



Australian Government



Towards a National Carer Strategy

A discussion paper from the Australian Government

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Towards a National Carer Strategy

A discussion paper from the Australian Government

This discussion paper has been prepared by the Australian Government as a basis for consultation with carers, carer support organisations, service providers and the community on the development of the National Carer Strategy (Strategy).

This discussion paper informs stakeholders on the proposed outline of the Strategy. Your views will inform the development of the Strategy in more detail.

You can call 1800 057 616 or email nationalcarerstrategy@health.gov.au to obtain copies of the discussion paper, to request accessible formats, or to query the contents of this discussion paper.

The discussion paper can also be accessed online at: www.health.gov.au

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Ministers' foreword

The Gillard Labor Government recognises the immense social, emotional and financial pressures that carers face in caring for the frail aged, people with disability, mental illness or medical condition. Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life.

One of the ways the Government is supporting carers is through delivering a National Carer Strategy (Strategy) to shape the long term agenda for carers. This will set out goals to guide policy development and service delivery for carers. Most importantly, it will set out clearly how all levels of government will work together to make this policy a reality.

We will work closely with carers and carer support organisations to ensure the Strategy responds to carers' needs and experiences. This discussion paper provides a proposed outline of the Strategy. Your feedback and input will be invaluable in helping us to develop the Strategy so it delivers practical benefits to carers.

The Gillard Labor Government is committed to better responding to the needs of carers. We have provided increased financial security for carers by delivering increases to Carer Payment of more than \$100 a fortnight for single pensioners on the maximum rate over the last year. To formally acknowledge the role of carers at a national level, the Government has introduced national carer recognition legislation into Parliament.

The Government wants to listen to the voices of carers to make sure we've got it right.

We encourage everyone to take the opportunity to provide feedback as we work together to develop the Strategy.

Thank you for taking the time to join in this consultation process to help us develop the Strategy.



Jenny Macklin

The Hon Jenny Macklin MP
**Minister for Families,
Housing, Community Services
and Indigenous Affairs**



Nicola

The Hon Nicola Roxon MP
Minister for Health and Ageing



Jan McLucas

Senator the Hon Jan McLucas
**Parliamentary Secretary
for Disabilities and Carers**



M Butler

The Hon Mark Butler MP
**Minister for Mental Health
and Ageing**

1. What is the purpose of the discussion paper?

This discussion paper provides an outline of what the National Carer Strategy (Strategy) could look like. It seeks your views to further inform the development of the Strategy.

The discussion paper should be used as a guide for written submissions and provides the basis for workshops with carers, carer support organisations and service providers.

2. The Australian Government's commitment

The Australian Government believes that carers should have the same opportunities as other Australians to participate in work, community, social and family activities, and live a meaningful life.

The Australian Government is committed to leading the development of a National Carer Recognition Framework (Framework) to better recognise carers as part of its response to the report: *Who Cares ...? Report on the inquiry into better support for carers* by the House of Representatives Standing Committee on Family, Community, Housing and Youth.

The Carer Recognition Bill 2010 is the first element of the Framework and was introduced into Parliament on 29 September 2010. This Bill complements existing legislation in many States and Territories and is an important first step to give carers the recognition they deserve.

The Strategy is the second element of the Framework and is being developed in consultation with State and Territory Governments and with input from carers, carer support organisations and service providers.

3. Why are governments developing the National Carer Strategy?

Australia's 2.6 million carers are the foundation of Australia's community care, aged care, disability, mental health, primary health and palliative care systems. They play a vital role in looking after family members or friends so they can live at home and remain connected with their communities.

Caring can bring a personal sense of satisfaction and achievement. However, many carers face challenges including lack of recognition, poor health and wellbeing, financial stress, and social exclusion. It can be hard for carers to access services and supports for both themselves and the person they care for.

These messages came through loud and clear in the *inquiry into better support for carers*. Throughout the inquiry many carers told us their stories, some of which are below:

"It is a hidden life because most of it occurs behind closed doors. Nobody, apart from my husband and children – not my extended family or even my closest friends and definitely not my neighbours – know what I do and how hard I work."¹

"At every job interview I went to, I advised them that I was a primary carer for my mother and explained what that entailed. I believe that this was to my disadvantage to tell them as I am sure that I was rejected for many roles due to this commitment."²

"How stupid am I? I performed the task of primary care giver for more than twelve years before I even became aware that there was such a thing as a Carers Allowance"³

"I am 11 and since I still go to school caring disturbs my learning and my mum gets angry with me."⁴

"We find it difficult to stay balanced and healthy or be positive and objective, to enjoy retirement together like ordinary Australians."⁵

The Australian Government is developing the Strategy to respond to these challenges. A national approach is needed to place carers at the centre of government policy and to improve how governments and the community care, aged care, disability, mental health, primary health and palliative care systems work together to better support carers.

1 House Standing Committee into Family, Community, Housing and Youth, *Who Cares...? Report on the Inquiry into Better Support for Carers*, Submission 1248

2 As above, *Inquiry into better support for carers*, Submission 367

3 As above, *Inquiry into better support for carers*, Submission 3

4 As above, *Inquiry into better support for carers*, Submission 119

5 As above, *Inquiry into better support for carers*, Submission 136

4. How will the National Carer Strategy help carers?

The Strategy will set clear goals, and align and target government policies, services and supports for carers to these goals. It will help carers access the supports and services they need to make caring easier. It will support carers in balancing caring with work, social, community and family life.

We need to make sure different parts and different levels of government work effectively with each other to achieve these goals, rather than at cross-purposes – simplifying access to support for carers and the people they care for.

The Strategy will also increase awareness of carers' needs and issues at the national level. This includes awareness of the different circumstances facing different groups of carers, whose needs can differ greatly. It will respond to the diverse needs young carers, older carers, Indigenous carers, carers from culturally and linguistically diverse backgrounds, carers living in rural and remote areas and veteran and war widow/widower carers.

The Strategy will be a 10 year agenda for better supporting carers. It will include shorter three year plans that will set out clear directions to be taken by government agencies and non government organisations that work with carers.

The first of these plans will include what the Australian Government agreed to do in its response to the *Inquiry into better support for carers*.

5. How does the National Carer Strategy fit in with other government reforms?

The disability, mental health, primary health, hospital and aged care systems are all important to carers and the people they care for. But they don't always work in the interests of carers or fully take carers' needs into account.

There are a large number of reforms underway across these sectors. Developing the Strategy will help ensure these other reforms align with its goals and directions – and are conscious of their impact on the wellbeing of carers – as they are rolled out.

In the disability sector the *National Disability Agreement* is being implemented to improve services for people with disability their families and carers. The Australian Government has doubled its funding to State and Territory Governments by providing \$5.8 billion over five years to support specialist disability services. A draft *National Disability Strategy* has been released which outlines a 10 year national plan to improve the lives of people with disability, promote participation and create a more inclusive society. This draft highlights the importance of the *National Carer Strategy* in addressing the needs and improving the lives of carers.

The Productivity Commission is conducting an inquiry into the costs, benefits and feasibility of a long term care and support scheme for people with disability. Such a scheme has the potential to transform the lives of people with disability, their families and carers. However, as this transformation will take time, the National Carer Strategy will play an integral role in supporting carers in the short to medium term.

The Australian Government recently made a number of commitments to ensure people with disability are able to fulfil their full potential and which will help provide relief to carers. The Better Start for Children with Disability initiative will provide more than \$122 million over four years for early intervention services for children diagnosed with sight and hearing impairments, cerebral palsy, Down Syndrome, or Fragile X syndrome. The Better Start for Children with Disability initiative will

ensure that children with disabilities that affect their development have access to intensive early intervention therapies and treatments from expert health professionals. The Australian Government will also establish a new capital fund of \$60 million to build up to 150 new innovative, community based supported accommodation places for people with disability. For the first time, community organisations will have the opportunity to apply for direct capital funding from the Australian Government for supported accommodation.

The Australian Government is providing \$10.5 million to 2013 to continue support for 262 Mytime peer support groups across Australia and is expanding the age limit to carers of children with disability up to 16 years. Young carers will continue to be supported with flexible respite, education, information, referrals, advice and support with funding of \$25 million over the next three years.

In the mental health sector the Australian Government has committed to working with the States and Territories on the scope of mental health service system reform. This includes looking at the inconsistencies and gaps in services and current roles and responsibilities in the mental health sector.

Under the *National Mental Health Strategy*, of which the *Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009–2014* and the Council of Australian Governments' National Action Plan on Mental Health 2006–2011 are components, Health Ministers' acknowledge that carers provide a vital role in the prevention, early intervention, treatment and recovery for people with mental illness.

The Australian Government's *Mental Health Community Based initiative* provides around \$38 million over four years to support families, carers, children and young people affected by mental illness, through a diverse range of locally based community services. Funding of \$202 million over four years for the *Mental Health Respite initiative* will provide a range of flexible respite and support options for carers of people with severe mental illness and carers of people with intellectual disability.

In the health and aged care sectors, the Australian Government is delivering a *National Health and Hospitals Network* – the most significant reform to Australia's health and hospital system since the introduction of Medicare. This includes the Australian Government taking full funding and policy responsibility for aged care services, including the transfer to the Commonwealth of current resourcing for aged care services from the Home and Community Care program except in Victoria. This will enable the development of a consistent aged care system covering basic care at home through to higher level care in aged care homes. It will drive increased integration between acute care, public hospitals, general practitioners, primary health care and aged care.

These reforms include the establishment of a national network of one stop shops to help older Australians, their families and carers more easily access the services available to them in the community. Opportunities will also be explored to better meet the information and support needs of vulnerable groups including carers in the Australian Government's service delivery reform agenda. These reforms will link in with the National Carer Strategy goal of providing better information and support for carers.

In addition to these reforms and investments, the Australian Government has asked the Productivity Commission to undertake a major inquiry into the aged care sector.

The introduction of the *Fair Work Act 2009* recognises that many working Australians are responsible for the care of others and gives rights for employees caring for a child with disability under the age of 18 to request flexible working arrangements.

The Australian Government's *National Strategy for Young Australians* includes a focus on improving health and wellbeing and supporting young people in their families including young carers and those who are the children of carers. The National Carer Strategy will respond to the diverse needs of carers including young carers.

6. Goals and directions for the National Carer Strategy

The Australian Government has been listening to carers and their representatives in formulating the goals and directions for the Strategy, outlined below. These goals and directions will be the foundations of the Strategy and will guide government policy and programs across the wide range of areas that impact on carers.

This means these goals and directions are inevitably quite high-level. But it also means they will play a critical role in shaping and guiding the actions of governments across many important areas of activity to better respond to the needs of Australia's carers.

Your input will help us ensure we get these goals and directions right and build on them appropriately as we develop the Strategy.

6.1 Vision

Carers are recognised and supported at all stages of caring so they can maintain their health and wellbeing and take part in all aspects of life in Australia, including work, community and family life.

6.2 Aim

Policy, programs and services for carers are coordinated, responsive and targeted at all stages of caring.

6.3 Goals

Goal 1: Better recognition for carers

Achieving this goal will result in:

- Carers being recognised and acknowledged for their caring responsibilities
- Carers being actively consulted, and their needs considered, in the development and implementation of policies, programs and services affecting them
- Carers being recognised by health and community care professionals as partners in the provision of care.

Goal 2: Better support to help carers work

Achieving this goal will result in:

- Carers being supported to balance caring and work responsibilities at all stages of caring
- Eligible carers who are unable to work being supported by the income support system.

Goal 3: Better information and support for carers

Achieving this goal will result in:

- Carers having improved access to appropriate and timely information that enables them to make informed decisions about support options as their needs change
- Carers being supported with appropriate, accessible and timely services that respond to their individual circumstances
- Improvements in data and research on carers' needs to support better services and increased accountability.

Goal 4: Better education and training for carers

Achieving this goal will result in:

- Carers having the resources and opportunities to participate in education and training
- Carers being supported with the training and skills they need to undertake their caring responsibilities.

Goal 5: Better health and wellbeing for carers

Achieving this goal will result in:

- Better support for carers' physical, mental health and emotional wellbeing at all stages of caring
- Carers having the capacity and opportunity to participate in community and social life and to balance caring with other aspects of life.

7. What do you think?

It is important that we get the Strategy right as it will guide the development and implementation of policies, programs and services to support carers over the next 10 years.

The Australian Government has been listening to carers and their representatives in formulating the goals and direction of the Strategy. To ensure we have heard you correctly, please consider the following questions (also on the submission form at **Attachment A**) and provide feedback on:

1. Do you think the Strategy as outlined in this discussion paper sets the right direction to meet the vision and aim to better support carers?
2. Do you agree with the five goals outlined in this discussion paper?
3. Tell us if you have any suggestions about how the goals could be improved.
4. What should the Australian Government focus on under the goals to better support carers now and into the future?
5. Is there anything else that you would like to add that has not already been captured?

8. How to have your say

To help you have your say, this discussion paper is available online on the Department of Health and Ageing website www.health.gov.au with links on the Department of Families, Housing, Community Services and Indigenous Affairs website www.fahcsia.gov.au/sa/carers. The discussion paper is also available in range of accessible formats.

Workshops for carers

Carers Australia will be running a series of workshops with carers in **October** and **November 2010** in capital cities and selected regional and remote locations. For further information on these workshops visit carersaustralia.com.au

Children with Disability Australia will be holding discussion forums with carers in early **December 2010**. For further information on these forums email info@cda.org.au

Workshops for carer support organisations and service providers

The Australian Government will be conducting a series of targeted workshops in **November** and early **December 2010** with carer support organisations and service providers to gain their views on the discussion paper. These will be held in capital cities and selected regional and rural locations.

The Australian Government will invite carer support organisations and service providers to attend workshops. You can register your interest in attending a workshop by emailing: nationalcarerstrategy@health.gov.au; by phoning 1800 057 616; or on-line at www.health.gov.au.

9. Written submissions

The closing date for submissions is **5 December 2010, 5pm EDST**. Postal and email submissions will be accepted after 5 December 2010 as long as they are postmarked by 5pm, 5 December 2010 EDST.

A submission form (**Attachment A**) has been included in this discussion paper as a method for providing feedback. If you are providing feedback, not all questions on the submission form have to be completed. You may answer all or any of the questions.

You can provide your feedback by:

Email: nationalcarerstrategy@health.gov.au

Post: National Carer Strategy
Mail drop point 600
GPO Box 9848
Canberra ACT 2601, Australia

Fax: (02) 6289 1563

10. Privacy and confidentiality

The information, including any personal information, you provide in your submission will be used for the purpose of informing the development of the Strategy and for providing information to the Australian Government about the feedback received from this consultation process.

Any personal information you provide may be disclosed to the Department of Families, Housing, Community Services and Indigenous Affairs or to the Department of Health and Ageing and may be disclosed by that department to the other department for the purpose described above. It may also be disclosed to other Commonwealth agencies but only where this is necessary for the purpose described above, or to inform government as a whole in relation to development of the Strategy.

Your submission will be used, depending on its content and format, along with other submissions, to produce summaries, analyses and abstracts as appropriate having regard to the purpose identified above. These summaries, analyses and abstracts may be placed on the Department of Health and Ageing and Department of Families, Housing, Community Services and Indigenous Affairs websites and, if they are, we will not include any information about you or any details which may identify you or any other person.

We reserve the right, at our absolute discretion, in preparing summaries and analyses etc and before placing anything on our website, to edit any part of your submission, including deleting or summarising material and combining content with that of other submissions.

Intellectual property

By providing a submission you will be taken to be warranting to the Commonwealth that any intellectual property (including copyright and trade marks) in your submission, or any part of it, is either:

- (a) owned by you, in which case you are giving to the Commonwealth a royalty-free, irrevocable licence to use and publish the material as we, in our absolute discretion see fit; or
- (b) owned by a third party who or which has consented to your provision of it to the Commonwealth for the purpose of informing the development of the Strategy and of providing information to the Australian Government about the feedback received from this consultation process.

We reserve the right, at our absolute discretion, to decide not to use your submission or, if we do use it, to edit any part of it, including deleting or summarising material and combining its content with that of other submissions.

Other information

To help us analyse the responses we receive, we would like to know a little bit more about you. These questions are optional and you don't have to answer them for your submission to be considered. However, please note page 12 explains information regarding privacy and confidentiality of any information you choose to submit.

Section A is for individual carers. Section B is for organisations. Please answer the questions in one section only.

Section A – Carer

How many people do you care for?

- 1 2 3 4

What is your relationship to the people you care for?

- | | |
|----------------------------------|---|
| <input type="checkbox"/> Parent | <input type="checkbox"/> Other relative |
| <input type="checkbox"/> Child | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Spouse | <input type="checkbox"/> Neighbour |
| <input type="checkbox"/> Sibling | <input type="checkbox"/> Other _____ |

What are the main conditions of the people you care for?

- | | |
|---|---|
| <input type="checkbox"/> Autism | <input type="checkbox"/> Mental Illness |
| <input type="checkbox"/> Acquired Brain Injury | <input type="checkbox"/> Neurological |
| <input type="checkbox"/> Dementia | <input type="checkbox"/> Physical Disability |
| <input type="checkbox"/> Drug or Alcohol related condition | <input type="checkbox"/> Psychiatric Disability |
| <input type="checkbox"/> Frail Aged | <input type="checkbox"/> Specific Learning/ADD |
| <input type="checkbox"/> Hearing Impairment | <input type="checkbox"/> Speech Impairment |
| <input type="checkbox"/> Intellectual Disability | <input type="checkbox"/> Vision Impairment |
| <input type="checkbox"/> Medical Condition (incl. terminal illness) | <input type="checkbox"/> Other _____ |

What is your age?

- | | | |
|-----------------------------------|--------------------------------|----------------------------------|
| <input type="checkbox"/> Under 18 | <input type="checkbox"/> 35–44 | <input type="checkbox"/> 65–74 |
| <input type="checkbox"/> 18–24 | <input type="checkbox"/> 45–54 | <input type="checkbox"/> 75–84 |
| <input type="checkbox"/> 25–34 | <input type="checkbox"/> 55–64 | <input type="checkbox"/> Over 85 |

What is your gender?

Male

Female

Please indicate which of the following categories apply to you. You may indicate more than one category.

A full-time carer

An employed carer

A full-time or part-time carer who is studying

A person with multiple care responsibilities (e.g. caring for elderly parent and child with disability)

A carer from a culturally or linguistically diverse background

An Indigenous carer or a carer of an Indigenous person

A veteran or war widow/widower carer or a carer of a veteran or war widow/widower

In a 'typical' week, how many hours do you spend caring for the person or people in your care?

Up to 10 hours per week

Between 20 and 40 hours per week

Between 10 and 20 hours per week

More than 40 hours per week

How many years in total have you been caring?

Less than 1 year

More than 10 years

Between 1 and 5 years

Episodic
(over a period of more than 12 months)

Between 5 and 10 years

In which state or territory are you located?

ACT

NT

SA

VIC

NSW

QLD

TAS

WA

In which area are you located?

Metro

Rural

Regional

Remote

If you would like to be kept updated on the Strategy, please provide your email address below.

_____ @ _____



Section B—Organisation (e.g. support organisation, service provider, education and training providers, employment services, other government services, political party etc.)

Type of organisation

- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Government | <input type="checkbox"/> Business |
| <input type="checkbox"/> Non Government Organisation/
Private Provider | <input type="checkbox"/> Peak body |
| | <input type="checkbox"/> Other _____ |

Where does your organisation operate?

- | | |
|---|------------------------------|
| <input type="checkbox"/> Australia wide | <input type="checkbox"/> SA |
| <input type="checkbox"/> ACT | <input type="checkbox"/> TAS |
| <input type="checkbox"/> NSW | <input type="checkbox"/> VIC |
| <input type="checkbox"/> NT | <input type="checkbox"/> WA |
| <input type="checkbox"/> QLD | |

In which area are you located?

- | | | | |
|--------------------------------|--------------------------------|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Metro | <input type="checkbox"/> Rural | <input type="checkbox"/> Regional | <input type="checkbox"/> Remote |
|--------------------------------|--------------------------------|-----------------------------------|---------------------------------|

What products or services do you or your organisation provide?

- | | |
|---|--|
| <input type="checkbox"/> Advocacy | <input type="checkbox"/> Peak body |
| <input type="checkbox"/> Aids and equipment | <input type="checkbox"/> Peer support |
| <input type="checkbox"/> Community aged care packages | <input type="checkbox"/> Policy |
| <input type="checkbox"/> Counselling | <input type="checkbox"/> Respite |
| <input type="checkbox"/> Funding | <input type="checkbox"/> Supported accommodation |
| <input type="checkbox"/> HACC services | <input type="checkbox"/> Training |
| <input type="checkbox"/> Information/referral | |

Size of organisation

- | | | |
|-------------------------------------|--------------------------------------|---|
| <input type="checkbox"/> 0–25 staff | <input type="checkbox"/> 25–50 staff | <input type="checkbox"/> More than 50 staff |
|-------------------------------------|--------------------------------------|---|

If you would like to be kept updated on the Strategy please provide your email address below.

_____ @ _____

