Former carers: the forgotten carers
Presenter: Freya Saich
Authors: Freya Saich and Timothy Broady, PhD.
About
The peak non-government organisation for people in New South Wales (NSW) who provide informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail.

Vision
Our vision is an Australia that values and supports all carers. Our goals are to:
• Work with carers to improve their health, wellbeing, resilience and financial security
• Have caring recognised as a shared responsibility of family, community and government
Definitions

• A **carer** is anyone who provides care and support to a family member or friend with a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or is frail. A **primary carer** is the person who provides the most care to someone.

• **Former carers** are partners, relatives, friends or neighbours (not paid workers) who have completed their caring role either because of the death of the person they were supporting or because the carer no longer has any involvement in caring.

• This definition **does not** include carers whose relative, friend or neighbour has entered residential care or supported accommodation where these carers are still actively involved in the care of the resident.
Impacts of caring

• While there are positive aspects of caring, there are also significant impacts.

• Overall, carers have lower levels of health and wellbeing, income, workforce participation, educational attainment and increased social isolation.

• Even after the caring role ends, these impacts are likely to continue – known as the “legacies of caring”*

*McLaughlin and Ritchie (1994)
Profile

• There is limited data on the number as well as the needs and experiences of former carers.

• Former carers are not included in the Australian Bureau of Statistics, Survey of Disability, Ageing and Carers, although the Census can provide a general indication.

• The 2006 Census counted 1.62 million carers (based on the Census definition). Of those, 1.04 million (64%) did not report being a carer in 2011, while 585,000 (36%) were still carers. 1.27 million people who were not carers in 2006 had become carers by 2011.

• Former carers are not recognised under Commonwealth and State Carer Recognition Legislation.
Carers NSW conducts bi-annual surveys of carers and former carers in NSW.

A total of 657 participants indicated that they had previously held caring roles that had now ended (former carers).

Of those, 534 were still caring for someone else and 123 were no longer carers.
Demographics of former carers

Carers NSW 2016 Carer Survey

Former carers only
- More likely to be **male**
- Have a **disability**
- Be **older** on average

Current and former carers
- More likely to be **female**
- Be aged 45-64
- More likely to be **Aboriginal** or **Torres Strait Islander** or **CALD**
- More likely to be **LGBTI**
Characteristics of the caring role

Carers NSW 2016 Carer Survey

Reason the caring role ended

- person died: 68%
- admitted into residential care: 19%
- no longer required care: 12%
- couldn't cope: 5%

Time since the caring role ended

- <1 year: 11.4%
- 1 year: 27%
- 2 years: 18%
- 3 years: 11%
- 4 years: 7%
- 5+ years: 23%
“My wife is now in dementia specific residential care. While the care is of high quality, there are often staff shortages. This is why I go in daily to be with my wife for about 2 to 3 hours and to help feed my wife at lunch time.”
Characteristics of the caring role

Carers NSW 2016 Carer Survey

Number of people previously cared for

<table>
<thead>
<tr>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>62%</td>
</tr>
<tr>
<td>2</td>
<td>19%</td>
</tr>
<tr>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>4</td>
<td>6%</td>
</tr>
<tr>
<td>5+</td>
<td>8%</td>
</tr>
</tbody>
</table>

Relationship to the person

- Parent: 62%
- Spouse/partner: 19%
- Son/daughter: 13%
- Sibling: 6%
- Friend/neighbour: 8%
- Other: 16%
Health and wellbeing

Literature

- Majority of carer research focuses on the health and wellbeing of current carers or bereaved carers.
- In addition to grief, former carers often struggle with the loss of purpose, identity, routine, and contacts.*
- Distress associated with the caring role can continue for one to two years following the end of the caring role.**
- Sustaining employment and social connections during the caring role has been shown to mitigate these factors.***
- Physical injuries, exhaustion and other health conditions as a result of their caring role – no longer providing care presents an opportunity for former carers to attend to their own health needs.****

*Hoerger et al. (2014); Larkin (2009); McLaughlin and Ritchie (1994); Orzeck (2016)
** Orzeck (2016)
*** McCarron et al. (2011); McLaughlin and Ritchie (1994)
**** Larkin and Milne (2017); McLaughlin and Ritchie (1994) Payne (1999);
Compared to those with current caring responsibilities, former carers reported better health, higher wellbeing, more social support, lower distress, and reflected more positively on their caring experiences.

**Self-rated health**

<table>
<thead>
<tr>
<th></th>
<th>Current</th>
<th>Both</th>
<th>Former</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>42%</td>
<td>42%</td>
<td>49%</td>
</tr>
</tbody>
</table>

**Distress**

<table>
<thead>
<tr>
<th></th>
<th>Current</th>
<th>Both</th>
<th>Former</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>32%</td>
<td>31%</td>
<td>22%</td>
</tr>
</tbody>
</table>
Health and wellbeing

Carers NSW 2016 Carer Survey

Social Support

Positive aspects of their caring role

Former | Both | Current

Former | Both | Current

64% | 54% | 53%

65% | 56% | 56%
Wellbeing was also found to improve across all of these measures as the time since caring roles had ended increased. This is supported by international literature which suggests that mental health outcomes of former carers improves over time.*

* Bond et al. (2003); Hirst (2005); Masterson et al. (2015)
Employment

Literature

There is a significant body of research regarding the impacts of caring on employment which continue even after the caring role ends.

Former carers often find that they have;

- Gaps in resumes
- Out-dated skills – need to retrain
- Injuries sustained during their caring role – implications for manual occupations
- Loss of confidence and self-esteem
- Experience age related bias and discrimination

*Arksey (2003); Larkin (2009); McCarron et al. (2011); McLaughlin and Ritchie (1994)*
Employment status

Carers NSW 2016 Carer Survey

Employment status

- Former: 66.70%
- Current: 47.80%
- Both: 49.90%

Employment status

- Full-time
- Part-time
- Casual
- Self-employed

- Former
- Current
- Both
Financial impacts

Literature

Caring incurs significant additional costs often associated with medication, equipment, vehicle modifications, transport and energy costs.* Long-term caring also has substantial financial impacts.

Former carers commonly experience**;

- Decline in income support from Carer Payment to Newstart
- Loss of subsidies that were previously available
- Accumulation of debt
- Inadequate savings and superannuation
- Homelessness amongst older women linked to those who previously held caring roles

* Hill et al. (2012)
** McLaughlin and Ritchie (1994); Larkin (2009); McCarron et al. (2011); Carers UK (2014); Larkin and Milne (2017).
Carers NSW 2016 Carer Survey

Household Income

- <$800
- $800-1999
- $2000-2999
- $3000-3999
- $4000+

Legend:
- Former
- Current
- Both
Continuum of care

Phases of the caring role

- Something is wrong
- Confirmation
- Adjustment
- Management
- Purposeful caring
- End of the caring role
- Post-caring phase

Supports during the caring role

- Contact with GP and health professionals
- Assessment of needs
- Income support, workplace adjustments
- Formal services – home care, respite
- Support – counselling, carer support group
- Palliative care/bereavement support
- Targeted services for former carers
Recommendations

Legislative recognition

Evidence base

Employment support

Caring credits

Proactive support

Future planning

Policies for former carers

Ongoing follow-up
References


