



# Developing the NSW Carers Strategy

*Creating Innovative Solutions with Carers*

Background Paper





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# Developing the NSW Carers Strategy

## Introduction

The NSW Government is developing a Carers Strategy (the Strategy). The Strategy is being led by Family and Community Services with assistance from the Ministry of Health and Carers NSW. Broader community representation will also contribute to its development including working groups that have been formed to help us design solutions and approach for the Strategy.

## Who are carers?

About one in ten (850,000) people in NSW provide ongoing unpaid support to family or friends who need help with everyday aspects of life because of:

- disability
- chronic illness
- mental illness, or
- frail age.

Carers come from all walks of life, cultural backgrounds and age groups. Each caring situation is unique, and each carer has individual needs. Carers can be family members, friends, housemates or neighbours. Both men and women can become carers although women are more likely to take on the primary caring role.

Many of us will find ourselves either caring for someone or being cared for at some stage in our life.

## Why develop a Carers Strategy?

The recognition of care provision, both paid and unpaid, reflects the value placed on our shared humanity and the periods throughout our lives in which we all experience a need for support.

- Human Rights Sex Discrimination Commissioner Elizabeth Broderick,  
Carers NSW 2013 Biennial Conference

Carers play an invaluable role by supporting people to live full and independent lives, to remain in their own home and in their own communities. This type of care is fundamental to family life and our community wellbeing.

Carers are central to the success of our health and community welfare systems and make an enormous contribution to our economic prosperity. In 2010 it was estimated that it would cost the Australian taxpayer over \$40 billion to replace the billions of hours of unpaid care provided. (*The economic value of informal care in 2010*; Access Economics 2010)

Carers tell us that caring can be rewarding but that it also creates significant challenges as a result of the lack of recognition, poor health and wellbeing, financial stress and social exclusion. There is an urgent need to address these issues as the demand for carers is set to grow. One reason is our ageing population and the increasing demand for care - formal and informal. This is a global phenomenon and many governments are working hard to find ways to better support carers.

## What is the Carers Strategy about?

The Carers Strategy will create a shared agenda with common goals for government and others to implement. Its implementation will help to strengthen the role carers play in our society and better support the good work they do.

Five focus areas will shape development of the Strategy. These focus areas have been identified through extensive consultation with carers and other stakeholders.

Vision for carers in NSW	
Carers in NSW fully participate in social and economic life	
Focus Area	Broad aims
<b>Employment &amp; Education</b>	Carers have choices and opportunities to participate in paid work and education.
<b>Health &amp; Wellbeing</b>	Carers experience good health and wellbeing.
<b>Information &amp; Community Awareness</b>	Carers have access to information when they need it to support them. The community understands the role of carers.
<b>Carer Engagement</b>	Carers are recognised and actively involved in decisions that affect them and the people they care for.
<b>Improving the Evidence Base</b>	Quality data and research about carers is available to inform policy and practice.

## NSW Government's commitment to carers

The *NSW Carers Action Plan 2007-2012* and the *NSW Carers (Recognition) Act 2010* established the NSW Government's commitment to carers.

The *NSW Carers (Recognition) Act 2010* places obligations on all public sector agencies to recognise and value carers and to ensure carers are consulted on policy matters that impact on them. Schedule 1 of the Act established the NSW Carers Charter and underpins the Government's commitment to carers having the same opportunities and choices as other Australians. This relates to participation in the workforce, having good health and wellbeing, feeling included in the community and being recognised and valued for the contribution they make to the lives of the people they care for and the broader community.

The development of the Strategy will complement the *NSW Carers (Recognition) Act 2010* and support government and non-government organisations to go beyond the minimum expectations enshrined in legislation. It will give carers a more prominent place in public policy, reflecting the need to respond to the pressing issues they currently face and equip NSW to manage the increasing demands on care and carers.

## The scope of the Carers Strategy

The Carers Strategy will shape the way NSW supports carers between 2014-2019, forming the basis of a NSW Carers Strategy Implementation Plan.

The Strategy may include a mix of initiatives ranging from concrete service delivery actions to building strategic partnerships that influence change for carers. Some initiatives may be ready to implement in a relatively short time frame by building on existing capacity and reforms. Initiatives that involve establishing new partnerships or new approaches may take longer to shape.

The Strategy will focus on the core areas of State Government responsibility and influence. It is hoped that actions will be designed and implemented in partnership with others.

Where we are unable to directly influence proposed initiatives, the ideas will be honoured and heard by Government and we will seek to influence change where possible.

We will build on what currently works well for carers and on important reforms such as:

- NSW Ageing Strategy
- Stronger Together 2: a new direction for disability services in NSW 2006-2016
- NSW Mental Health Strategic Plan
- National Disability Insurance Scheme
- NSW State Plan 2021
- National Carer Strategy and Implementation Plan.

It is not anticipated that additional NSW Government resources will be available for the implementation of the Strategy. The Strategy may however impact on how current spending is used.

## How are we developing the Carers Strategy?

The Carers Strategy is being developed through a collaborative co-design process. We will be working with carers and diverse stakeholders (employers, government, non-government, industry representatives, experts and researchers) to help us develop better ways to support carers. We will identify areas of shared value, opportunities for innovation and new ways of thinking. Most importantly, we will develop some practical solutions and strategies to improve existing services and practices. The collaborative process involves the following stages:

November 2013	Workshop 1 – in each focus area	<b>Share an understanding of the issues</b> Representatives from government, non-government, industry and community develop a shared understanding of the problem.
December 2013	Workshop 2 – in each focus area	<b>Design the solutions</b> Representatives from government, non-government, industry and community design and prioritise solutions.
February 2014	NSW community engagement	<b>Consensus building</b> Individual and community input on workshop recommendations using the <i>Have Your Say</i> online consultation website.
March- April 2014	Ministerial Carers Summit	<b>Looking forward</b> Presenting solutions, priorities and actions for further refinement.
Mid 2014	NSW Carers Strategy launch	<b>Launch of the Strategy</b> Ministerial launch of the NSW Carers Strategy

# **NSW Carers Strategy**

## **The five focus areas**

# 1. Economic Participation

## What are we aiming for?

Carers have choices and opportunities to participate in paid work and education.

## Employment

### A carer's perspective

*I find it difficult financially because we were in our 40s when my husband became sick and could not work anymore. We were not able to work to retirement age and retire with superannuation, which was always our intention. I also had to give up my job to care for my husband. So we not only lost his wage but mine as well. I was earning more per week 12 years ago, than I get a fortnight.*

- Carer for husband with heart condition and mental illness

### The headline issues

- Carers are more likely to experience financial hardship than other Australians.
- Many carers struggle to combine caring and work.
- Financial hardship impacts on carer's wellbeing.
- Caring responsibilities and the shortage of feasible care alternatives are the main reasons carers relinquish or reduce employment participation.
- The peak age for caring is between 45-65 years. It is also a time when employers are more likely to lose employees, often at significant cost in terms of resource investment. Retraining is also hard.
- There are significant economic and social gains to be realised by supporting people to balance care and work - for carers, employers and the wider community.

### What success could look like

- Carers feel they have choices and opportunities to participate in paid work.
- Employed carers find it easier to balance work and caring.
- Carers find it easier to return to paid work after a period out of the workforce.
- Carers can complete training that will lead to paid work.



### Employment case study - UK Employers for Carers ([www.employersforcarers.org](http://www.employersforcarers.org))

The UK Employers for Carers was set up in 2009 as an innovative service for employers to:

- provide practical advice and support for employers seeking to develop carer-friendly policy and practice and retain skilled workers
- identify and promote the business benefits of supporting carers in the workplace
- influence employment policy and practice to create a culture supportive of carers
- work with government to deliver commitments made to carers.

Employers for Carers is funded by member employers through annual fees. Membership includes large and small organisations from government, non-government, industry and peaks. Benefits come from networking opportunities, services and expertise and working closely with Carers UK.

It has become a well established organisation with influence, having regular dialogue with Ministers and key government departments as well as helping to shape Human Resources and policies. The current Chair is British Gas.



# Education

## A carer's perspective

*It took courage to tell the school about Mum, I didn't want to have to repeat my story every day, to every teacher that asked. That I was doing my best - when I told you I was tired and stressed it was true. It made such a difference when you were flexible with schoolwork and deadlines. Getting approval to do my Year 11 and 12 over three years was bliss. It was the reason I could finish and go to Uni.*

- Carers Australia, Young Carers in Education: Supporting Rural & Remote Young Carers 2011

Young carers are defined as aged 25 years and under.

### The headline issues

- Young carers are nine times more likely to live in an area of high socio-economic disadvantage than their peers.
- Young carers have lower levels of educational attainment and workforce participation than their non-caring peers.
- Low levels of caring responsibility are an accepted part of childhood and family life but when caring responsibilities become more intense for young people and children, this may lead to long term disadvantage and negative life outcomes.
- Identifying and supporting young carers as early as possible can be effective in preventing the young carers under-achieving at school and experiencing lifelong lower socio-economic status.

### What success could look like

- Young carers complete school and transition successfully to further education and/or employment.



### Education case study – Access and Inclusion booklet – Sydney University

Student carers at the University of Sydney have developed a booklet aimed at raising awareness about young carers in tertiary education and outlining simple strategies universities can adopt to support young carers. The booklet contains factual and demographic information about young carers with personal stories from carers studying in universities across NSW, highlighting the challenges they face to remain in higher education while maintaining their caring role.

With funding from Carers Australia and the support of the Disability and Carers Collective they have recently started advertising and distributing the booklets.



### Education case study – Young Carers Passport ([www.calderdale.gov.uk](http://www.calderdale.gov.uk))

Calderdale Council in the UK launched a Young Carers Passport in 2012 to help young carers to receive the support they need in school.

The passport was the idea and design of young adult carers who felt that a quick and discrete method to alert teachers to their situation would have made a big difference to their lives and schooling.

The passport is aimed at young carers between the ages of 16-18 years and lets them tell teachers when they are struggling in school or need extra help because of their caring responsibilities.

## 2. Health and Wellbeing

### What are we aiming for?

Carers experience good health and wellbeing.

#### A carer's perspective

*Apart from the isolation and loneliness I was experiencing, like many carers I experienced anxiety and depression, trauma and grief as a direct result of the caring role. Whilst these conditions are considered mental illnesses in their own right, they are a fundamental part of the lived experience for carers.*

- Carer for family member with a mental illness

### The headline issues

- Carers are more likely to experience physical and mental ill health and disability than the general population (Australian Unity Wellbeing Index, 2007, Survey 17.1 *The Wellbeing of Australians – Carer Health and Wellbeing*).
- Carers are more likely to experience social isolation than the general population.
- Carers commonly cite the demands of their caring responsibilities as the primary reason they do not access health services for themselves.
- Services that come into contact with carers do not routinely ask about the carer's own health and wellbeing.

### What success could look like

- Carers recognise their own health needs and access services accordingly.
- Health services are responsive to the needs of carers.
- Carers have the choice and opportunity to participate in community life.
- Carers report improved health and wellbeing.



#### Case study – UK Carewell Project ([www.carewelluk.org](http://www.carewelluk.org))

Carewell is a partnership between Bupa and Carers UK.

Created in 2012, with help from carers, Carewell is an online resource aimed at supporting carers to make positive changes to their lives through health tips, resources and an online forum for carers to discuss health and wellbeing with other carers and experts.



#### Case study – Partners in Depression ([www.partnersindepression.com.au](http://www.partnersindepression.com.au))

Partners in Depression is a national program funded from various sources including the *nib foundation* and *beyondblue*. The Hunter Institute of Mental Health delivers the program and is registered as a not-for-profit business unit of the Hunter New England Mental Health Service.

Partners in Depression is a six week education, support and skill building program designed to address the needs of people who care for someone with depression. The program was recognised for its partnership practices, receiving the Special Judges Partnership Practices Award at the Australian and New Zealand Mental Health Services Conference in 2013.

# 3. Information and Community Awareness

## What are we aiming for?

Carers have access to information when they need it to support them.

The community understands the role of carers.

### A carer's perspective

*Getting access to services is a challenge. I work full time, and between the national helpline and local council it involved many phone calls, I didn't know where to go. I felt helpless, no-one would take responsibility.*

- Carer for an elderly father

## The headline issues

- Access to information, advice and guided referral can better assist carers to make informed decisions, plan for the future and balance care and other responsibilities.
- Carers report the information they need is unavailable, fragmented and/or difficult to access/navigate.
- Carers report their caring role is not understood by others, including the community at large.
- Carers often find the best information comes from other carers.
- Carers report that training to help them in their role as carers would be beneficial in responding to the needs of the person they care for.

## What success could look like

- Carers have a choice about how to access information.
- Services have integrated and simple information pathways for carers to navigate.
- Services provide information that is timely, meaningful and empowering for carers.
- Services have robust practices to support carer recognition, provide person centred advice and guided referral.
- Carers use information to successfully connect to other resources and sources of support.
- Carers receive the information and training they need to assist them to meet the needs of the person they care for.
- Greater public awareness of the role and diversity of carers.



## Mobile Apps

There are many media apps emerging to assist carers in their caring role. Examples of mobile apps that could be developed for the Australian market:

- Personal Caregiver app – developed to track medications, schedules and receive alerts.
- Yecco app - a social network tool for carers, connecting them to family members, friends and care professionals to help coordinate support for the person in need of care and subsequently reduce the demands placed on a single carer. The app uses a shared calendar, alerts and reminders, private network messaging system and provides access to a directory of services and online resources. As well as improving the communication and coordination of care, the app also helps foster closer connections within the family and between those involved in the task of caring.



### **Building information and community awareness through networks**

Weavers - a South Australian project that puts carers in touch with each other to troubleshoot issues, share support and build capacity through sharing insights, experience and skill. The project helps carers to activate networks of support, navigate local services, learn strategies and balance care with living. The project was designed and piloted by the Australian Centre for Social Innovation and is looking for partners to take the Weavers project to the next stage.



### **Building community awareness through campaigns**

Carers Week UK – Members of Parliament and celebrities are encouraged to become Carer Ambassadors for Carers Week through an online application process. They are encouraged to join the Carers Week Campaign, provide a statement, promote Carers Week on social media and talk to carers. MPs are encouraged to hold an open day for carers in their constituency.

## 4. Carer Engagement

### What are we aiming for?

Carers are recognised and actively involved in decisions that affect them and the people they care for.

#### A carer's perspective

*When you get a staff member that recognises that you, as the primary carer KNOWS the child better than they do- then you feel more confident that your child will have unique needs met. It relieves a lot of distress.*

- Carer of a child with a disability

### The headline issues

- Carers report that they feel their caring role is not understood by others, including service providers.
- Carers consistently want service providers to work with them to meet the needs of people who are being cared for. This includes recognising and valuing the expertise and knowledge carers bring to care planning, review and service delivery.
- Carers report more service providers are recognising their role but that recognition alone is not producing a better response.
- The *NSW Carers (Recognition) Act 2010* requires NSW Government agencies to recognise carers and involve them in the development of policy and programs that impact on carers.

### What success could look like

- Services include carers as partners in the planning and delivery of services.
- Carers contribute to public policy and the programs that impact on them and the people for whom they care for.
- A reduction in the demand for crisis intervention through early identification and intervention for carers.



#### Case study – TOP5 Clinical Excellence Commission

TOP5 is a patient-centred initiative that promotes dialogue between hospital staff and the patient's carer. The carer's knowledge and expertise in communicating with and caring for the patient are acknowledged, and strategies are identified and recorded in bed chart notes for medical and nursing staff.

The project is simple. Hospital staff are asked to:

- T – talk to the carer
- O – obtain information about the patient
- P – personalise the care using the carer's suggestions
- 5 – develop 5 strategies to personalise the care.

TOP5 was conceived and piloted by the Central coast Local Health District. Currently rolled out to 20 hospitals in NSW (15 public and five private), the NSW Clinical Excellence Commission is supported by a HCF Foundation grant to deliver this project to the next stage. A Report of the evaluation of this project will be available in early 2014.

## 5. Improving the evidence base

### What are we aiming for?

Quality data and research about carers is available to inform policy and practice.

*...without comprehensive, consistent and integrated data it remains difficult to plan future services and, more importantly, accurately determine the levels of unmet need.*

- House of Representatives Standing Committee on Family, Community, Housing and Youth  
*Who Cares...? Report on the Inquiry into Better Support for Carers (2009)*

### The headline issues

- There are significant gaps in the data available on carer numbers, profile, patterns of service use and needs (e.g. carers under the age of 15 as primary carers and data on short term or intermittent carers, such as those caring for people with a mental illness).
- Carers are not consistently identified in data collected through services and programs.
- There is limited evidence about the impact on carers of programs that support their care recipients.

### What success could look like

- Carers are defined and identified in a consistent way across collections and service data.
- Evaluation of the impact of services and programs on carers informs policy and program development.
- Policy makers have access to better long-term evidence about carers.



#### Case Study – UK Social Care Online ([www.scie-socialcareonline.org.uk/default.asp](http://www.scie-socialcareonline.org.uk/default.asp))

Social Care Online is a database of information and research on all aspects of social care in the UK. Updated daily resources include legislation, government documents, practice and guidance, systemic reviews, briefs and events.



#### Case Study – Australian Policy Online ([www.apo.org.au](http://www.apo.org.au))

Australian Policy Online is a research database and alert service providing free access to full text research reports and papers, statistics and other resources essential for public policy development and implementation in Australia and New Zealand.

# How to have your say

## WORKSHOPS

Invited carers, government, non government and industry groups participate in workshops and the Ministerial Carers Summit.

## HAVE YOUR SAY

*Have Your Say* is an online opportunity for all community members to contribute to the Carers Strategy. Visit the website [www.haveyoursay.nsw.gov.au](http://www.haveyoursay.nsw.gov.au) during February to comment on the recommendations from workshops.

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