers who may be reluctant to disclose their role to others.

Recommendation 3

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing propose to the Health,

Community and Disability Services Ministerial Council (HCDSMC) that the Australian Government and each jurisdiction review existing legislation and policy relating to health and community care to ensure that carers are adequately recognised.

If legislation affecting carers falls beyond the jurisdiction of HCDSMC then it should be referred to the appropriate ministerial council for review.

Recommendation 4

That the Minister for Families, Housing, Community Services and Indigenous Affairs seek the Health, Community and Disability Services Ministerial Council to develop a nationally consistent carer recognition framework, comprising:

- national carer recognition legislation, which complements state and territory carer legislation; and
- a national carer strategy which builds on and complements state and territory carer policies.

Recommendation 5

That the Department of Prime Minister and Cabinet establish a national office for carers, either within the Office of Work and Family or as a new office within the Department.

That the Australian Government nominate a lead Minister to be responsible for overseeing the development of nationally coordinated carer legislation, policy, programs and services so that these are effectively linked across all levels of government and portfolios.

Recommendation 6

That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department.

Recommendation 7

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, seek agreement through the Health, Community and Disability Services Ministerial Council to extend the Access Points Demonstration Projects to include disability services and community mental health services.

Recommendation 8

That the Australian Government make locally based peer support carer groups a priority within existing community grants programs available across portfolios.

Recommendation 9

That the Minister for the Department of Families, Housing, Community Services and Indigenous Affairs fund the expansion of the MyTime Peer Support Program to:

- include parents of school aged children with disability; and
- increase geographical coverage.

Recommendation 10

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing request that the Health, Community and Disability Services Ministerial Council develop a national strategy to address the training and skills development needs of carers.

Recommendation 11

That the Minister for Families, Housing, Community Services and Indigenous Affairs and Minister for Department of Health and Ageing direct their Departments to review the adequacy of case management or care coordination for carers and care receivers using community care, aged care, disability and community mental health services.

Recommendation 12

That the Minister for Families, Housing, Community Services and Indigenous Affairs extend the National Disability Advocacy Program to:

- provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers; and
- provide formal advocacy for carers in their own right when this is required.

Recommendation 13

That the Minister for Health and Ageing review arrangements for systemic carer advocacy provided through Carers Australia and the network of state and territory Carer Associations.

The review should examine the extent to which arrangements for systemic advocacy represent the diversity of carer groups and consider whether these arrangements might need to be extended or reformed.

Recommendation 14

That the Attorney-General, in conjunction with the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, investigate whether the National Privacy Principles and the Information Privacy Principles, and equivalent provisions in state and territory privacy and mental health legislation, adequately allow carers to be involved in the treatment of the individuals for whom they care.

The Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing promote to health and community care providers the importance of involving carers in the treatment and services for those receiving health and community care services.

Recommendation 15

That the Attorney-General promote national consistency and mutual recognition governing enduring powers of attorney and advanced care directives to the Standing Committee of Attorneys-General.

Recommendation 16

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.

Recommendation 17

That the Minister of Families, Housing, Community Services and Indigenous Affairs examine how carer payments may be restructured to better reflect differences in the levels of care provided.

Recommendation 18

That the Australian Government significantly increase the base rate of carer payments.

Recommendation 19

That the Minister for Families, Housing, Community Services and Indigenous Affairs examine and implement the most appropriate option(s) to reduce the disincentive for carers to earn supplementary income.

Recommendation 20

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and

Indigenous Affairs to review its assessment for Carer Payment/ Allowance (adult) with a view to:

- extending the range of health and allied health professionals who are authorised to verify the applicant's claim;
- enabling acceptance of recent supporting documents that may already be held by the carer to verify the claim where these documents provide a sufficient level of detail regarding the care needs of the care receiver;
- developing a new assessment process that acknowledges the level of support provided by carers of people with intellectual disability, mental illness or with challenging behaviours. The assessment should also have regard to the episodic nature of some conditions; and
- reviewing the purpose and frequency of review processes, particularly in circumstances where it is evident the needs of the care receiver will not decrease over time.

Recommendation 21

That the Minister for Human Services, in consultation with the Minister for Families, Housing, Community Services and Indigenous Affairs, direct their Departments to review Centrelink's application processes for income support for carers and care receivers with a view to streamlining processes and simplifying the content and design of its claim forms.

The review should also include consideration of how Centrelink's data capture and management systems might be improved to reduce the need for carers to provide the same information on multiple occasions.

Recommendation 22

That the Minister for Human Services direct Centrelink to establish a dedicated Carer/Disability Unit with staff to provide specialist advice to carers and care receivers, including those with complex care and family issues.

Recommendation 23

That the Minister for Families, Housing, Community Services and Indigenous Affairs through the Department of Families, Housing, Community Services and Indigenous Affairs fund a survey to measure the financial costs to households of caring for people with disability.

Recommendation 24

That the Minister for Health and Ageing increase the level of the subsidy available to eligible clients for the purchase of continence aids through the Continence Aids Assistance Scheme.

Recommendation 25

That the Minister for Families, Housing, Community Services and Indigenous Affairs negotiate through the National Disability Agreement to extend considerations in relation to developing more consistent access to aids and equipment, to also include consideration of a more consistent framework to assist with capital costs incurred as a result of disability and care, such as vehicle and home modifications.

Recommendation 26

That the Treasurer ensure that the review of Australia's Future Tax System include consideration of options for tax concessions or rebates to apply to items associated with disability and caring such as medication, therapy, aids and equipment.

Recommendation 27

That the Minister for Families, Housing, Community Services and Indigenous Affairs advocate for Health Care Cards to be issued under the same means test as Carer Payment to those receiving Carers Allowance.

Recommendation 28

That the Minister for Families Housing, Community Services and Indigenous Affairs direct the Department of Families Housing, Community Services and Indigenous Affairs to investigate the benefits of introducing a national carer card for recipients of Carer Payment and Carer Allowance in order to verify the relationship between a primary carer and a care receiver.

Recommendation 29

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to expand the nationally consistent assessment process based on the Carer Eligibility and Needs Assessment-Revised questionnaire.

This will need to ensure the inclusion of carers accessing services offered through the Department of Families, Housing, Community Services and Indigenous Affairs and the state and territory governments.

Recommendation 30

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing address the shortages of health and community care services for people living in regional and remote locations.

Recommendation 31

That the Minister for Families, Housing, Community Services and Indigenous Affairs fund research into the profiles and specific needs of Indigenous carers.

Recommendation 32

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing examine the adequacy of culturally appropriate community care services funded by the Australian Government for Indigenous carers, particularly for those living in remote areas, with the intention of increasing the accessibility and availability of those services.

Recommendation 33

Recognising the ageing demographic of the carer population and the increased longevity of many care receivers, that the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing increase capital and recurrent funding for respite care services funded by the Australian Government as a matter of urgency to more closely match demand across the country.

Particular attention should be paid to improving the:

- availability and accessibility;
- affordability;
- responsiveness to the needs of both carer and care receiver of respite services; and
- responsiveness to the needs of carers and care receivers in living regional, rural and remote areas.

Recommendation 34

That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs increase funding for in-home assistance for carers in order to more closely meet demand.

Recommendation 35

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing undertake pilot studies to test the potential for the Australian Government's funding for carer respite and in-home assistance to be re-allocated directly to carers through 'individualised funding programs' (also known as 'consumer directed care' and 'self managed funding').

Recommendation 36

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to collect nationally consistent data to more accurately determine the number of carers, their profile and the level of unmet need for community based carer support services.

Recommendation 37

That the Minister for Education, Employment and Workplace Relations examine options to build capacity in the community care workforce, particularly initiatives to encourage retention of trained workers in the sector.

Recommendation 38

That the Minister for Families, Housing, Community Services and Indigenous Affairs through the Health, Community and Disability Services Ministerial Council, encourage states and territories to provide additional funding for disability support workers in long day care, out of hours care and school holiday care to improve access for employed carers.

Recommendation 39

That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs expand any continuation of the Employed Carers Respite Initiative to provide extended respite and support for all working carers, including those who provide care to people with disabilities or mental illness who are under the age of 65 years.

Recommendation 40

That section 65(1) of the *Fair Work Act 2009* be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including to those who are caring for adults with disabilities, mental illness, chronic illness or who are frail aged.

Recommendation 41

That the Minister for Education, Employment and Workplace Relations ensure that employment service providers:

- consider the specific needs of carers seeking suitable employment; and
- encourage and support employers to provide employment opportunities for carers.

Recommendation 42

That the Minister for Education, Employment and Workplace Relations ensure that employment service providers consider the skills development and training needs of carers, particularly long-term carers, when developing plans to assist those wishing to enter or re-enter the workforce after a period of absence.

Recommendation 43

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to increase the number of hours of work, volunteering or study that those receiving Carer Payment can undertake.

Recommendation 44

That the Minister for Education, Employment and Workplace Relations direct the Department of Education, Employment and Workplace Relations, in association with state and territory education departments, to develop flexible policies to make it easier for students to combine education with caring.

Recommendation 45

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to extend the eligibility criteria for its Respite for Young Carers at Risk Program to include assistance for more than one young carer in a family unit where the care responsibilities are shared.

Recommendation 46

That the Minister for Health and Ageing direct the Department of Health and Ageing to provide a preventative health care program targeted at carers. This could be achieved by extending the Enhanced Primary Care Program to include carers who receive Carers Payment and/or Carer Allowance as an at risk population group requiring intervention under this program.

Recommendation 47

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to review the temporary cessation of care requirements for Carer Payment and Carer Allowance recipients, particularly in relation to:

- the adequacy of the 63 days of respite per year particularly in comparison to minimum conditions of paid employment; and

- the requirement of carers to use all or part of the allowable period of time to cover periods of time, when as a result of illness, they are unable to provide care.

Recommendation 48

That the Minister for Health and Ageing expand the National Carers Counselling Program to better meet the demand for counselling services by carers.

Recommendation 49

That the Minister for Health and Ageing direct the Department of Health and Ageing to raise awareness among General Practitioners of the high incidence of mental health problems among carers and their families and of the options available for support.

Recommendation 50

That the Minister for Social Inclusion nominate carers as an early priority for social inclusion on the social inclusion agenda and with the Australian Social Inclusion Board.

