



# Understanding the social and emotional needs of carers: Final Report

Prepared for: NSW Carers Advisory Council

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# Glossary

ACAT	Aged Care Assessment Team
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study of Women's Health
CALD	Culturally and Linguistically Diverse
CBT	Cognitive Behavioural Therapy
CHSP	Commonwealth Home Support Programme
DSS	Department of Social Services
FACS	NSW Department of Family & Community Services
HCP	Home Care Package
ICSS	Integrated Carer Support Service
K10	Kessler 10
MBIs	Mindfulness-Based Interventions
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PWI	Personal Wellbeing Index
RDPs	Regional Delivery Partners
UK	the United Kingdom
USA	the United States of America
WHO	World Health Organisation

# Executive Summary

Carers provide invaluable, ongoing unpaid support to people who need it because of their disability, chronic illness, mental ill-health, dementia or frail age.

Programs to support carers' social and emotional wellbeing are framed by the context of shifting policies and support service arrangements for carers, people with disability and older people in Australia. The key recent policy changes include the introduction of the Integrated Carer Support Service (ICSS), the National Disability Insurance Scheme (NDIS) and My Aged Care.

## **Social and emotional needs and wellbeing**

Social and emotional wellbeing is closely related to the concept of mental health and requires that social, emotional and psychological needs are able to be met and that distress resulting from unmet needs in other domains is minimised (e.g. physical, informational, practical and spiritual needs).

For Aboriginal and Torres Strait Islander peoples, social and emotional wellbeing refers to a broader concept with seven overlapping domains including: body, mind and emotions, family and kin community, culture, country and spirituality and ancestors.

A range of outcome measures are used to assess carers' social and emotional needs and wellbeing, including general population measures for mental health, psychological wellbeing, coping, resilience and quality of life, as well as carer specific measures of needs, satisfaction, burden and stress.

Changes that occur with the onset of, and during, a caring role due to illness, disability or ageing can impact on carers' social and emotional wellbeing. While carers report positive aspects of caring, such as companionship, fulfilment, enjoyment and satisfaction, there is also strong evidence of the negative effects on emotional and psychological health, such as depression, anxiety, burden, anger, resentment, worry, sleep interruptions and suicidal thoughts. Caring can also lead to social isolation, loneliness, loss of social relationships and lack of support, and the experience of stigma. The impact of caring can increase over time and have greater effects for specific groups of carers.

To support their social and emotional wellbeing, carers reported needs for more information and accessible, affordable services providing practical and emotional support.

## **Interventions to support carers' social and emotional wellbeing**

In seeking to identify evidence as to what works to support carers' social and emotional wellbeing, this review focused on systematic and meta reviews of studies

that have employed rigorous evaluative methods to assess effectiveness and grey literature that has highlighted key areas of concern.

Interventions designed to improve the social and emotional wellbeing of carers that were considered in this review encompass:

- respite care/replacement care
- education and training and psychoeducation
- counselling/psychosocial interventions/therapy
- support groups
- practical help in the home
- physical exercise
- technological interventions.

While there is evidence to support some types of interventions for some groups of carers, a consistent theme in the reviews is that, despite the extensive research in many cases, the evidence about effectiveness is inconclusive, and that it is not possible to say definitively what works to support carers' social and emotional wellbeing.

A key issue identified in the literature is that while carers often report satisfaction with interventions, evidence about changes in social and emotional wellbeing outcomes is less robust. Careful consideration of the goals, objectives and measures used in programs and evaluations and the combination of quantitative and qualitative evidence is warranted.

Problems were also identified with the design, quality and incomparability of studies, which should be addressed in future research, specifically:

- the lack of a theory of change
- whether it was possible to identify a good control or comparison group
- small sample sizes
- relevance of outcome measures
- whether it was possible attribute change to specific aspects of the intervention
- the time period of evaluations
- the lack of cost-effectiveness analysis.

Most interventions have focused on outcomes for carers grouped by the condition of the care recipients, with fewer looking at groups based on the characteristics of carers themselves. Some have focused on outcomes for the carer dyad - both the carer and the person being cared for - and others have considered the relationships between carers and formal care workers or health professionals.

Other important themes in the research on the effectiveness of carer support refer to the availability, accessibility and comprehensiveness of support and whether it reflects what carers want.

While there is a vast literature identifying specific issues and concerns for different socio-demographic groups of carers, few systematic reviews focused on the characteristics of carers when considering interventions to support carers' social and emotional wellbeing outcomes. Further research is required to identify specific programs that will best support carers of different age groups, culturally and linguistically diverse (CALD) carers and Aboriginal and Torres Strait Islander carers. Carers in these demographic groups have diverse care situations and may require different types of interventions. Thus, effective programs may exist but may not yet be evaluated or be part of broader reviews.

### **Future research**

While this rapid literature review could not be comprehensive, some gaps in the research regarding programs and interventions that could be further explored include the effectiveness of:

- care coordination in promoting carers' social and emotional wellbeing
- advocacy training for carers or support from carer advocates and the extent to which it enables carers to access appropriate services and support, and improves their social and emotional wellbeing
- support for transition to non-parental or non-family care for older carers of adult children
- interventions specifically targeting working carers, or carers seeking to return to employment
- how support for both identifying and accessing appropriate home modifications may affect carers' social and emotional wellbeing
- resources that aim to advise and support carers about how to let others know about their care responsibilities
- holistic support programs for family members and networks of carers who may support a single person, rather than focusing on one carer or the primary carer
- financial literacy, financial counselling and financial capability training and support for carers
- programs that seek to reduce financial stress and improve carers' financial wellbeing and assess the effect of financial stress on carers' social and emotional wellbeing.

Further research could also aim to identify specific programs and seek to identify the design and effective elements of interventions to support social and emotional wellbeing that are:

- age-relevant and age-appropriate for young carers and older carers
- culturally appropriate for carers from the range of different CALD communities
- appropriate to support carers in Aboriginal and Torres Strait Islander communities
- effective to support parents and working age carers in balancing work and care commitments.

## Practical policy options

The findings of this review suggest that a range of broad practical policy options could be explored to support carers' social and emotional wellbeing. Principles underpinning the approaches to developing specific support programs could include:

- a 'pick-and-mix' approach: provide multicomponent interventions for carers to use at different points in time
- consultation: have conversations with carers that enable them to reflect about what they need and want, with a focus on person-centred approaches
- appropriateness: consider whether support is available, accessible, individualised, flexible, comprehensive and reflects what carers want
- 'whole of family/care' approach: develop programs that include services for the person being cared for and address the complexity of the care dyad and networks of care.

Specific options include:

- ensuring that carers have information about, and access to, flexible individualised multicomponent interventions
- building on research that has identified preferred types of respite for different groups of carers and developing well designed and evaluated interventions, of which emergency and planned respite are key components
- identifying effective education and training programs that assist carers to gain the skills they need to support them in their caring role
- ensuring that carers have information about and access to multiple forms of counselling
- identifying different groups of carers' needs and preferences for support groups and ensuring a range of support groups are available through different modalities
- ensuring carers are able to access adequate support in terms of practical help in the home, such as cooking, cleaning and transport
- identifying good practice interventions to support carers' physical health through further research.
- developing co-design projects with carers and technological innovators that could facilitate well designed technological components as part of multicomponent interventions
- ensuring carers have technological skills and support to access interventions if they wish to do so.

In the context of the changing policy landscape, it is important and timely to monitor the impact of the ICSS, NDIS and changes in aged care provision on the extent to which the social and emotional needs of carers are recognised and supported and the effects of these policy changes on carers' social and emotional wellbeing outcomes.

# 1 Introduction

## 1.1 Aims

This Rapid Literature Review was commissioned by Family & Community Services (FACS) on behalf of the NSW Carers Advisory Council. The review aims to contribute to the evidence to help the Council to better understand the social and emotional health and wellbeing of the carer population and the specific issues and their impact in the carer population. Carers provide ongoing unpaid support to people who need it because of their disability, chronic illness, mental ill-health, dementia or frail age.

This report outlines the findings regarding existing evidence in relation to three components:

1. evidence and concerns relating to the social and emotional health and wellbeing of the general carer population
2. the extent and prevalence of, and specific issues posed by, the social and emotional health and wellbeing issues of the following carers:
  - a) young carers
  - b) carers aged 25 to 60 years
  - c) older carers
  - d) culturally and linguistically diverse carers and
  - e) Aboriginal and Torres Strait Islander carers
3. possible solutions identified in the literature review.

The primary focus of this review is on evaluations of interventions or programs to support the social and emotional wellbeing of carers. The review also describes the key issues identified in the literature and what is known about the social and emotional health and wellbeing in the carer population. As this is a rapid literature review, it focuses on key issues, themes and solutions identified and may not be comprehensive or exhaustive.

## 1.2 Methods: Identifying evidence about what works

### Literature search

This review aimed to provide an overview of key findings in the literature about 'what works' or effective programs to improve the social and emotional wellbeing of carers. Searches of academic data bases in the fields of social sciences, psychology, public health and medicine revealed a wide range of concerns about

carers' social and emotional wellbeing and numerous studies that have conducted evaluations of interventions aimed at supporting carers.

This review began by focusing on some key recent meta-reviews of carer support that brought together information about a wide range of interventions to support carers in order to gain an understanding of the contemporary scope of the field. A search of academic databases was then conducted focusing on publications in English of reviews of evaluations of non-medical and non-pharmacological interventions in the years between 2013 and 2018. Some key meta-reviews and systematic reviews published between 2008 and 2013 were also included. Specific searches were also conducted to aim to identify interventions and literature relating to the social and emotional wellbeing of young carers, CALD carers and Aboriginal and Torres Strait Islander carers. Academic literature was selected after a review of titles and/or abstract and after meeting the additional inclusion criteria of referring to interventions conducted within Australia, New Zealand, Canada, the USA, the UK, Europe and preferably peer reviewed. Citation searches through Google scholar and reference list searches of key texts were also undertaken (details in Appendix A).

A search of 'grey literature', reports published by organisations and government agencies and departments, was also conducted focusing on key carer, mental health, disability and ageing organisations and relevant government agencies.

Other literature which contained one or more of the following elements was also identified and reviewed when it contributed to understanding about what works to support carers' social and emotional needs regarding:

- providing evidence relating to social and emotional needs and wellbeing of carers
- describing issues relating to the social and emotional needs and wellbeing of carers
- outlining measures to assess the social and emotional needs or wellbeing of carers

### **Assessing the quality of the evidence**

This rapid literature review draws primarily on meta reviews and systematic reviews that have assessed the quality of evidence from evaluations according to a range of rigorous criteria<sup>1</sup>. Such studies assess for quality, robustness and reliability of evidence. Studies often focused on quantitative outcome measures over time or compared carers' outcomes to some form of control or comparison group who did not receive the intervention. Qualitative studies in the form of narrative reviews, literature reviews and grey literature reports from key stakeholders that provided other insights into the issues and what works to improve the social and emotional wellbeing of carers have also been included.

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<sup>1</sup> For example criteria used in the Database of Abstracts of Reviews (DARE), PRISMA and Cochrane Collaboration.

## **Analysis and Synthesis: Bringing the findings together**

There is an extensive literature on carers' social and emotional wellbeing across the disciplines of medicine, public health, psychology and social sciences. Studies have employed a wide range of quantitative and qualitative methods and outcomes and findings are not always comparable. The following elements of interventions were considered in the analysis of the different studies:

- outcome/s measured in the intervention (e.g. mental health, coping and social wellbeing)
- target group for the intervention (based on characteristics of carer or person being cared for or both)
- what is provided as the intervention (e.g. education, counselling, support groups and/or practical support)
- who provided the intervention (e.g. peer support, professionals and/or volunteers)
- how the support was provided (e.g. group, individually or online)
- where the support was provided (settings) (e.g. at home, hospitals, clinics, professional office or social meeting point)
- at what point in the caring journey the support was provided (e.g. onset of condition or event, sustaining care or relinquishing care)
- why the intervention should help: underlying theory of change or explanatory mechanism (e.g. stress theory, cognitive appraisal, coping styles theories)
- study design: (e.g. changes over time or a comparison group)
- any evidence of improvement in social and emotional wellbeing (measures used, qualitative evidence)
- any evidence of short and/or long-term effects (e.g. length of intervention and follow-up)

The findings were then grouped by broad types of interventions and summarised.

### **1.3 Policy context**

Programs to support carers' social and emotional wellbeing are framed by the context of shifting policies and support service arrangements for carers, people with disability and older people in Australia. The key recent policy changes include the introduction of the Integrated Carer Support Service (ICSS), the National Disability Insurance Scheme (NDIS) and My Aged Care.

The Integrated Carer Support Service (ICSS), developed by the Department of Social Services (DSS), will provide ten services commencing through the Carer Gateway from October 2018 and through Regional Delivery Partners (RDPs) in September 2019. The ICSS Draft Support Framework (DSS 2018a) and ICSS Service Blueprint (DSS 2018b) indicate that these services will include:

- Carer Support Planning (needs assessment and development of Action Plan). Carers' needs will be assessed and monitored using the Carers Star™ that covers the following domains:

Health – e.g. current health status and impact of caring role on physical health.

The caring role – e.g. challenges and support needs, services and networks of support.

Managing at home – e.g. managing day to day tasks and suitability of home.

Time for yourself – e.g. time to attend to own needs, time with family and friends, hobbies and interests.

How you feel – e.g. impact on mental health, support from family and friends, relationships stress and strain

Finances – e.g. income support and impact of caring on financial situation

Work – e.g. employment status, volunteer work and study, support from employers, impact of care on employment, support to return to work (DSS 2018a: 12-13).

- Digital Counselling in the form of multiple one-hour sessions will be provided ‘for carers experiencing difficulties with anxiety, stress depression and low mood’ (DSS 2018b: 28. Services will be prioritised on the basis of assessment of ‘safety to them and others followed by the level of carer strain’ (DSS 2018b: 28).
- In-Person Counselling of up to six sessions will be available for ‘carers experiencing difficulties with anxiety, stress depression and low mood’ (DSS 2018b: 32). Access to the services will be prioritised on the basis of ‘carer strain level and safety factors such as risk of self-harm and harm to others’ (DSS 2018b: 32).
- Online Education will provide ‘information and courses to help carers in their caring role’ (DSS 2018b: 20).
- Carer Coaching will support ‘carers to acquire skills and resilience’ for their role (DSS 2018b: 20). Coaching will be delivered face-to-face and online, with face-to-face services prioritised on the basis of ‘safety to them and others followed by the level of carer strain’ (DSS, 2018b: 29).
- Online Peer Support will provide an online forum to connect carers to peers (DSS 2018b: 20).
- In-Person Peer Support will be a facilitated forum to connect carers to peers (DSS 2018b: 20).
- Carer Directed Support will encompass practical support, such as planned respite, cooking and assistance with transport. Support will be in the form of One-Off Support to the value of \$1500 or Carer Directed Packages to the value of \$3,000 over a 12-month period (DSS 2018b: 33).
- Young Carer Bursary Program provides funds to support young carers in greatest need of study (DSS 2018b: 20).
- Emergency Respite Care will be available for unplanned situations (DSS 2018b: 34).

Depending on the level of resources available, the ICSS could potentially provide an important mechanism to identify carers’ social and emotional needs as well as support for carers to maintain their social and emotional wellbeing.

The National Disability Insurance Scheme (NDIS) provides individual packages of ‘reasonable and necessary supports’ to people under the age of 65 years with a ‘significant and permanent’ disability<sup>2</sup>. The NDIS commenced its full roll-out in 2016 and is still in the transition phase. Carers can be involved in the planning of

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<sup>2</sup> <https://www.ndis.gov.au/about-us/what-ndis.html>

supports, obtaining referrals, and funding that assists in sustaining the caring relationship may be provided by the NDIS<sup>3</sup>.

Support for older Australians is provided through the Home Care Packages (HCP) and the Commonwealth Home Support Programme (CHSP). HCPs are individual packages of support provided at four different levels based on an assessment of need by an Aged Care Assessment Team (ACAT)<sup>4</sup>. CHSP provides a lower level of support for older people who are ineligible for the HCP<sup>5</sup>. A range of practical and allied health supports and respite services are available through these programmes.

Support and interventions for carers' social and emotional wellbeing are also framed by mental health and wellbeing policies and by carer specific legislation and policies at the national and state level including:

- NSW Mental Health Commission:
  - *Living Well: Putting people at the centre of mental health reform in NSW*
  - *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*
- *Fifth National Mental Health and Suicide Prevention Plan*
- *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023*
- *Carer Recognition Act 2010 (Cth)*
- *NSW Carers (Recognition) Act 2010*
- *NSW Carers Strategy 2014-2019*

Evidence of solutions and support for carers' social and emotional wellbeing need to be considered within this policy context.

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<sup>3</sup> <https://www.ndis.gov.au/families-carers/family-supports.html>

<sup>4</sup> [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/06\\_2018/your-guide-to-home-care-packages-services-may-2018.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/06_2018/your-guide-to-home-care-packages-services-may-2018.pdf)

<sup>5</sup> <https://www.myagedcare.gov.au/help-home/commonwealth-home-support-programme/accessing-commonwealth-home-support-programme>

## 2 Frameworks

### 2.1 Social and emotional wellbeing

Social and emotional wellbeing is closely related to the concept of mental health. The World Health Organisation (WHO) defines mental health as:

a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.<sup>6</sup>

The term 'social and emotional wellbeing' has been explored within broad philosophical notions of wellbeing and used in narrow applied approaches to empirical measurement in specific contexts (Hamilton and Redmond 2010; AIHW 2012).

Social and emotional wellbeing is a result of meeting social and emotional needs and reducing distress arising from unmet needs in other domains (see, for example, discussion in Fitch 2008). Developed in the context of supportive care practices for patients with cancer, Fitch (2008) distinguishes between different types of needs for patients and carers in the *Supportive Care Framework*: physical, informational, emotional, psychological, social, spiritual and practical. This framework has been used in the context of changes in needs arising from a cancer diagnosis and treatment and may have broader relevance to other care situations. This framework provides the following descriptions of needs:

- social needs: needs related to family relationships, community acceptance and involvement in relationships
- emotional needs: needs for a sense of comfort, belonging, understanding and reassurance in times of stress and upset
- psychological needs: needs related to the ability to cope with the illness experience and its consequences (Fitch 2008:9).

In the Australian context, the AIHW has discussed social and emotional wellbeing in relation to children with a view to developing headline indicators:

Broadly, social and emotional wellbeing refers to the way a person thinks and feels about themselves and others. It includes being able to adapt and deal with daily challenges (resilience and coping skills) while leading a fulfilling life. Hence, there is an emphasis on the behavioural and emotional strengths of children, as well as how they respond to adversity. Many of the characteristics or attributes of social and emotional wellbeing follow a developmental pathway, and age-appropriateness is therefore a key factor in measurement (Denham et al. 2009; Humphrey et al. 2010). Cultural background is also an important consideration in measurement, due to

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<sup>6</sup> <http://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response>

differences in social norms and values between cultural groups (Hamilton & Redmond 2010) (AIHW 2012:8).

The concepts of coping and resilience are linked to social and emotional wellbeing as elements contributing to carers' wellbeing. The concept of coping refers to:

'thoughts and acts' that carers bring to solving problems and thereby reducing stress. These coping strategies are usually classified as emotion-focused, and problem-focused; and approach or avoidance (Henwood et al. 2017: 60, based on the research of Lazarus and Folkman 1984).

The idea of resilience refers to 'the capacity to cope, adapt and grow in the face of stress or adversity' (NSW Mental Health Commission, 2014:10). It is a term used in many disciplines and a comprehensive definition refers to resources, as well as individual responses, across the life course:

Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary (Windle 2011: 163).

One study identified the following characteristics of resilient carers:

- [stay] positive in the face of care demands and actively maintain and preserves their relationship and loved one's former self.
- have access to and use services such as respite care and may actively engage with innovative schemes that aim to 'give back' to others in similar situations.
- are knowledgeable and well supported by family but especially friends, with whom they share this knowledge
- [have] support group friends [who] share emotional and practical advice and reassurance that may help the carer manage their role better. (Donnellan, Bennett, & Soulsby, 2015: 938 in Henwood 2017:63).

The Social Care Institute for Excellence (2015:5) outlines nine elements of wellbeing: 'personal dignity; physical and mental health and emotional wellbeing; protection from abuse or neglect; control by the individual over their day-to-day life; participation in work, education, training or recreation; social and economic wellbeing; domestic, family and personal domains; suitability of the individual's accommodation; and the individual's contribution to society' in their guidance around eligibility determination in the UK Care Act 2014 legislation. The range of descriptions of social and emotional needs and wellbeing highlight the broad range of components that support carers' social and emotional wellbeing.

In Australia, the concept of social and emotional wellbeing has also been employed in the *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023* to outline a broad concept of wellbeing:

In broad terms, social and emotional wellbeing is the foundation for physical and mental health for Aboriginal and Torres Strait Islander peoples. It is a holistic concept which results from a network of relationships between individuals, family, kin and community. It also recognises the importance of connection to land, culture, spirituality and ancestry, and how these affect the individual.

... a model of social and emotional wellbeing with seven overlapping domains is proposed including: body; mind and emotions; family and kin; community; culture; country; and spirituality and ancestors (Commonwealth of Australia, 2017:12).

Day and Francisco note that this broad concept of social and emotional wellbeing can encompass the range of adverse experiences that may affect people from Aboriginal and Torres Strait Islander cultural backgrounds and has been measured in studies examining 'psychological distress, impact of psychological distress, life stressors, discrimination, anger, removal from natural family, cultural identification and positive wellbeing' (2013: 351).

## 2.2 Assessing social and emotional wellbeing outcomes

In the intervention literature, a wide range of concepts and systems of classification are used in the assessment of carers' social and emotional wellbeing outcomes. For example, Thomas et al. (2017) broadly group outcome measures as follows:

<b>Broad outcomes</b>	<b>Specific outcomes</b>
Mental health, psychological wellbeing	Depression, anxiety, self-efficacy, psychological distress, caregiver distress, grief, pre and post-bereavement outcomes, insomnia, social dysfunction, somatic symptoms, mood
Carer burden and stress	Burden, stress and strain, stress and burden, perceived stress, stress or distress, caregiver burden, pre-bereavement burden, family burden
Coping	Coping skills, coping strategies (including problem-solving and reduction of ineffective coping, such as avoidance and denial), caregiving competence; perceived affective and confidant support, ability to achieve previously set objectives; confidence in caregiving skills; and control of worry, loneliness and reliance on support systems
Wellbeing and Quality of life	Quality of life, social isolation, social support needs, caregiving experience, sleep quality, marital-family relationships, social functioning and ability to perform activities of daily living, positive aspects of caregiving
Satisfaction	Carer satisfaction, satisfaction with care, evaluation satisfaction, intervention satisfaction, pre and post-bereavement satisfaction with care, satisfaction with services

Many measures that have been used to assess the social and emotional wellbeing of carers are standard tools to assess anxiety, stress, or depression in the general population and thus provide a basis for comparison between carers and non-carers, as well as before and after interventions. Australian and international research also contains measures that have been developed specifically to assess carers' needs and wellbeing, which explore specific domains. Examples include:

- Carers Star™
- Carer's Assessment of Satisfaction Index
- Carer's Assessment of Managing Index
- Carer Well-Being and Support Questionnaire
- Carer Well-being Scale
- Positive Aspects of Caregiving
- Positive and Negative Outcomes of Caring Scales Young carers (PANOC-Y20)

(Henwood et al. 2017; Cunningham et al. 2018; Dow et al. 2018; Carers NSW 2018; DSS 2018; Becker et al. 2008).

Further examples of some of the measures used to assess outcomes in the table above are listed in Appendix B.

## 3 Issues and concerns

### 3.1 Effects of caring

Australian and international research has documented the positive and negative aspects of caring and identified mixed effects. Studies have found that carers report positive aspects of caring, such as companionship, fulfilment, enjoyment and satisfaction, as well as the negative effects on psychological health, such as depression, anxiety and burden (Bauer and Souza-Poza 2015; Brimblecombe et al. 2018).

A key study in Australia in 2007 identified carers as having ‘the lowest collective wellbeing of any group we have yet identified’ (Cummins et al. 2007:vi)<sup>7</sup>. This study used the *Personal Wellbeing Index (PWI)* to assess carer wellbeing across ‘seven aspects of personal life – health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security’ (Cummins et al. 2007:vi). The finding of relatively low wellbeing among carers using this measure has been confirmed in recent surveys of carers conducted by Carers NSW in 2014, 2016 and 2018 (Carers NSW, 2014, 2016a, 2016b and 2018)<sup>8</sup>. In 2018, carers living in NSW responding to this survey reported the lowest level of wellbeing for the domains of health, achieving in life and future security (Carers NSW 2018a).

The most comprehensive nationally representative survey of carers in Australia is the Australian Bureau of Statistics’ (ABS) *Survey of Disability, Ageing and Carers (SDAC)*. The SDAC contains an assessment of psychological distress using the Kessler 10 (K10) measure. Compared to non-carers, carers were more likely to report high and very high levels of distress (Carers NSW 2018a:29). Based on the SDAC data for 2015, one in four (26.5%) primary carers had ‘high or very high levels of psychological distress’ (ABS, 2015 in Broady and Aggar 2017:5).

The SDAC also contains data on the effect of the caring role on the emotional wellbeing of primary carers<sup>9</sup>. Nearly three quarters of primary carers (72.2%) reported that they were not satisfied due to the caring role (ABS 2014: Table 24). Around one in ten (11.2%) carers frequently felt angry or resentful due to the caring role or had been diagnosed with a stress-related illness due to the caring role

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<sup>7</sup> Carers in this study were recruited through Carers Associations member databases and may not be representative of the general carer population.

<sup>8</sup> It should be noted that the Carers NSW surveys are ‘not representative of the wider NSW carer population’.... The surveys use convenience sampling and are ‘likely to over-represent carers who identify as carers and already have contacts with supports and service’ (Carers NSW 2018a:9).

<sup>9</sup> The ABS defines a primary carer as: ‘a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities, with one or more of the core activities of mobility, self-care or communication’.

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4436.0Glossary12012?opendocument&tabname=Notes&prodno=4436.0&issue=2012&num=&view=>

(10.3%) (ABS 2014: Table 24). Just over one quarter of primary carers reported that they had their sleep interrupted frequently (25.3%) or frequently felt worried or depressed (27%), and around one third (35.6%) frequently felt weary or lacked energy due to the caring role (ABS 2014: Table 24). Women who were primary carers reported higher rates on all negative effects of caring on psychological wellbeing than male primary carers (ABS 2014: Table 24). Among male and female carers, those caring for longer hours (40 or more hours per week) also reported more negative effects (ABS 2014: Table 24). Co-resident primary carers, caring for people with profound core activity limitations or for care recipients aged under 15 years also generally reported relatively high rates of negative effects (ABS 2014: Tables 26 and 27).

The Australian Longitudinal Study of Women's Health (ALSWH) is a nationally representative study that records a broad range of health data for three cohorts of women. For the two younger cohorts (born between 1946-51 and 1973-78), the data generally shows that carers living with the person they cared for had higher levels of perceived stress, anxiety and depression than other carers and non-carers (Tooth et al. 2018). In contrast, no significant differences between carers and non-carers on the measures of anxiety and depression were noted for the older cohort born between 1921-26 (Tooth et al. 2018). The ALSWH data also showed that co-resident carers in the younger cohorts had more visits to GPs and higher numbers of prescriptions filled than other carers and non-carers (Tooth et al. 2018).

Surveys of carers conducted by carers organisations in Australia have described isolation and emotional burden, with up to half of carers surveyed believing that their mental health had been negatively affected by caring, and 40% reporting a need for mental health support (Carers NSW 2016a).

International research has also emphasised the impact of caring on carers' psychological wellbeing. In research examining the experiences of people aged 50 years and older in Europe, carers were found to have poorer mental health than non-caregivers and the effect was greater for older and retired carers (Hiel et al. 2015). A survey by Carers UK found 72% of carers reported that they had suffered mental ill health as a result of caring (Carers UK 2018). In Europe, carer advocacy organisations have highlighted that:

The psychological burden on carers is immense; carers must deal with financial pressures as well as the burden of new diagnoses of those they are caring for. This can lead to anticipatory grief and stress, amongst other psychological issues (European Cancer Patient Coalition and Eurocarers, 2017:9).

The impact of caring on carers' mental health may be particularly acute for some carers. A study examining the ALSWH data identified that middle-aged female carers were slightly more likely than their non-carer peers (7.1% vs 5.7%) to report that in the last week they had felt that life was not worth living (O'Dwyer et al. 2014). Carers reporting suicidal thoughts scored lower on a range of psychosocial variables

and multivariate models identified that 'social support, mental health, carer satisfaction and depression' were factors significantly associated with reporting suicidal thoughts (O'Dwyer et al. 2014: 377). The authors suggest that future research could explore the factors that contribute to carer dissatisfaction, as one 'potentially modifiable risk factor', and could also examine this issue for male carers (O'Dwyer et al. 2014: 378).

As well as mental and psychological health issues, numerous studies have identified negative impacts and changing aspects for carers' social needs and social wellbeing, such as relationships and social networks (Keating and Eales, 2017), social exclusion (Greenwood et al. 2018) and social participation (Nay et al. 2015).

Carer organisation surveys have identified that higher scores on social support are associated with better outcomes for wellbeing and psychological distress and the identification of more positive aspects of caregiving (Carers NSW 2016b). Changes in relationships for carers may reduce that social support. In Australia, around one third (35%) of primary carers reported that they had lost touch or changed their circle of friends, a similar proportion (34%) indicated that family relationships had become strained or lacking in time together, and nearly one in five (18%) carers reported strains in the relationship with people they cared for (ABS 2008: 39). A UK carer organisation survey found that over half (53%) of the carers were concerned about the impact of caring on their relationship with the person they care for, and 61% were worried about the impact their caring role would have on relationships with friends/family over the next year (Carers UK 2015c).

UK research has highlighted issues of social isolation and loneliness. Carers responding to carer organisation surveys in the UK indicated that 83% felt lonely or socially isolated as a result of their caring responsibilities and 57% lost touch with friends and family (Carers UK 2015b). Among older carers, only one in four (24%) reported that they are able to spend their time as they want and 61% do not have time to do enough of the things they enjoy (Carers UK 2015a). Carers who reported that they had reached breaking point as a result of caring were twice as likely as other carers to say that they were socially isolated due to being unable to leave the house and were more likely to have experienced depression as a result of caring (Carers UK 2015b).

Reasons for loneliness among carers included:

- not being comfortable talking about caring with their friends (32%)
  - not having time to spend on social activities (48%)
  - not being able to afford to participate in social activities (31%)
  - not being able to get out of the house much (49%)
- (Carers UK 2017).

Social isolation and social exclusion can also occur as a result of a lack of understanding and stigma related to the illness of the person being cared for, such

as dementia, HIV/AIDS, mental illness and intellectual disabilities (Keating and Eales 2017; Greenwood et al. 2018).

## **3.2 Effects of caring over time**

Studies examining longitudinal data have also examined the effects of caring over time on carers' mental health. In Australia, carers' mental health declined over time if they cared for long hours, with women who combined high levels of care (over 20 hours per week) with employment experiencing significant declines after 2 years, and men with high level care roles experiencing mental health declines after 4 years (Kenny et al. 2014). In the UK, women who were long-term (more than three years) or intermittent carers had small increases in levels of psychological distress compared to women who were not carers, but no effect was found for men (Lacey et al. 2018). In a study of 10 European countries, (including countries with different types of support services, such as Sweden and Spain), carers reported more depressive symptoms than non-carers, and co-resident carers experienced a decline in their mental health after taking on the caring role across most countries in the analysis (Kaschowitz and Brandt 2017).

## **3.3 Specific concerns: groups and risk factors**

Research has also examined which groups of carers may be most affected by caring. In Australia, carer organisation surveys have highlighted that groups at greatest risk of poor wellbeing as measured by the PWI and the K10 include: carers with a long-term illness or disability themselves, those who had been caring for longer, those providing more hours of care per week, female carers, younger carers, those receiving government financial assistance, Aboriginal and Torres Strait Islander carers, and those living outside Greater Sydney (Carers NSW 2016a). Carers from CALD backgrounds reported higher levels of psychological distress and less social support, but also more positive aspects of caring (Carers NSW 2014).

Young carers aged up to 25 years face specific issues relating to their social and emotional needs and wellbeing. Many young carers support parents who have an illness or disability. They may experience worry and suppress the expression of their own needs as a result of the changes in their family life stemming from the illness or disability; they may experience anxiety, guilt, shame and embarrassment, and effects on their social and school lives (Chikhradze et al. 2017). Stigma, bullying and harassment can be a particular problem for young carers at school and among their peers (Chikhradze et al. 2017). Young carers are also likely to take on more practical tasks around the house than their non-carer peers, such as cooking, cleaning and looking after younger siblings (Cass et al. 2011). Data from the ABS *Census of Population and Housing* show that young carers report that they spend more time compared to non-carers their age in domestic tasks (Cass et al. 2011). While young carers report a range of positive experiences of caring, such as pride, satisfaction, skills and a sense of perspective, their caring role also impacts on their

use of time, social activities and their own physical and mental health (Cass et al. 2011).

Research about social and emotional wellbeing in the general population of Aboriginal and Torres Strait Islander peoples provides a context for understanding the wellbeing of carers in these communities. Day and Francisco report findings from the National Aboriginal and Torres Strait Islander Health Survey 2004-05 which show that just over 'one quarter (27%) of the sample Aboriginal and Torres Strait Islander adults reported experiencing high levels of psychological distress' (2013:351). Findings on other aspects of wellbeing showed that:

- four in 10 people reported they had experienced, or knew someone who had experienced, the death of a family member or friend in the last year;
- nearly one-third (28%) reported serious illness or disability;
- one-fifth (20%) reported alcohol-related issues (Day and Francisco 2013:351).

Day and Francisco (2013) also note that research in Australia has shown that:

- life expectancy was seventeen years shorter than for non-Indigenous Australians; and
- despite poorer health, Aboriginal and Torres Strait Islander adults were unlikely to seek healthcare due to factors including, but not limited to, cost, transport, cultural barriers and lack of services.

One study identified social disadvantages stemming from marginalisation and discrimination from colonisation as some of the underlying causes of the rates of psychological distress for Aboriginal and Torres Strait Islander peoples being double that of non-Indigenous peoples (McNamara et al. 2018). A study of carers of Aboriginal children with a disability highlighted psychological stress generated by behavioural problems amidst other stressors and the experiences of 'sleep deprivation, worry, frustration, anger, and grief' and negative impacts on relationships and social participation (di Giancomo et al. 2017:4-7).

Internationally, studies have highlighted different effects for some groups of carers:

- Older carers were more likely than older non-carers to report feeling anxious or depressed, especially if they were providing high levels of care (Carers UK 2015a).
- Male carers were 1.6 times more likely to have lower quality of life than female carers in Ireland (Care Alliance Ireland 2015).
- An increase in depressive symptoms was found among married men and women and single men aged 50-64 years caring for mothers (but not single women) in the USA (Coe and Van Houtven 2009).
- Higher levels of care (more than 10 hours per week) were associated with negative effects on mental health and higher psychiatric symptom scores (Smith et al. 2014).

Factors affecting the social and emotional wellbeing of carers identified in the literature include:

- The quality of relationships between carer and person cared for have a significant impact on the experience of caregiving burden and caregiver satisfaction and was greater than the 'objective difficulty or severity of caring demands' (Iecovich 2011 in Henwood et al. 2017). The relationship can also be affected by the motivation of carers (Kaschowitz and Brandt 2017).
- Respite care can reduce the feeling of burden through allowing carers to connect with their other identities (De la Cuesta-Benjumea, 2011 in Henwood et al. 2017).
- An external rather than internal Locus of Control for carers can increase carer burden (Bruvik, Ulstein, Ranhoff, & Engedal, 2013 in Henwood et al. 2017).
- Financial resources can have an impact as carers are more likely to be in receipt of income support and have lower levels of income than non-carers (ABS 2016: Table 36.3). Research by carer organisations also indicates that carers in receipt of income support have lower wellbeing as measured by the PWI (Carers NSW 2016b). While further research is required on the impact of financial stress on carers' social and emotional wellbeing, research has shown that carers were more likely to report financial disadvantage than non-carers on a range of measures that identified relatively low income, relatively high housing costs, perceptions of oneself as poor and financial stress (Hill et al. 2011). Carers who had been caring for two years rather than one year were also more likely to perceive themselves as poor (Hill et al. 2011).

### **3.4 Supports for carers**

To support their social and emotional wellbeing, carers reported needs for more information and accessible, affordable services providing practical and emotional support (Carers NSW 2016a, 2016b; Care Alliance Ireland 2015; National Alliance for Caregiving 2015; Carers UK 2015b, 2017).

In Australia, the introduction of new systems of individually funded support packages for aged and disability care, and the new model for carer support, has changed the landscape for the delivery of support services. As noted above, services with a specific focus on carers' needs commenced in October 2018 through the Carers Gateway, with the full roll-out of the Integrated Carer Support Service (ICSS) in 2019. The ICSS will focus on providing carers with 'early-intervention, prevention and skill building supports to improve carers' well-being and long-term outcomes'<sup>10</sup>, and includes some practical support.

Research by carer organisations has reported on the experiences of carers in the transition to the NDIS and My Aged Care. Some carers have reported that accessing aged care and disability services for the person they care for has had positive outcomes for their wellbeing. In the carer organisation surveys, most carers

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<sup>10</sup> <https://www.dss.gov.au/disability-and-carers/carers/integrated-carer-support-service-model>

engaging with aged care services have indicated that they were included in decision making in the process of accessing services, but less than half (43%) reported that their needs were part of the conversation (Carers NSW 2018a). Some carers indicated that the service provided had enabled them to take a break (51%) or look after their own health (40%) (Carers NSW 2018a). The NDIS commenced its full roll-out in 2016. Recent surveys of carers have indicated that most (72%) were included in the planning process, but only 38% were asked about their own needs, 40% felt the NDIS services enabled them to take a break, and 30% agreed that the services enabled them to look after their own health (Carers NSW 2018a). In other situations, however, older people and people with disability and their carers may be missing out on support services due to eligibility criteria, delays in receiving packages and lack of appropriate support to access a package and lack of an adequate package of support (Carers NSW 2018b). The extent to which the new service systems are meeting the needs of, and improving the wellbeing of, carers and the people they care for, needs to be monitored over time.

# 4 What works to support carers' social and emotional wellbeing?

## 4.1 Overview

A number of broad reviews of carer support interventions have provided the basis for identifying key issues when assessing the evidence about what works to support carers' social and emotional wellbeing (Victor 2009; Parker et al. 2010; Gilhooly et al. 2016; Thomas et al. 2017; Broady and Aggar 2017; Brimblecombe et al. 2018; Dalton et al. 2018; Zarit 2018). The evidence discussed below primarily draws on these reviews and more recent rigorous reviews that focus on specific types of interventions. Where relevant, findings from grey literature studies have also been included.

The majority of reviews focus on interventions aimed at carers of different care recipient conditions rather than the characteristics of carers. The reviews have different ways of categorising and classifying interventions with some focusing on different types of outcomes (mental health, coping, depression anxiety) and others on the types of interventions (e.g. respite and technological). This review provides a summary of some of the key findings by type of intervention classified under the headings below. It should be noted that interventions are not consistently classified across all studies and often contain multiple components across these categories.

- Respite care/replacement care
- Education and training and psychoeducation
- Counselling/psychosocial interventions/therapy
- Support groups
- Practical help in the home
- Physical exercise
- Technological interventions

Many reviews emphasised the diversity of carers' situations and outcomes in the studies and that there is no "one size fits all" approach (Thomas et al. 2017). As will be discussed further below, a number of reviews argued for adaptable multicomponent interventions comprising combinations of approaches and tailored to the carers' needs (Gilhooly et al. 2016; Broady and Aggar 2017; Thomas et al. 2017; Brimblecombe et al. 2018; Dalton et al. 2018; Zarit 2018). It should be noted that the time constraints of a rapid literature review mean that there will inevitably be gaps in the comprehensiveness of studies selected in each area and some important programs and studies may not be included if they have not yet been part of a major review.

## 4.2 Respite care/replacement care

The aim of respite care is to provide alternative care so that carers can have a break from their caring role, which in turn may reduce stress associated with caregiving (Maayan et al. 2014). Respite care should also provide a 'positive and meaningful experience' for the person being cared for (ADHC 2011:3). Studies have found that carers report satisfaction with respite and that it enables them to get a rest and engage in other activities, including social activities (Victor 2009; Henwood et al. 2017; Thomas et al. 2017; Brimblecombe et al. 2018). Studies have identified mixed effects for different types of respite care for carers of people with dementia, with evidence of reductions in carer burden and social isolation for day care centres and reductions in caregiver burden for residential respite (Tretteteig et al. 2016; Vandepitte et al. 2016). However, negative effects, such as greater stress after the respite period, were also identified (Vandepitte et al. 2016; Broady and Aggar 2017). Key factors in the use of respite were quality and flexibility (Tretteteig et al. 2016; Broady and Aggar 2017). A study of respite care for parents with children with Autism Spectrum Disorder also found both positive and negative effects on stress and suggested that accessibility, adequacy and quality of respite services may be factors affecting carers' outcomes (Whitmore 2016). Further research is needed on the effectiveness of in-home and community respite (Vandepitte et al. 2016).

Overall, many reviews have commented on the 'paradox' of the evidence of carer satisfaction but lack of evidence of improved social and emotional wellbeing outcomes in relation to respite care (e.g. Thomas et al. 2017; Brimblecombe et al. 2018). In reviewing the evidence, researchers have called for better quality studies that use both qualitative and quantitative methods (Thomas et al. 2017; Dalton et al. 2018; Brimblecombe et al. 2018). The evidence about the effect of respite on social and emotional wellbeing is thus inconclusive and further high-quality research is needed (Parker et al. 2010; Maayan et al. 2014; Thomas et al. 2017; Brimblecombe et al. 2018). Carers in Australia consistently report that they would like to access more respite services suggesting that they perceive benefits (Carers NSW 2016b). Findings from a broad consultation about respite services across NSW indicated that key principles underpinning good respite included that: the services are person-centred, promote self-determination in decision making, are flexible to meet changing needs, focus on early intervention, responsive to needs of the carer and the person with disability, are age appropriate and are provided in ways that are culturally competent (ADHC 2011:3-4).

## 4.3 Education and training and psychoeducation

Education and training programs can assist carers' social and emotional wellbeing through the provision of skills and information to assist them in managing their caring role (Victor 2009). One review found that educational interventions that focused on teaching skills relevant to dementia carers had moderate effects on reducing burden for carers of people with dementia and a small effect on depression

(Jensen et al. 2015; Thomas et al. 2017; Dalton et al. 2018; Brimblecombe et al. 2018). Interdisciplinary education combined with support was also found to be effective in reducing carer burden for carers of people with dementia (Marim et al. 2013; in Thomas et al. 2017; Dalton et al. 2018). A systematic review of educational interventions that provided information on the progression of the disease for carers of people with dementia found evidence that these interventions may improve knowledge, and reduce depression, carer burden and stress (Lee et al. 2017). Evaluated interventions for education and training related to manual handling were not identified in this literature review, although a need for such support has been identified in the Australian context (e.g. Thomas et al. 2016), and specific programs may have been implemented and evaluated but are not yet part of systematic reviews.

The term 'psychoeducation' encompasses a wide range of interventions in the literature, often combining education with 'the development of problem-solving coping strategies' (Gilhooly et al. 2016:6). A review examining a range of such interventions found that psychoeducational elements were effective in improving psychological wellbeing for carers (Gilhooly et al. 2016). Effectiveness in improving carer wellbeing was also found in family psychoeducational programs for carers of people with major depressive illness, comprising information, 'problem solving, communication and coping skills and enhancement of social support' (Brady et al. 2017:245). Results for effectiveness were, however, mixed with another review, which found no effects of psychoeducation on the wellbeing of siblings caring for people with mental illness (Sin et al. 2015). Broady and Aggar's (2017) review of studies also concluded that the evidence for psychoeducation is 'somewhat inconclusive' but noted that studies had indicated that such approaches were able to be developed and tailored for specific cultural groups (Chua and Pachana 2016, in Broady and Aggar 2017).

#### **4.4 Counselling/ psychosocial interventions/therapy**

Counselling and psychosocial interventions encompass multiple approaches to providing carer support that operate through a range of mechanisms including 'the provision of information; development of coping skills, stress management and relaxation techniques; emotional processes such as having the chance to express oneself and to feel valued; and the exchange of social support' (Victor 2009:7). Counselling can be delivered through different methods and modalities, such as Cognitive Behavioural Therapy (CBT), strengths-based approaches and mindfulness programs (Carers NSW 2017). Cognitive reframing, as one component of CBT was found to be effective as part of individualised multicomponent interventions in reducing anxiety, depression and stress in carers (Vernooij-Dassen et al. 2011 in Thomas et al. 2017:57; Piersol et al. 2017; Dalton et al. 2018). A number of primary studies have reported positive effects of CBT and that it can be helpful for carers from culturally and linguistically diverse backgrounds (Carers NSW 2017). However, a review of studies of carers of cancer patients found 'negligible'

effects of CBT on mastery, psychological wellbeing, interpersonal wellbeing or quality of life (O'Toole et al. 2017:434).

Mindfulness approaches employ practice in 'nonjudgmental, moment-to-moment awareness, and attention in the present moment, with acceptance and nonreactive responses to current thoughts and emotions' (Rayan and Ahmad 2017:324). Reviews have found some evidence that mindfulness-based interventions (MBIs) reduced parenting and psychological distress for parents of children with disabilities (Rayan and Ahmad 2017); improved carer mental health and reduced stress and burden for carers of people with Alzheimer's disease and related major neurocognitive disorders (Piersol et al. 2017); reduced depression, perceived stress and improved mental health quality of life for carers of people with dementia, but had no effect on carer burden or anxiety (Liu et al. 2017); and reduced stress, depression and anxiety for carers of people with various conditions (Li et al. 2016). Another review by Jaffray et al. (2016) for effectiveness of mindfulness for informal palliative caregivers did not find as robust effects but did report some reductions in depression and caregiver burden as well as increased quality of life.

Psychosocial interventions 'address the development of emotion-focused coping strategies' (Gilhooly et al. 2016:6). Effectiveness for psychosocial interventions was reported for improving carers' psychological wellbeing (Gilhooly et al. 2016) and quality of life (Waldron et al. 2013 in Thomas et al. 2017; Dalton et al. 2018), and reduced psychological distress for a couples-based intervention (Regan 2012 in Thomas et al. 2017; Dalton et al. 2018). Computer-mediated psychosocial interventions were also found to reduce anxiety, burden and stress, and depression for dementia carers (McKechnie et al. 2014). Mixed evidence was found for psychosocial interventions in a review by Dickinson et al. (2017:31), who indicated that the most effective interventions contained both 'an educational component and a therapeutic component'.

More broadly the meta-review by Thomas et al. 2017 (also Dalton et al. 2018) found evidence that:

- Counselling was found to improve quality of life and relationship functioning for carers of people with cancer (Regan et al 2012 in Thomas et al 2017) and family functioning for carers of people who have had strokes (Cheng et al. 2014 in Thomas et al. 2017; Dalton et al. 2018).
- Telephone counselling reduced depression for carers of people with dementia (Lins et al. in Thomas et al. 2017; Dalton et al. 2018).
- Meditation-based interventions reduced depression for carers of people with dementia (Hurley et al. 2014 in Thomas et al. 2017; Dalton et al. 2018).
- Art therapy was beneficial for mental health (anxiety, stress and negative emotions) for carers of people with cancer (Lang and Lim in Thomas et al. 2017; Dalton et al. 2018).

## 4.5 Support groups

Support groups provide a way for carers to interact with other people with similar situations and experiences, share information, discuss problems, share coping strategies and support each other (Worrall et al. 2018). They can be peer led, professionally led or a combination of both and can be face-to-face or conducted via technology, which enables carers to engage from home. The early review by Victor found evidence that support groups contributed to carer 'satisfaction, social support, access to and improved relationships with services, practical support' and relationships (2009:60). A review by Chien et al. (2011) found support groups to be effective in reducing burden and depression for carers of people with dementia (in Thomas et al. 2017; Dalton et al. 2018). In reviewing studies on the effectiveness of support groups for carers and people living with mental illness, Worrall concluded that there was evidence that they contributed to carer wellbeing and highlighted factors such as 'peer leadership, family involvement, professional facilitation or co-facilitation, and the use of manualized programs' as positive components of the programs (2018:91). Parker Oliver et al. (2017) found moderate quality evidence that internet support groups improved social support and self-efficacy but were not able to assess effectiveness with regard to caregiver burden. Lee (2015) reviewed studies of technology-based support groups for dementia carers. They noted issues about attrition from technology-based support groups and the feasibility of technology use for older carers and suggested that technology support could be useful for older carers to enable them to fully participate (Lee 2015).

## 4.6 Practical help in the home

No specific reviews of practical support in the home were identified among the reviews of interventions aimed at improving carers' social and emotional wellbeing identified in the literature search. However, such practical support may be a part of multicomponent interventions. One meta review identified that they did not review studies of 'generic services such as home care' but noted that 'we know from other research, [that] these services can be crucial in maintaining carers' physical and psychological well-being' (Parker et al. 2010:2). UK studies examining the effectiveness of carer assessments have also considered the provision of services as an outcome of these assessments but not the impact of the take-up of services on carers' social and emotional wellbeing, although some studies noted that carers were not satisfied with the services (Victor 2009). The issue of practical help in the home is relevant for all carers but may be very important for young carers caring for parents who are more likely than their peers to live in lone parent, low resource households and take on a greater share of household tasks (Cass et al. 2011).

## 4.7 Physical exercise

Physical activity interventions are based in preventative health approaches that aim to enhance psychological, as well as physical, health through physical exercise (Lambert et al. 2016). Three reviews examined the effect of these interventions on carers' psychosocial outcomes (Loi et al. 2014; Ortega et al. 2014; and Lambert 2016). Limited evidence was found for a program of low to moderate supervised aerobic exercise or endurance training to reduce carer burden for dementia carers (Ortega et al. 2014), and physical activity interventions were found to reduce carer stress, depression and burden for female carers aged 60 and over (Loi et al. 2014). A more extensive review examined the effects of physical activity interventions on both the carer and care recipients and included activities such as yoga, walking, meditation, strength training, stretching, gardening, housework, stair climbing and dancing in group and home-based exercise settings (Lambert et al. 2016). The findings showed that interventions had positive effects on carers' psychological distress, 'wellbeing, quality of life, sleep quality, physical activity levels and self-efficacy for caregiving or exercise and readiness for exercise' (Lambert et al. 2016:907-8). The research to date for these interventions is mainly with small sample sizes and not high quality and so further rigorous evidence would be required to draw conclusion about their effectiveness.

## 4.8 Technological interventions

Brimblecombe et al. (2018) suggest that interventions using technology that could potentially support carers' social and emotional wellbeing can be broadly divided into two groups: those that use assistive technology to support the care recipient (providing reminders, enhancing security and safety, and enabling more independent living) and those that are focused on the carer in the form of information and support provided through technological mechanisms. Carers whose responsibilities make leaving home difficult or who live in rural and regional areas may find that support provided through the phone, internet or a mobile device can reduce social isolation and facilitate support for their caring role (Broady and Aggar 2017).

Few recent reviews of high-quality studies on the effectiveness of assistive technologies that related to the wellbeing of carers were identified. One study found assistive technologies to be effective for parents with children with disabilities in supporting carers in the tasks of mobility, self-care and social functioning and in improving children's emotional states, which in turn affected the carers' psychological wellbeing (Nicholson et al. 2012). A wide range of reviews examined effectiveness of different types of assistive technology for the person being cared for but none reporting on the effects on carer wellbeing were identified. Additional research may be able to locate high-quality single studies of assistive technological interventions and their impact on carers' social and emotional wellbeing.

Numerous recent reviews of the effectiveness of information and communication technological (ICT) interventions on carers' wellbeing have been conducted with positive, although mixed results. A review of web-based health interventions for family caregivers of elderly individuals predominantly targeted at dementia carers, but also including carers of people who had experienced stroke, cancer, diabetes and frailty, found mixed results and reported consistent reductions in carer burden, self-efficacy and depression (Wasilewski et al. 2017). These authors also noted that use of web-based interventions declined over time, which may need to be addressed in future programs. Touchscreen interventions for people with dementia and their carers were found to reduce perceived carer burden and improved relationship quality (Tyack and Camic 2017). Andersson et al. (2017) reviewed a range of information and communication technology interventions for working carers of older family members and found that telecare interventions, focusing on the older person's independence, reduced burden and perceived burden. Web-based interventions with multiple components were found in some cases to reduce carer stress, while a study examining the use of distance communication technology and assistive technology to support the older person's independence found that carers were interrupted less at work and so reduced their work-care stress (Andersson et al. 2017). A review by Ruggiano et al. (2017) of internet-based interventions for dementia carers identified reduced depression and anxiety in some studies but no effects on carer skills or self-efficacy.

Brimblecombe et al. conclude that the reviews of the technological interventions find that 'overall there is some evidence for improved health and wellbeing of carers, again particularly if part of a broader package of services and support' (2018:33). The literature to date also suggests that not all aspects of technological interventions are positive (Brimblecombe et al. 2018) and technological interventions also require that carers have access to technology, the skills to use it effectively and the motivation to engage with it for the duration of an intervention (Zheng et al. 2016 in Broady and Aggar 2017; Wasilewski et al. 2017). Technology was also viewed as potentially being cost effective means for interventions, although few rigorous studies have been conducted (Brimblecombe et al. 2018).

## **4.9 Evidence for “what works”**

A consistent theme in the reviews is that, despite the extensive research in many cases, the overall evidence about effectiveness is inconclusive, and it is not possible to say what definitely works to support carers' social and emotional wellbeing, but it is possible to point towards potentially effective interventions or combinations of interventions and some evidence of positive outcomes (Victor 2009; Parker et al. 2010; Lopez-Hartmann et al. 2012; Piccenna et al. 2014; Gilhooly et al. 2016; Thomas et al. 2017; Broady and Aggar 2017; Brimblecombe et al. 2018; Dalton et al. 2018; Zarit 2018).

A key reason for the inconclusive findings is both the extensiveness and the nature of the available evidence. Concerns identified in the literature included the diversity and incomparability of studies, the quality of the evidence assessed in the reviews and the design and focus of interventions, particularly issues relating to:

- small sample sizes in many of the primary studies (Parker et al. 2010 in Dalton et al. 2018)
- lack of theory-based interventions or a description of explanatory mechanisms for how an intervention might work (Victor 2009; Parker et al. 2010; Thomas et al. 2017; Dalton et al. 2018)
- whether the outcome measures used were the most relevant to the people receiving the intervention (Parker et al. 2010; Dalton et al. 2018:196; Zarit 2018)
- the extent to which interventions actually measure the effects of programs (e.g. whether carers do apply the skills they have learnt and whether this results in decreased problems and lower stress (Zarit 2018))
- study designs: whether it is possible to define a good control or comparison group given the diversity of carers' situations (Thomas et al. 2017; Dalton et al. 2018)
- the challenge of attributing changes in outcomes to one aspect of the intervention in multicomponent interventions (Thomas et al. 2017; Dalton et al. 2018)
- the time period of interventions and evaluations: whether the intervention itself is designed for long-term support and assesses the effects over time at the initial phase of intervention and some follow-up point (Zarit 2018)
- the lack of analysis of the cost effectiveness of interventions (Victor 2009; Parker et al. 2010; Thomas et al. 2017; Dalton et al. 2018; Brimblecombe et al. 2018).

Most interventions have focused on outcomes for carers grouped by the condition of the care recipients, with fewer looking at groups based on the characteristics of carers themselves. Some have focused on outcomes for the carer dyad - both the carer and the person being cared for (Thomas et al. 2017) and others have considered the relationships between carers and formal care workers or health professionals.

Carers consulted about the review of the intervention research by Thomas et al. (2017) noted that:

carers of people with different conditions experience different caring experiences and trajectories. Thus, what might be useful and effective for one sort of carer might not be useful or effective for another. Similarly, what might be useful and effective at one stage in the trajectory might not be useful or effective at another stage...

... variations in caring situations and across carers made it difficult to see that a single intervention could be the 'answer' in supporting carers. Rather, as one put it, 'because of the complexities of the situations there is unlikely to be a one size fits all that will be right at any one time'... a 'pick-and-mix' approach, whereby various support options were on offer, would be the ideal. (Thomas et al. 2017: xxv/74)

These views of carers reflect the views of researchers that interventions offering a range of components that could be used at different points in time may be beneficial (Gilhooly et al. 2016; Broady and Aggar 2017; Thomas et al. 2017; Dalton et al. 2018; Brimblecombe et al. 2018; Zarit 2018).

Other important themes in the research on the effectiveness of carer support refer to the availability, accessibility and comprehensiveness of support and whether it reflects what carers want (Thomas et al. 2017; Carers NSW 2014, 2016a in Broady and Aggar 2017). The research shows that carers also strongly value support for the person being cared for (Thomas et al. 2017; Broady and Aggar 2017; Zarit 2018). It is suggested that in designing interventions to support carers' social and emotional wellbeing, it is important to:

...go back to basics by having discussions with caregivers about what they need and want. We have incorporated person-centered perspectives in our views of individuals with dementia and other health problems. We ought to take similar approaches with family caregivers.

This effort should involve more than a checklist in order to capture a full range of possible responses. Caregivers need to be engaged in a conversation that gives them the opportunity to reflect on their circumstances (Zarit 2018:719).

While the research highlights some interventions that have the potential to be effective, it also cautions that more good quality research is needed to confirm effectiveness. It has been noted that carers often report satisfaction with interventions but that there is less robust evidence of changes in outcomes for carers' social and emotional wellbeing (Kavaliertatos et al. 2016 in Broady and Aggar), particularly in relation to respite (Victor 2009; Thomas et al. 2017).

# 5 Evidence and issues for carer cohorts

## 5.1 Young carers

To date, no systematic or meta reviews have been identified that focused explicitly on evaluations of effectiveness of interventions for all young carers' social and emotional wellbeing, although they may have participated in other interventions targeted at carers of people with specific conditions. One recent review of individual-level interventions focusing on the mental health and wellbeing of vulnerable adolescents aged 10-24 years found no rigorous evaluations of studies on young carers (Vojt et al. 2018). One review focused on the effectiveness of psychoeducation for siblings of people with severe mental illness but did not find sufficient evidence to draw conclusions (Sin et al. 2015).

Research has discussed the needs and outcomes for young people caring for parents with a mental illness (Reupert and Maybery 2016). These studies have identified a range of needs for these young carers including: positive emotional connection with the family; respite for children who provide care; support and recognition from family, schools and health professionals; information and knowledge about their parent's illness; 'open and honest communication' with their families; 'opportunities for emotional expression'; peer support and support from networks; and crisis plans (Reupert and Maybery 2016:103-4). One review of community-based interventions of children caring for parents with a serious mental illness found that the 'evidence was lacking' for clinical effectiveness of interventions and recommended that better quality research needed to be undertaken, including child-centred intervention design and outcome measures (Bee et al. 2014: viii). Other studies have highlighted single evaluations rather than a broad review of evidence. One Dutch study reported on an evaluation of an expert facilitated peer support program for children aged 8-12 years and found effects for reducing negative cognitions and seeking social support (van Santvoort et al. 2014). Other interventions have targeted the parent or the whole family using CBT or skill building through coaching (Reupert and Maybery 2016). Researchers have also called for more 'culturally sensitive and/or targeted interventions' in this field (Reupert and Maybery 2016:108).

No rigorous reviews were identified that looked at services for young carers more broadly, which may assist young carers who have additional household responsibilities. More generally, studies have looked at the aims of services designed to support young carers. An Australian study outlined a framework to assess the goals of services, their effectiveness and the extent to which they were focused on 'assisting young people who provide care; mitigating the care-giving responsibility; and preventing the entrenchment of a young person's caring role' (Purcal et al. 2012: 788). This study highlighted key elements of a preventative approach that included:

- age appropriate, flexible services tailored to individual and family needs
- inter-agency co-operation and coordination to streamline referrals
- a key worker or case management approach to develop trust over time and maintain communication
- a whole-of-school approach to recognize the needs of the young person
- a whole-of-health-services approach to identify and support young carers, [which] needs to occur in a very timely manner to provide health or disability services to the family member requiring them
- a whole-of-family approach, where young carers are supported in the context of the family but their need for time away from the family is also recognised (Purcal et al. 2012: 802).

## 5.2 Carers aged 25 to 60 years

Carers of working age encompass a diverse range of carers who are caring for children with disability, their spouses and/or their parents. The different types of carers will be likely to have different needs, which will also be affected by the specific condition of the person receiving care. Many of the findings discussed in Section 4 about the various interventions that are effective for different groups of carers will have direct relevance to the support that carers in this age group may find effective to maintain their social and emotional wellbeing.

Specific concerns that were not so comprehensively addressed in the literature discussed in this review relate to parents of children with disability, ‘sandwich carers’ (carers caring for children and their ageing parents), and the effects of balancing work and care on social and emotional wellbeing.

Carers caring for children under 15 years of age reported relatively high levels of negative effects of caring on emotional wellbeing in the SDAC (ABS 2014). A number of reviews focused on the needs of parents with children with disabilities (e.g. Whitmore 2016; Rosenberg et al. 2013; Lindo 2015). Such interventions sometimes incorporated parenting skills as components of the intervention.

Carers in this age group are also negotiating employment and care roles. Carers have been found to report higher work-to-life interference than people with no care responsibilities (Carers NSW 2016b), which may impact on their social and emotional wellbeing. The evidence suggests that some technological interventions that foster the independence of the person cared for can reduce the burden and stresses of managing work and care (Andersson et al. 2017). A study in the UK also suggested that services to support carers, including home care, personal assistants, day care, meals, and short-term breaks, are associated with carers remaining employed (Pickard et al. 2018). This study found that receipt of services enabled carers to feel less anxious about the person being cared for while they were at work due to the replacement care and receiving help with practical tasks also enabled them to continue to remain in employment (Pickard et al. 2018).

## 5.3 Older carers

Older carers are often caring for spouses and adult children. Milne and Hatzidimitriadou highlight that older carers are likely to provide care ‘within the context of a long-term relationship ... and having health problems of their own’ (2003 in Henwood et al 2017: 39) and are likely to be caring for people with ‘more complex health needs’ (Henwood et al 2017: 41). Such factors may impact on their social and emotional wellbeing. Social isolation and the impact of changes in relationship between spouses can be key issues affecting older carers (Henwood et al. 2017). It is suggested that older carers are ‘relatively invisible in both research and policy (Henwood et al. 2017:39).

No systematic or meta reviews that specifically focused on older carers were identified, although many of the reviews on effectiveness of support for dementia, cancer and palliative carers would be relevant to carers in this age group. Thomas et al. (2017) outline a wide range of effective interventions for addressing anxiety, burden, stress and depression in carers of people with dementia and cancer: cognitive reframing, psychosocial interventions, education interventions, support groups, meditation-based interventions, art therapy and counselling. The development of technological interventions requires that older carers are supported to develop digital literacy to be able to engage with technology, if it is to provide effective support.

Studies have examined issues for parent carers of adult children with intellectual disability and mental health issues. These studies have identified issues such as ‘perpetual parenting’ and ‘futures planning’ that may have effects on older carers’ wellbeing (Walker and Hutchinson 2017, 2018). More research is required on what is effective to support the social and emotional wellbeing of older carers who are caring for adult children.

## 5.4 Culturally and linguistically diverse (CALD) carers

Carers from culturally and linguistically diverse (CALD) backgrounds have been identified as a group reporting relatively high levels of psychological distress and lower levels of social support, but also more positive aspects of caring (Carers NSW 2016b). Carers within this group come from diverse and heterogeneous communities and may have different social and emotional needs that are specific to their cultural context. Research suggests that key issues to address are information gaps, language barriers and digital literacy to facilitate access to appropriate information and support, working with communities to develop solutions (Rees and McCallum 2018) and addressing the ‘barriers created by implicit and explicit racism and prejudice’ (Katbamna et al. 2002 in Henwood et al. 2017:44).

Reviews identified in this study have mainly focused on the issues and needs of specific groups of carers and the people they care for from CALD, ethnically diverse or minority backgrounds. No reviews were identified that specifically focused on the effectiveness of interventions to support these carers' social and emotional wellbeing, although some of the reviews discussed in Section 4 may have included primary studies with carers from diverse cultural backgrounds. Psychoeducational and counselling intervention approaches were identified as being adaptable to different cultural groups (Chua and Pachana, 2016 in Broady and Aggar 2017; Carers NSW 2017).

## 5.5 Aboriginal and Torres Strait Islander carers

No systematic reviews of interventions to support the social and emotional wellbeing of Aboriginal and Torres Strait Islander carers were identified. One study conducted a systematic review of psychosocial interventions to improve the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples generally (Day and Francisco 2013). The study found that there were only a small number of programs that have been evaluated and met standard criteria for a systematic review and that these reported positive outcomes. The authors suggest that it is important to not only consider the evidence that exists about program outcomes, but also understand how and why particular programs have been successful. They further suggest that evaluation outcomes could be framed within the concepts of 'grief and loss' and 'healing' and note that 'high levels of social disadvantage have an impact on service utilisation and outcomes' (Day and Francisco 2013:350).

One primary study focused on Aboriginal men's mental health and found that:

- 'Aboriginal fathers in particular, can greatly benefit from tailored, targeted and culturally safe support programs and services' (Kickett-Tucker et al. 2015:5).
- 'Recognition of Aboriginal men's needs and mental health issues and stresses, as well as strength, resilience and centrality to Aboriginal families, were critical aspects to the program' (Kickett-Tucker et al. 2015:5).
- 'Core building blocks to successfully relieving men's stress and fostering their wellbeing are:
  - Providing support services that address men's need for communication and experience-sharing with other men;
  - Getting men outdoors and on country, reconnecting with culture; and
  - Facilitating re-engagement with partners and family' (Kickett-Tucker et al. 2015:5).

Drawing on a wide range of sources, a literature review focusing on overcoming social isolation for Aboriginal and Torres Strait Islander carers recommended a range of actions to support carers at the individual, group and community and broader context (e.g. policy) levels. At the individual level, examples of such actions included culturally appropriate:

- information and awareness-raising [campaigns] about rights, entitlements and navigating the system
- carer education programs (e.g. lifting techniques, medication management, relaxation, use of equipment and managing health conditions)
- hardcopy and online resources in plain English, pictorial, traditional languages, large text and Braille formats
- face-to-face support groups
- carer events (e.g. special days and healing camps)
- counselling, brief interventions, family therapy, narrative therapy and art therapy
- primary health interventions
- home support services
- respite (especially in home)
- individual advocacy (Carers Australia 2013:22).

## 5.6 Summary

While there is a vast literature identifying specific issues and concerns for different socio-demographic groups of carers, few systematic reviews focused on the characteristics of carers when considering interventions to support carers' social and emotional wellbeing outcomes. Further research is required to identify specific programs that will best support carers of different age groups, CALD carers and Aboriginal and Torres Strait Islander carers. Carers in these demographic groups have diverse care situations and may require different types of interventions. Thus, effective programs may exist but may not have been evaluated yet or be part of broader reviews.

# 6 Conclusion

## 6.1 Future research

In seeking to identify evidence as to what works to support carers' social and emotional wellbeing, this rapid literature review has focused on reviews of studies that have employed rigorous evaluative methods to assess effectiveness and grey literature that have highlighted key areas of concern. The literature search revealed numerous studies and evaluations of interventions for many groups of carers and given the time constraints of this review, it was not possible to review all studies comprehensively.

This literature review has highlighted the challenges of identifying what definitely works for carers to improve their social and emotional wellbeing. However, the evidence to date suggests that it is possible to point towards potentially effective interventions or combinations of interventions. Many of the reviews synthesised evidence from a range of specific studies addressing specific groups of carers. Identifying specific programs that might be used as models for interventions would require further research into specific promising programs and their characteristics that could inform intervention design.

A key issue identified in the literature is that while carers often report satisfaction with interventions, evidence about changes in social and emotional wellbeing outcomes is less robust. Careful consideration of the goals, objectives and measures used in programs and evaluations and the combination of quantitative and qualitative evidence is warranted.

Problems were also identified with the design, quality and incomparability of studies, which should be addressed in future research, specifically:

- lack of a theory of change
- whether it was possible to identify a good control or comparison group
- small sample sizes
- relevance of outcome measures
- whether it was possible attribute change to specific aspects of the intervention
- the time period of evaluations
- the lack of cost-effectiveness analysis.

While this rapid literature review could not be comprehensive, some gaps in the research regarding programs and interventions that could be further explored include the effectiveness of:

- care coordination in promoting carers' social and emotional wellbeing
- advocacy training for carers or support from carer advocates and the extent to which it enables carers to access appropriate services and support and improves their social and emotional wellbeing

- support for transition to non-parental or non-family care for older carers of adult children
- interventions specifically targeting working carers, or carers seeking to return to employment
- how support for both identifying and accessing appropriate home modifications may affect carers' social and emotional wellbeing
- resources that aim to advise and support carers about how to let others know about their care responsibilities
- holistic support programs for family members and networks of carers who may support a single person, rather than focusing on one carer or the primary carer
- financial literacy, financial counselling and financial capability training and support for carers
- programs that seek to reduce financial stress and improve carers' financial wellbeing and assess the effect of financial stress on carers' social and emotional wellbeing.

Further research could also aim to identify specific programs, and also seek to identify the design and effective elements of interventions, to support social and emotional wellbeing that are:

- age-relevant and age-appropriate for young carers and older carers
- culturally appropriate for carers from the range of different CALD communities
- appropriate support for carers in Aboriginal and Torres Strait Islander communities.
- effective to support parents and working age carers in balancing work and care commitments.

## 6.2 Practical policy options

The findings of this review suggest that a range of broad practical policy options could be explored to support carers' social and emotional wellbeing. Principles underpinning the approaches to developing specific support programs could include:

- a 'pick-and-mix' approach: provide multicomponent interventions for carers to use at different points in time
- consultation: have conversations with carers that enable them to reflect about what they need and want, with a focus on person-centred approaches
- appropriateness: consider whether support is available, accessible, individualised, flexible, comprehensive and reflects what carers want
- 'Whole of family/care' approach: develop programs that include services for the person being cared for and address the complexity of the care dyad and networks of care.

Specific options include:

- ensuring that carers have information about, and access to, flexible, individualised multicomponent interventions
- building on research that has identified preferred types of respite for different groups of carers and developing well designed and evaluated interventions, of which emergency and planned respite are key components
- identifying effective education and training programs that assist carers to gain the skills they need to support the caring role
- ensuring that carers have information about and access to multiple forms of counselling
- identifying different groups of carers' needs and preferences for support groups and ensuring a range of support groups are available through different modalities
- ensuring carers are able to access adequate support in terms of practical help in the home, such as cooking, cleaning and transport
- identifying good practice interventions to support carers' physical health further research
- developing co-design projects with carers and technological innovators that could facilitate well designed technological components as part of multicomponent interventions
- ensuring carers have technological skills and support to access interventions if they wish to do so.

In the context of the changing policy landscape, it is important and timely to monitor the impact of the ICSS, NDIS and changes in aged care provision on the extent to which the social and emotional needs of carers are recognised and supported and the effects of these policy changes on carers' social and emotional wellbeing outcomes.

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# Appendix A Literature Search

The literature search was designed with the advice of a research consultant from UNSW Library to meet the aims of the project and to fit within the time and budget constraints of this project.

**Academic databases** searched included cross-disciplinary databases and discipline specific databases:

1. Cross-disciplinary: (Google Scholar)
2. Psychology: (OVID psychological databases, PsychINFO)
3. Health (Medline, Embase, PubMed)
4. Social Sciences (Proquest databases: Social Science databases, Sociological Abstracts)
5. Australian specific: Informit
6. Systematic Reviews: Cochrane Library

**Search terms** for academic databases initially included the following:

Systematic review/review/scoping review and carers/caregivers and:	<ul style="list-style-type: none"> <li>• mental health</li> <li>• psychological wellbeing*</li> <li>• social wellbeing</li> <li>• emotional wellbeing</li> </ul>
Carers/caregivers/young carers/CALD carers and:	<ul style="list-style-type: none"> <li>• mental health</li> <li>• psychological wellbeing</li> <li>• social wellbeing</li> <li>• emotional wellbeing</li> <li>• social needs</li> <li>• emotional needs</li> <li>• quality of life</li> <li>• emotional impact</li> <li>• stress and strain</li> <li>• anxiety</li> <li>• social isolation</li> <li>• crisis</li> <li>• relationships</li> <li>• family functioning</li> <li>• social support</li> <li>• networks</li> <li>• resilience</li> <li>• coping</li> <li>• depression</li> <li>• fatigue</li> <li>• sleep</li> </ul>
Aboriginal and Torres Strait Islander carers/Indigenous carers and social	<ul style="list-style-type: none"> <li>• social and emotional wellbeing</li> <li>• mental health</li> </ul>

disadvantage/racism/kinship/Stolen Generations/cultural safety/intergenerational trauma	<ul style="list-style-type: none"> <li>• resilience</li> <li>• social support and networks</li> <li>• relationships</li> <li>• disadvantaged families</li> <li>• disadvantaged communities</li> </ul>
Other carer specific terms: <ul style="list-style-type: none"> <li>• carer support</li> <li>• carer needs</li> <li>• satisfaction in caring</li> <li>• conflict in caring</li> <li>• burden of care</li> <li>• carer depression</li> </ul>	
Interventions/evaluations/what works/effectiveness and carers/caregivers/young carers	<ul style="list-style-type: none"> <li>• mental health</li> <li>• social wellbeing</li> <li>• emotional wellbeing</li> <li>• psychological wellbeing</li> <li>• carer support</li> <li>• resilience</li> <li>• social support and networks</li> <li>• counselling</li> <li>• coaching</li> <li>• peer support</li> <li>• training</li> <li>• support</li> <li>• services</li> </ul>

\*the terms 'wellbeing' and 'well-being' were used in searches.

**Grey literature:** key stakeholders websites included:

- the Mental Health Commission of NSW
- Mental Health Carers NSW
- Headspace
- Beyond Blue
- Suicide Prevention Australia
- Older Peoples Mental Health Networks
- NSW Health
- Department of Education
- Dementia Australia
- Carers NSW
- Carers Australia
- Eurocarers
- Carers UK
- Carers Ireland
- Carers Scotland
- Carers Canada
- Carers NZ
- National Alliance for Caregiving USA

**Specific historical studies:** The review also searched Google Scholar to identify relevant reports and articles citing key historical studies of carer wellbeing, such as *The Wellbeing of Australians - Carer Health and Wellbeing* (Cummins et al. 2007).

# Appendix B Carer needs and outcome measure examples

## Needs Assessments

- Supportive Care Needs Framework
- Carers' Needs Assessment for Dementia (CNA-D)
- Carers Star

## Outcome Measures

### Mental health

- Centre for Epidemiologic Studies Depression Scale (CES-D)
- Brief Symptom Inventory
- Beck Depression Inventory
- Hospital Anxiety and Depression Scale (HADS)
- GHQ-12 and GHQ-28
- Taylor Manifest Anxiety Scale (short form)
- The State-Trait Anxiety Inventory (STAI) (caregiver distress)
- Zung Depression Scale
- Hamilton Anxiety Rating Scale (HAM-A)
- Multiple Affect Adjective Check List: depression subscale
- Kessler Psychological Distress Scale (K10)
- Clinical Interview Schedule(revised) (CIS-R)
- Symptom Checklist 90 (SCL-90)
- Health Status Questionnaire (HSQ)
- General Depression Scale (GDS)
- Core Bereavement Items (CBri)
- SF-36 Mental Health

### Carer burden and stress

- Zarit Burden Scale
- Caregiver Appraisal Inventory (CAI)
- Caregiver Strain Index (CSI)
- Carer Burden Scale (CBS)
- Derogatis Affects Balance Scale (DABS)
- Perceived Stress Scale (PSS)
- Revised Memory & Behaviour Problem (RMBC)
- Screen for Caregiver Burden (SCB)
- Target Complaints Interview Assessment Tool (TCIAT)
- Lawton Subjective Burden Instrument
- Revised Burden Interview
- Carer Assessment of Difficulties Index (CADI)

## **Coping**

- Subscale of Duke UC Functional Support Questionnaire
- Ways of Coping Checklist-Revised
- Ways of Coping
- Caregiving Competence (Pearlin)
- Caregiver Burden Index (CBI)
- Carer Assessment of Managing Index (CAMI)

## **Satisfaction**

- Caregiver Satisfaction Questionnaire
- FAMCARE
- Consumer Satisfaction Questionnaire
- Carer Assessment of Satisfaction Index (CASI)